

Customer feedback report 2016

Highlights and summary

***"The more I see of the folks at Parkinson's UK, the more impressed I am with their attitude, energy, positivity and clarity of purpose. This is not an accident; it is a result of good leadership both at the centre and at the branch level."
(Person with Parkinson's, Q3 2016)***

At Parkinson's UK we aim to 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 and on social media, by email, telephone, through regular evaluation surveys, in person or using our feedback cards.

A key element of our accreditation through the Customer Service Excellence Standard is that we make it easy for people to interact with us and that we can show we respond to feedback within a set timeframe and to the customer's satisfaction. We are also able to demonstrate that we take account of this feedback in our planning and service development. This annual feedback report forms part of the evidence we provide on a yearly basis at the assessment. In 2016, we successfully maintained our Customer Service Excellence accreditation for the fifth year. We are fully compliant in all 5 criteria of the Standard: 1.Customer Insight; 2.Organisational Culture; 3.Information and Access; 4.Delivery; 5.Timeliness and Quality of Service.

In 2016, Parkinson's UK received

- 1684 positive comments and compliments
- 244 neutral comments and suggestions
- 170 complaints
- 4 complaints were formal complaints, with 2 being upheld

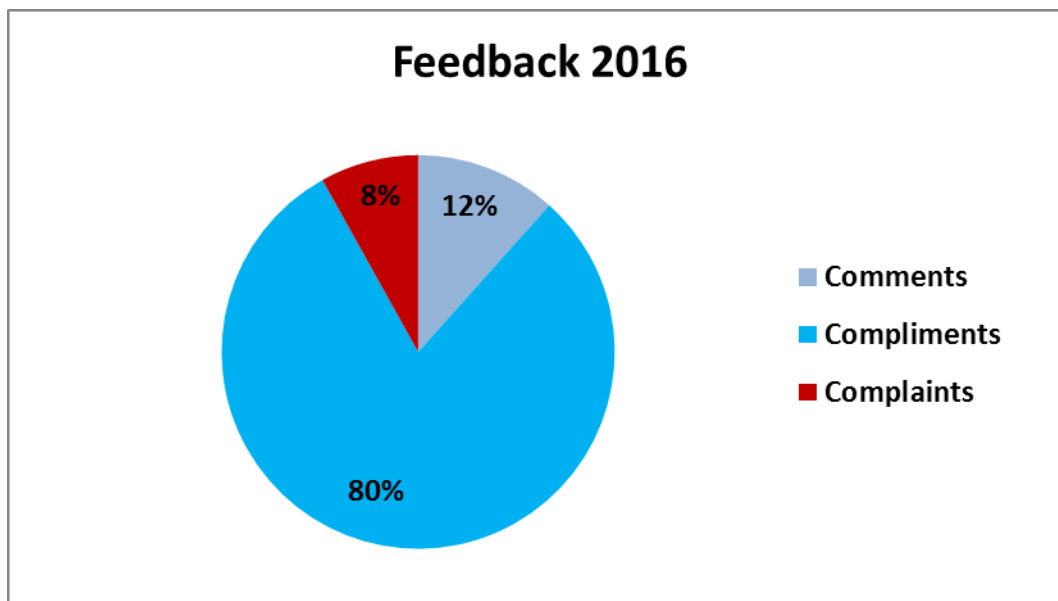


Figure 1: Feedback received – 2016

Compliments

Compliments were received from across the UK and relating to all areas of the charity, with an exceptionally high number of unsolicited positive comments (total: 1010)

Parkinson's local adviser service

This team consistently received a high proportion of all compliments in 2016, indicating how valued the service they offer is. Comments included:

"The local adviser gave us all the information we needed at this time, but also really inspired us to not let Parkinson's stop us living, not to be afraid to try different activities" (Q4, 2016)

Benefit and employment advisers (Telephone Services)

The importance of timely and accurate advice and guidance in the area of benefits and employment can be essential in supporting people affected by Parkinson's to maintain control and numerous compliments were received for this team:

"Thank you once again for your guidance and advice - we truly appreciate it and hope the result shows you what an impact your role has to help to improve the situation of those with Parkinson's - you're a star!" (Q1, 2016)

Information resources

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

Complaints

We weren't always able to meet our expected high standard of customer care, with 8% of all feedback received being negative. Overall though we received fewer complaints than in 2015: 174 compared to 197. Our Key Performance Indicator for feedback is no more than 25% negative feedback in any given year. Even if we discount neutral comments to arrive at a figure of 13% negative versus positive feedback, we continue to be well within this target.

The reduction in complaints in 2016 can be attributed, in part at least, to the investment in and restructure of the Supporter Services function, which deals with all membership and donation enquiries. In 2015 there was a significant pattern of complaints relating to **failure to receive a thank-you letter** after making a donation and **non-removal from database**. In 2015, 50 complaints were noted in these areas but in 2016 this reduced to just 9. This is a direct result of the restructuring of the Supporter Services Team, including an increase in the number of staff, and improved processes in place.

The main body of the report highlights all complaint themes (pages 10-14).

Summary

In 2016, unsolicited feedback increased by close to 90% compared with 2015. Of the feedback received, 80% was complimentary, 12% neutral (comments) and 8% negative/complaints. Some previously recurring themes for complaints, particularly not receiving thank-you letters and non-removal from database, have drastically decreased as a direct result of actions that have been taken to tackle these.

Our direct information and support services, in particular the Parkinson's Local Adviser service, received a high level of praise from users and many others areas were highlighted by people affected by Parkinson's as providing "excellent support".

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NB. To ensure continuity of reporting for the full year, this report maintains the charity's directorates' structure, which was in place up until August 2016.

Customer feedback 2016 – full report

This report provides an update on the key themes of customer feedback received during 2016 through our feedback channels – including online, emails, by phone and post and surveys.

Feedback received in 2016

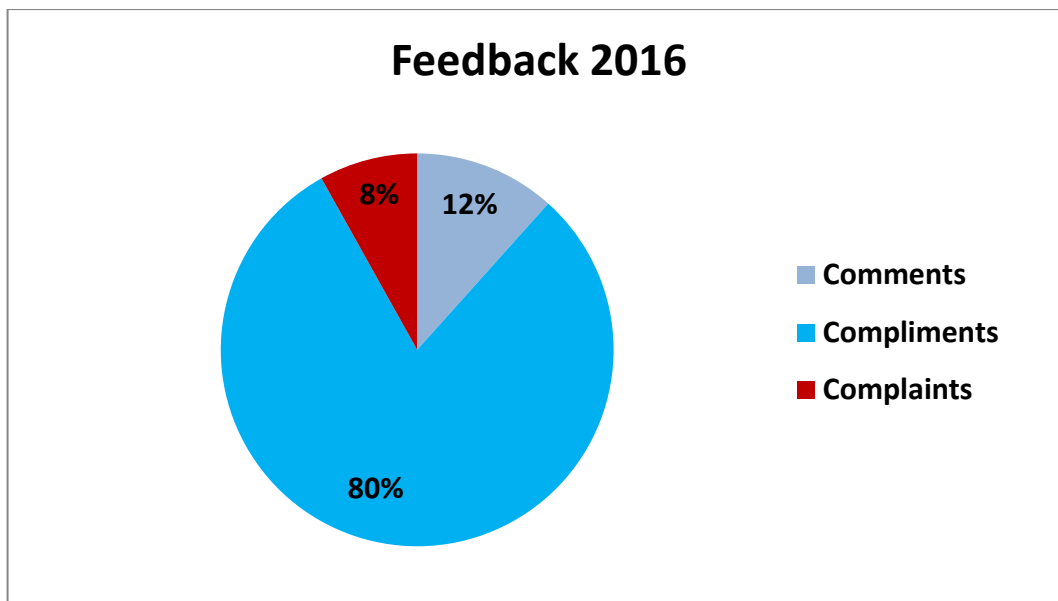


Figure 1: Feedback received – 2016

Definitions

Our 'feedback' includes:

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

Activity in 2016

To provide some context, in 2016:

- the helpline answered 16,900 phone calls
- the Parkinson's Local Adviser service received 12,642 referrals and handled 28,334 general enquiries
- fundraising campaigns and activities included
 - ✓ Direct Mail: approx. 500,000 pieces
 - ✓ Email: 1.5 m approx. broadcast
 - ✓ Telephone: 4,000 outbound conversations (Legacy and DD only)
13,000 inbound calls (Supporter Services only)

Breakdown of feedback items received in 2016

In 2016, we received 2102 items of feedback in total of which, 1684 items were positive and/or complimentary.

Feedback 2016	Q1			Q2			Q3			Q4		
	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Sep	Oct	Nov	Dec
Comments	31	26	23	28	11	20	20	17	28	10	9	21
Compliments	24	66	122	91	87	98	106	81	78	97	95	739*
Complaints	11	13	12	9	11	6	8	14	14	12	11	49*
Formal Complaints	0	2	1	0	1	0	0	0	0	0	0	0
Total	66	107	158	128	110	124	134	112	120	119	115	809

Table 1: Breakdown of all feedback – 2016

*includes a total of 674 positive and 24 negative survey responses

Feedback items received 2011-2016

The total feedback received in 2016 decreased when compared to 2015 but remains higher than all other years since 2011. Plus, as discussed below, there was a significant increase in unsolicited feedback, which is a particularly powerful indicator of the level of satisfaction

Feedback	2011	2012	2013	2014	2015	2016
Compliments	985 (61%)	1277 (64%)	1233 (71%)	1205 (77%)	2066 (84%)	1684 (80%)
Comments	370 (23%)	462 (23%)	313 (18%)	216 (14%)	199 (9%)	244 (12%)
Complaints	242 (15%)	235 (12%)	172 (10%)	131 (8%)	171 (6%)	170 (8%)
Formal complaints	5 (1%)	21 (1%)	26 (1%)	15 (1%)	26 (1%)	4 (0%)
Total feedback	1602	1995	1744	1567	2493	2102

Table 2: Breakdown of all feedback received during the last 5 years

Positive and negative feedback

After removing neutral comments and suggestions, of the feedback items received, 87% (1684 items) were complimentary and 13% (170 items) were complaints or negative comments (See Figure 2).

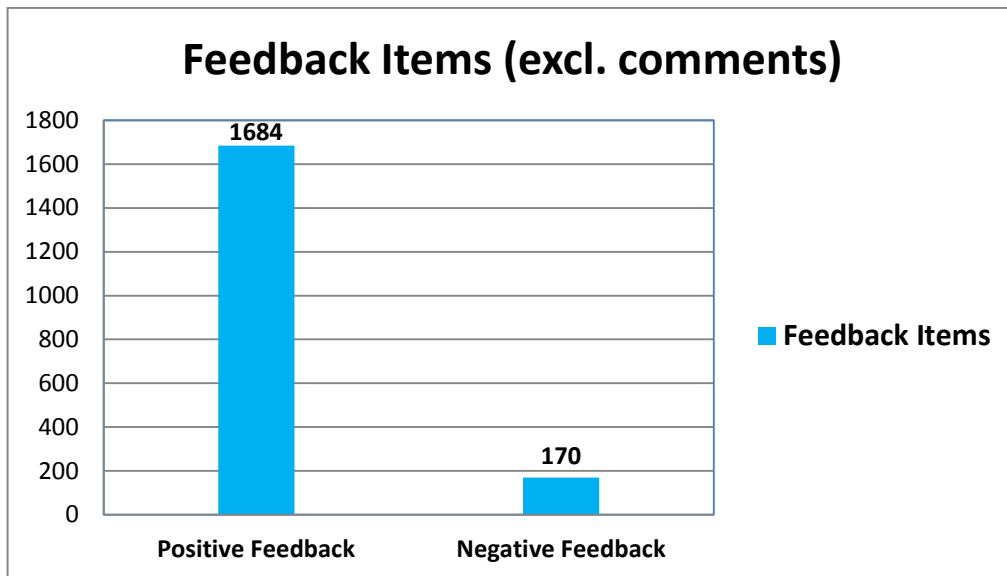


Figure 2: Number of positive and negative feedback items

Comparison to previous years

In 2015 91% of feedback received was positive and 9% negative, so we have seen a slight increase in the **percentage** of negative feedback when viewed in this way.

Our Key Performance Indicator for feedback is no more than 25% negative feedback in any given year. So we continue to be well within this target, as shown in Table 3.

Year	2011	2012	2013	2014	2015	2016
Target	< 25%	< 25%	< 25%	< 25%	< 25%	< 25%
Actual	20%	17%	14%	11%	9%	13%

Table 3: Percentage of positive to negative feedback since 2011

In 2016 we saw a reduction in the total number of positive feedback items received, resulting in the slight proportional increase in negative feedback of 4%. However the number of complaints reduced in 2016 as we received 174 complaints/negative items compared with 197 in 20 -see Figure 3.

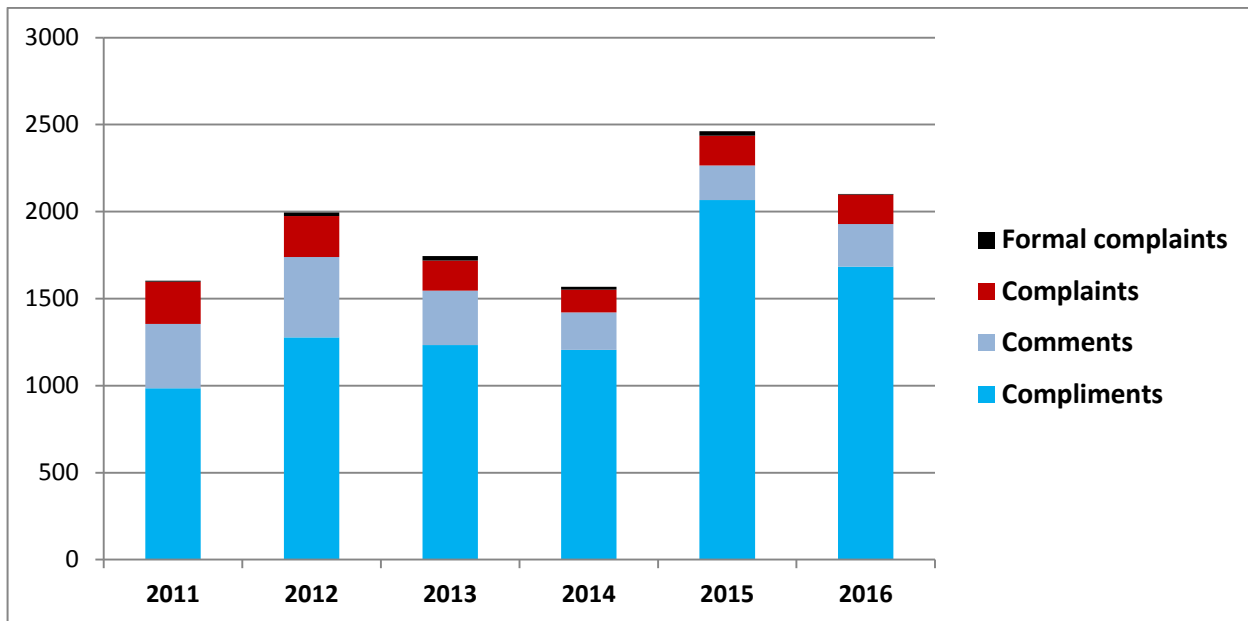


Figure 3: Breakdown of all feedback items over the last 6 years

Unsolicited feedback

Within our feedback figures, we include feedback gleaned from evaluation surveys. If we remove survey data, we received a total of 1156 items of unsolicited feedback (eg people complete a feedback card or email us). Of these, 1010 were positive and 146 were negative.

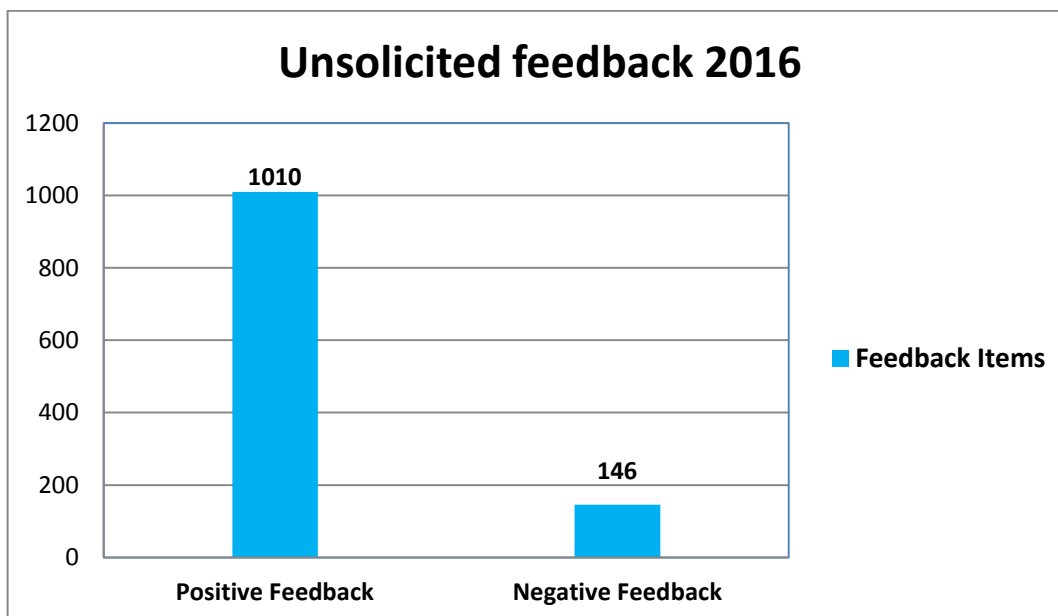


Figure 4: Number of positive feedback items versus negative item

The figures above represent a significant increase in unsolicited feedback items received compared to 2015 – an overall increase of 89%, as shown in the Figure 5 below. This is very encouraging and is a direct result of staff's engagement in ensuring that all feedback received is forwarded to the Involvement and Inclusion Team for logging.

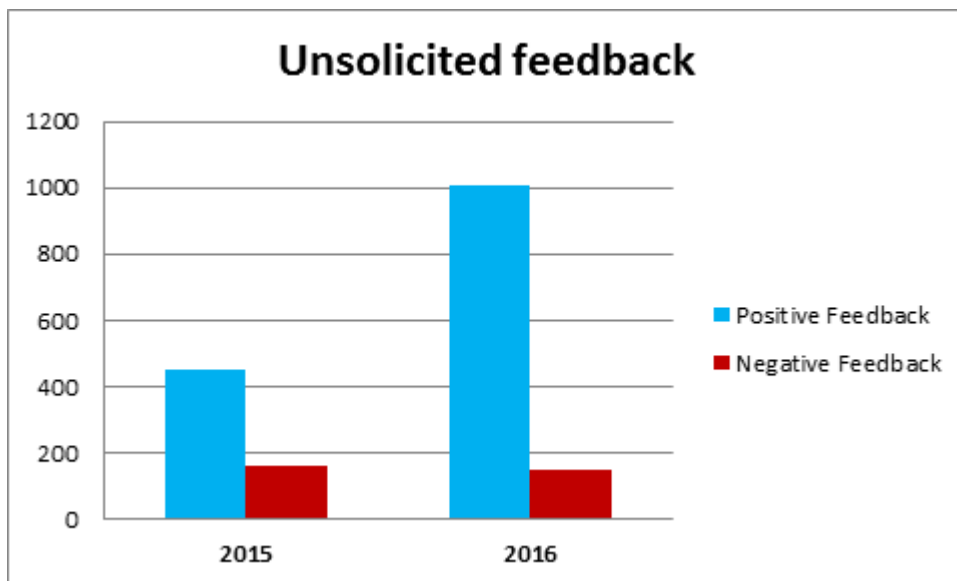


Figure 5: Unsolicited feedback items for 2015 and 2016.

Compliments

The following areas of our work have received the strongest positive feedback during 2016:

- **Parkinson's Local Advisers**

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 *"informative"* *"supportive"* and *"helpful"*. Furthermore many users specifically highlighted their personal Parkinson's local adviser, citing them as *"inspiring"* and *"essential"*.

- **Benefits and Employment Advisers**

A high number of service-users have provided unsolicited feedback highlighting the benefits and employment advisers. Particular advisers have been highlighted throughout the year specifically in relation to the *"advice, guidance and determination"* in assisting users in benefit applications as well as identifying and correcting errors made by the Department of Work and Pensions.

- **Helpline and peer support**

People have particularly praised the services for their accessibility as well as the emotional support provided, for both people living with Parkinson's as well as family, friends and carers.

- **Self-Management Programme**

The self-management programme has received excellent feedback, particularly from newly diagnosed users; they highlight the course as providing the *"tools for the future"* and enabling them to have a more positive outlook.

- **Information provision**

Information provided (via website and printed publications) continues to be received positively, with readers highlighting the palatable nature of information provided as well as the optimistic and inspiring nature of the website.

- **Editorial and Creative**

Users have highlighted the Editorial and Creative team for providing important and easy to read information within our publications. Publications receiving particular praise include My Gran has Parkinson's and an article in the winter edition of the Parkinson highlighting the LGBT Parkinson's community.

- **General services**

People in contact with us have shared excellent feedback regarding staff attitudes and positivity, whilst others highlight the all-round service received, including support to families and carers.

- **Website, forum and social media**

People have commented on the ease of access to plentiful information on the website. The forum and Facebook page continue to receive praise as opportunities for the Parkinson's community (including people with Parkinson's, family and carers) to come together and create additional support networks.

- **Research**

Widespread recognition for charity supported research has been received, with researchers highlighting the charity's encouragement and support to interact with people affected by Parkinson's, and those affected praising the informative talks outlining how research is progressing.

Complaints

Throughout 2016 complaint numbers reduced. 170 complaints were received in 2016 compared to 197 in 2015. The number of formal complaints also reduced significantly, from 26 in 2015 to 4 in 2016.

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

2016 has seen the fewest formal complaints in the past 6 years.

Formal complaints	2011	2012	2013	2014	2015	2016
Fully upheld	2	2	5	5	20	2
Partially upheld	3	3	4	0	4	1
Not upheld	0	16	17	10	2	1
Total	5	21	26	15	26	4

Table 2: Breakdown of formal complaints

In 2016 we dedicated significant effort to working with staff and managers on better resolving complaints in the first instance, avoiding them becoming formal complaints.

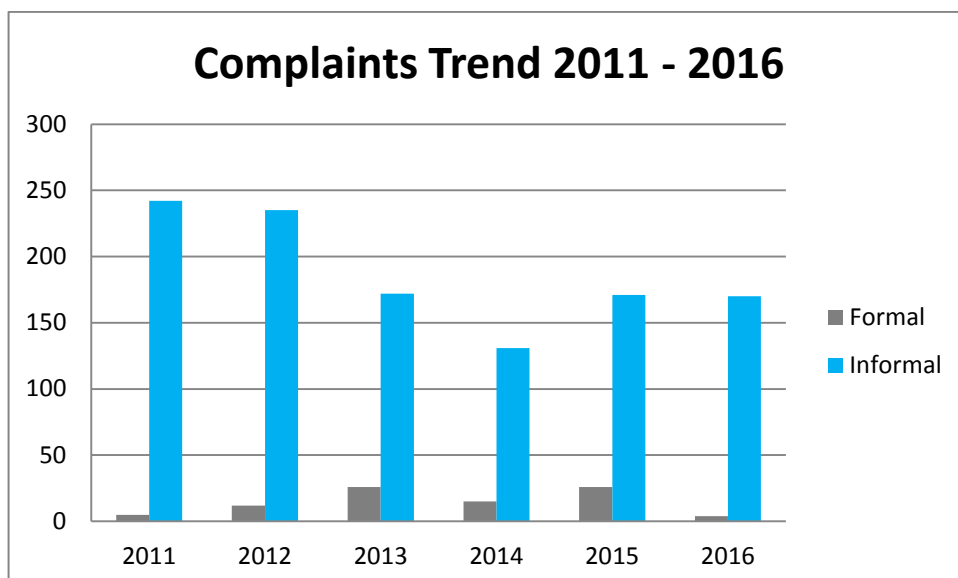


Figure 6: Trends in complaints over the last 6 years

Complaint Themes

A breakdown of the key complaint themes from 2016 is listed below. Further commentary is provided for the most recurring themes.

Formal complaints

There have been 4 formal complaints this year, with 2 being upheld:

Complaint Theme	No.	Upheld
Non removal from the mailing database	1	-
Slow/no staff response	1	1
Wrong contact details on database	1	1
Dissatisfaction with online forum/website	1	-

Informal complaints

Fundraising Directorate (59)	Complaint theme	Total No.
	Poor customer care	8
	Difficulties donating/becoming member online	4
	Admin Errors	4
	No thank you after donation	4
	Repeated mailings / Pressurised cold calling	7
	Non removal from database / Information error	3
	Waste of recourses	1
	Dissatisfaction with campaign	2
	Dissatisfied with Unique Insurance	1
	Dissatisfied with an event organisation / selection criteria / name	6
	No / slow staff response	7

	Product/shop	8
	Dissatisfied with forms in membership welcome pack	1
	Fundraising infographic not perceived as transparent	1
	Dissatisfied we do not work with BT MyDonate	1
	Child collecting money on behalf of charity in pub – <i>no further contact from complainant to supply further details</i>	1

Within the Fundraising Directorate, the significant reduction in complaints compared to 2015, relates to 2 areas: **non-receipt of thank- you letter** after making a donation and **non-removal from database**. In 2015, 50 complaints were noted in these areas but in 2016 this reduced to just 9. This is a direct result of the restructuring of the Supporter Services Team, including an increase in the number of staff and improved processes in place.

The **poor customer care** incidents noted above are related largely to queries not having been resolved to the satisfaction of the customer, usually due to miscommunication, or orders for fundraising materials not arriving on time. These complaints relate mainly to Support Services Team, Events and Fundraising Admin team. None of the complaints raise any concerns about staff behaviour or attitude. It is also important to note that these teams have the highest number of interactions with customers directly in the charity (see activity detail on page 3).

External Relations Directorate (30)	Complaint theme	Total No.
	Photography consent form	1
	Forum rules	1
	Mervyn Peake Awards suspension	2
	Not nominated for Mervyn Peake Awards	1
	Lack of digital support for fundraiser involved in a competition	1
	Disliked campaign	3
	Mistake on form	1
	Dissatisfaction with resource	1
	No mention on press release	1
	Forum rules	1
	Dissatisfaction with policy (BMA strikes)	1
	No emotional support to media case study	1
	No / late delivery from CDL	2
	Lack of information to local group about PAW events in local area	1
	Unable to recycle plastic envelope used for The Parkinson	1
	Paul-Mayhew-Archer's Radio 5 interview not representing "true" symptoms of Parkinson's	1
	Negative tone of Jane Asher's letter in local newspaper	1
	Carers' letter received after Carers' Week	1
	Wrong boiler plate used on resource	3

	Our ICB tool makes neurologist overly cautious	1
	Advert messaging on 215 building too negative	1
	Unhappy about Resources Team rescheduling a meeting	1
	Slow staff response	1
	Disappointed CDL do not accept payment via PayPal	1

Within External Relations no major recurring themes are noted. There were 3 complaints noted when the **incorrect boiler plate** was used on some information resources – the boiler plates were meant for resources used to engage funders and major donors but were incorrectly used on publications aimed at people affected by Parkinson's. The issue was dealt with as soon as it came to light.

Some comments (3) were received where people felt they disliked a campaign theme or approach.

Support and Local Networks Directorate (23)	Complaint theme	Total No.
	Lack of compassion from helpline adviser	2
	Dissatisfied with helpline info/advice offered	1
	Lack of local support	4
	Poor customer care	2
	Complaint about staff member	1
	Complaint about a volunteer	2
	General/Various	1
	Dissatisfaction with self-management programme	1
	Dissatisfied with local area development	1
	Concerned local groups not involved in new strategy	1
	Lack of support at later stages of Parkinson's	1
	Branch feels raised funds are not sufficiently valued	1
	Complaint about branch (withdrawn)	1
	Dissatisfied about the termination of the Mali Jenkins Fund	1
	Unhappy with Network News article	2
	Dismissal of Branch Treasurer	4

With Support and Local Networks, a **perceived lack of support** emerged 4 times. However, looking at the detail of these complaints, these related to misunderstandings or people expecting support for individuals who hadn't in fact requested any support. It also included people complaining about local non-Parkinson's UK services which had closed down. In relation to **lack of compassion** from a helpline adviser (2), one of these complaints relates to a caller with significant issues, including mental health problems, where helpline and local staff have tried all they can to provide support. In this particular case, the client presents very challenging communication style. The other complaint in this area was responded to by the Telephone Services Manager directly. Because the complaint was made some time after the event, it was impossible to conduct a full investigation. It was concluded that in all likelihood,

the caller was looking for emotional support where the adviser provided information and advice instead. The team is being supported to ensure this sort of issue is avoided.

In relation to **poor customer care**, one complainant felt the helpline hadn't been able to offer the advice she needed but the complaint could not be investigated as it was left by voicemail with no further detail.

The 4 complaints about the **dismissal of a Branch Treasurer** are all related to the same case and full details have been shared with the Board of Trustees.

Research and Innovation Directorate (10)	Complaint theme	Total No.
	Lack of information	1
	Concerns around not focusing on the role of Tumour Necrosis Factor in Parkinson's research	1
	Virtual biotech appeal and press release	3
	100forParkinson's research design restricted to smart phone users	1
	Brain donation – lack of information in relation to body temperature	1
	Concerns about the clarity of a Progress Magazine article	1
	Animal research	1
	Concerns about our research not focussing on the role of Tumour Necrosis Factor	1

The only recurring complaint in relation to the Research and Innovation Directorate concerned our **Virtual Biotech** appeal and press release where people felt the details provided were not fully transparent or accurate.

Organisational Development Directorate (9)	Complaint theme	Total No.
	No response after Trustee application	1
	Not receiving feedback at application stage	1
	Language of Volunteer Confidentiality Pledge	1
	Unhappy about interview involvement	1
	Wasting resources by sending out letters to volunteers during Volunteers' Week	1
	Complaint about a fellow volunteer	2
	Customer care at Reception (215)	1

Few complaints were recorded for the Organisational Development Directorate. More details are available on request.

Finance, IT and Performance Directorate (6)	Complaint theme	Total No.
	Admin error – discrepancy in payments	1
	Branch procedures for management of funds	1

Few complaints were recorded for Finance, IT and Performance Directorate.

General/CEO Office (9)	Complaint theme	Total No.
	Lack of support from charity	4
	Concerns about the direction of the charity	1
	Slow/no staff response to voice mail	1
	Charity does not do enough to raise awareness	1
	Brand tone too informal	1
	Concerns over executive salary	1

The main recurring general complaint relates to a perceived **lack of support** from the charity. For example, this included 2 people saying that after becoming members, all they received were a couple of magazines and numerous asks for money. The Support Services Team now ensure all new members receive more appropriate materials at sign-up, including an overview of services that they can access. Moving forwards, our Personalised Relationships work programme aims address issues of this sort.

Comments/suggestions

Below is a breakdown of some of the comments/suggestions we received in 2016.

*"I've had approximately 5 members recently ask that I suggest a **joint membership option**. The feedback I'm getting from these current members is that for couples, they join up separately and both receive the magazine, which they feel is wasteful having 2 copies in the same household. It's not the cost or the fact they are separate members which is the problem for them, it's just that they both receive the magazine."*

*"I spoke to [customer] this afternoon who asked that I pass on some comments about the magazines content. It wasn't a complaint; just something she felt needed addressing. She's said that she feels the **magazine could benefit from more articles about the difficulties people suffer in the end stages of Parkinson's**. As the magazine has a lot of info relevant to the early stages of the condition, but not the later stages, where she has said this was where she & her late husband had trouble getting the help they needed."*

*"Can I suggest that **more information is given about gambling and medication** as my husband has been affected by this, perhaps through the newsletters we get."*

*"Is it possible to have **Parkinson's Nurses' telephone numbers** on the website?? (If it isn't already on)."*

*"Had you ever thought of doing a **virtual event**? You provide a medal we provide you with evidence that we have run/walked/cycled, you send medal out, probably not as simple as it sounds, but would be good perhaps for Parkinson's awareness month."*

A supporter has contacted us to express his concerns with regards to **repeated requests for 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. – Still an issue with various comments (some more extreme and classed as complaints) claiming they receive too many requests or 'begging letters'

You said, we did

Following feedback received, various teams made changes as a result of the views and opinions received. See Appendix 1 below (pages 16-17).

Concluding remarks for 2016 feedback

The levels of unsolicited feedback received in 2016 indicate strong engagement with the Parkinson's community who seem able to communicate with us easily. We're committed to ensuring this continues. Customer feedback, positive or negative, can act as a mirror for the charity, telling us what we are doing well and what opportunities we have to do better.

In 2016, unsolicited feedback increased by close to 90% compared with 2015. Of the feedback received, 80% was complimentary, 12% neutral (comments) and 8% was negative/complaints. Some recurring complaint themes, especially in relation to non-receipt of thank-you letters and non-removal from database, have drastically decreased since this year.

There are opportunities to do better in some areas. The Involvement and Inclusion Team will continue to work closely with teams around the charity to ensure that instances of unsatisfactory customer care are reduced. Having achieved reaccreditation of the Customer Service Excellence Standard, we aim to keep a continued focus on providing the best possible customer care.

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Appendix 1 – You said, we did 2016

Set out below are some examples of how user feedback was taken on board during 2016.

You said	We did
<p>Research Support Network</p> <p>The research team have recently rebranded the Research Support Network with the help of both new and old members of the network through gathering their thoughts and opinions on being involved.</p>	<p>Based on their feedback, collated during focus groups and 1-2-1 interviews, the team have developed a new tag line and descriptors to describe the Research Support Network, along with a new visual identity. Also, at one of the focus groups a participant mentioned that it would be useful to make it clearer which email was for which type of opportunity - so from this we've actually worked to develop new icons to send out with our emails to ensure that everyone can see what the email is about as soon as they open it. This way they can select the opportunities that are of interest to them.</p>
<p>Saying thank you to local groups</p> <p>A local group told us they feel the charity doesn't show sufficient value or appreciation for funds raised, feeling an acknowledgement letter from Steve Ford, CEO, is not enough.</p>	<p>The Senior Leadership Team has launched a "ring up and say thank you" programme, where groups will receive personal calls to acknowledge cheques.</p>
<p>Brain bank donations</p> <p>We received feedback from people unable to donate their loved one's brains to research according to their wishes, due to not being made aware they needed to keep the body cool following death.</p>	<p>As a result, the team have implemented the following changes:</p> <ul style="list-style-type: none"> • a new information sheet explains, step-by-step, the process that families and professionals need to follow to have the best chance of a successful donation. This was sent to all registered donors in late 2015 and is now included in the pack sent to all new donors. • an update to the Brain Bank information booklet, which is given to anyone considering becoming a donor with information about body temperature for successful donation.
<p>Creative writing</p> <p>You told us we could do more to support and promote the creative writing of people affected by Parkinson's.</p>	<p>Throughout 2016 we worked with creative writers affected by Parkinson's to develop a creative writing toolkit, which aims to support and showcase this creative outlet. You can see find the toolkit here.</p>
<p>The Parkinson - Getting to know...</p>	<p>We've introduced the new <i>Getting to know...</i></p>

<p>Some people affected by Parkinson's on our Editorial Board told us that they're always hearing about local advisers and various other charity staff who might support them but don't necessarily understand what they do and can offer.</p>	<p>interviews in the magazine where people can find out more about the ways different Parkinson's UK staff and others can support them and get a much deeper understand of the charity staff and their roles.</p>
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