

Customer feedback 2017

- summary report

In 2017, Parkinson's UK received

- 1593 positive feedback
- 267 neutral feedback (comments and/or suggestions)
- 136 negative feedback (complaints)
- 4 formal complaints (1 partially upheld)

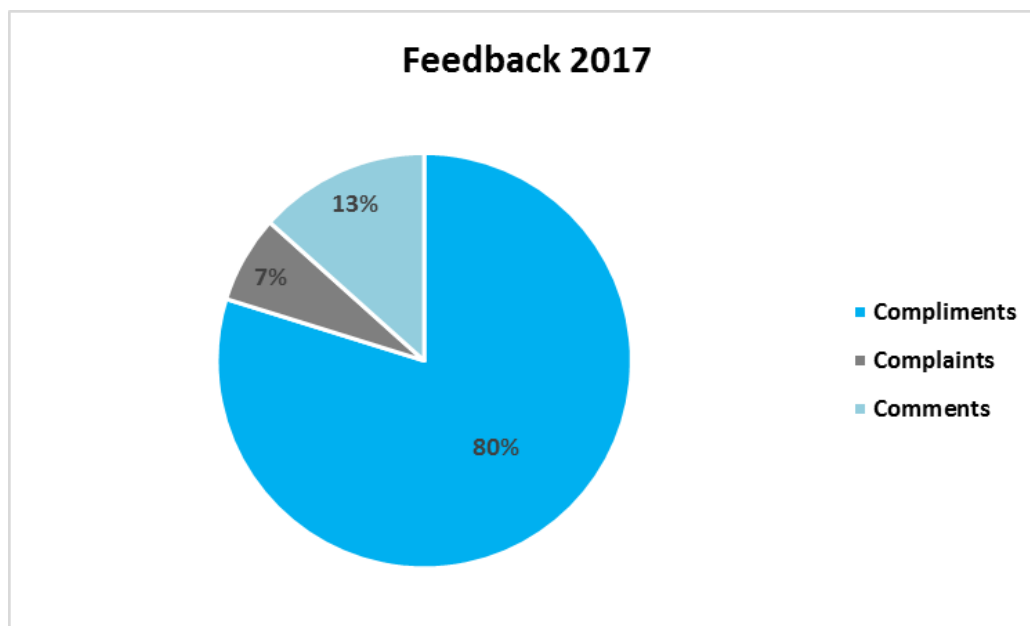
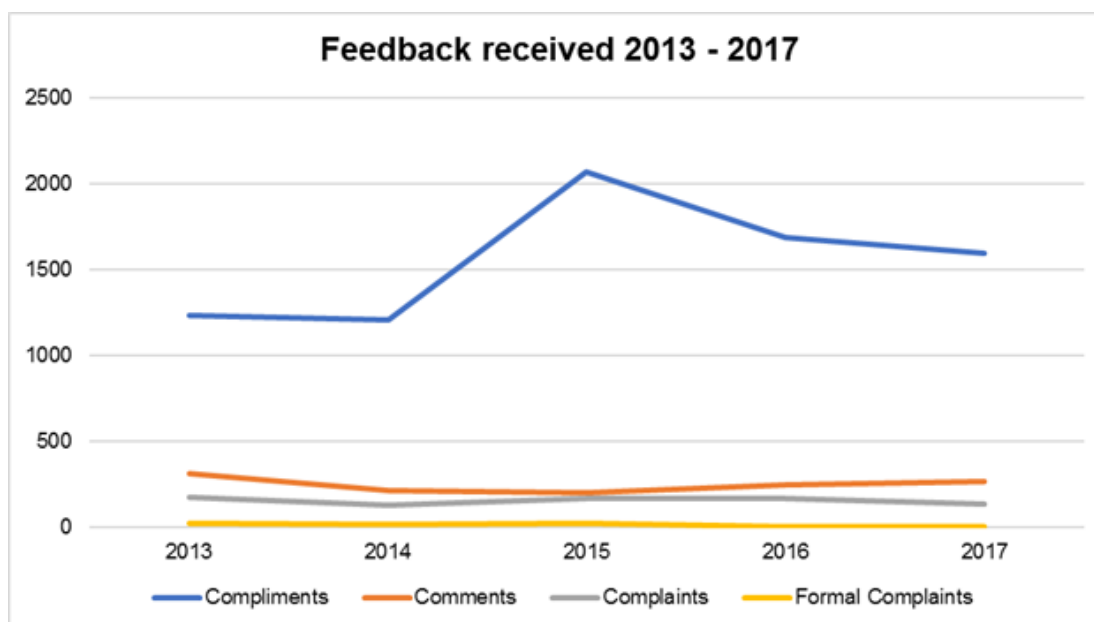


Figure 1: Feedback received – 2017



Graph 1: Feedback received 2013 - 2017

Customer Service Excellence Standard

In 2017 we retained our [Customer Service Excellence Standard](#) accreditation for the 5th year, following the annual compliance audit and re-assessment visit, which took place in November.



Key Performance Indicators

Feedback

The feedback key performance indicator monitors the ratio between positive feedback (compliments) and negative feedback (complaints) received. Our target is to receive no more than 25% negative feedback items in any given year. We performed within this target, as shown in Table 1.

Year	2013	2014	2015	2016	2017
Target	<25%	<25%	<25%	<25%	<25%
Actual	14%	11%	9%	13%	9%

Table 1: Percentage of negative to positive feedback since 2013

Response times

As outlined in our [customer pledge](#), we aim to respond to written correspondence, feedback and queries within 5 working days. Our target is to respond to a minimum of 85% of these items within the stated time frame. In 2017, we continued to perform well within the target, as detailed in Table 2 below.

Year	2013	2014	2015	2016	2017
Target	>85%	>85%	>85%	>85%	>85%
Actual	90%	89%	88%	92%	94%

Table 2: Percentage of feedback responded to within 5 working days since 2013

Complaints escalated to formal stage

We aim to resolve all complaints first time and to the satisfaction of the complainant. Where this isn't possible, the complaint moves to formal stage. Our key performance indicator is that no more than 10% of complaints in the year are escalated to formal stage. In 2017 we performed well within the target range as shown in Table 3:

Year	2013	2014	2015	2016	2017
Target	<10%	<10%	<10%	<10%	<10%
Actual	15%	11%	13%	2%	3%

Table 3: Percentage of complaints escalated to formal level since 2013

For further information, including feedback topics and trends, please refer to the full Customer Feedback 2017 report from the following page.

Customer Feedback Report 2017

“Thank you for making it easy to be a part of the movement that gives voices to us in a seemingly powerless group.”

(Person with Parkinson's, Q3 2017)

The charity's continuing aim to put the views of people affected by Parkinson's at the heart of everything we do is underpinned by various mechanisms, including our feedback channels which provide an immediate way for individuals to share their views about the charity with us. People can contact us in numerous ways – online, email, telephone, in person, using feedback cards and through surveys.

The feedback gathered is rich and varied. It helps to shape our work and provides insight to service-user perception of the charity and an overview of how we're performing in relation to customer care standards.

This report provides an overview of customer care practice and feedback received during 2017 from people affected by Parkinson's, supporters, volunteers and others within the Parkinson's community.

Activity in 2017

To provide context, 2017 was a busy year in relation to supporter contact and service use:

- Helpline answered 20,944 phone calls and responded to 3,328 email enquiries.
- Parkinson's Local Adviser service received 11,852 referrals (9,432 new) and had over 25,317 general enquiries;
- fundraising campaigns and activities included
 - Direct Mail: 80,037 pieces
 - Email: 12,355 broadcast
 - Telephone: 13,892 outbound conversations
- Information resources ordered: 310,500
- Information and support web page unique views: 2,095,739 (April-December)

Definitions

Feedback includes:

- Comments and suggestions – people sharing their thoughts about the charity 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 as they were not resolved first time
- Where a person has explicitly said they would like to make a formal complaint

Feedback received in 2017

In 2017 we received 1996 items of feedback overall, of which

- 1593 were positive/complimentary
- 267 were comments or suggestions
- 140 were complaints.

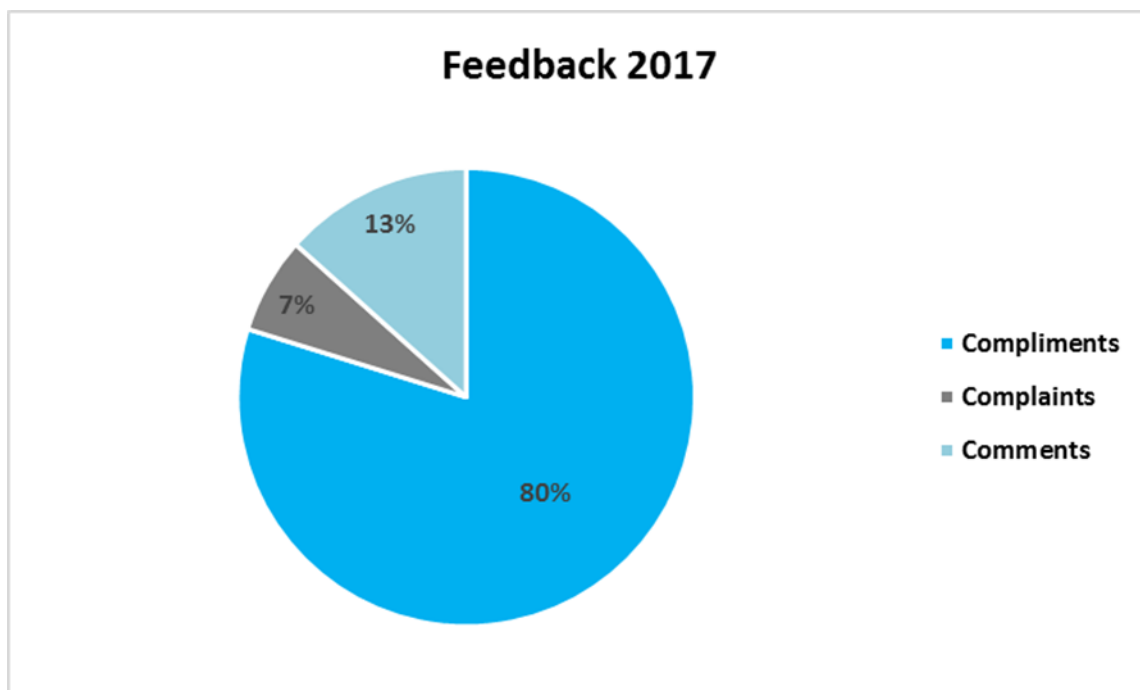


Figure 1: Feedback received – 2017

Breakdown of feedback in 2017

2017	Jan	Q1 Feb	Mar	Apr	Q2 May	Jun	Jul	Q3 Aug	Sep	Oct	Q4 Nov	Dec
Comments	17	10	16	25	27	20	25	21	26	22	32	26
Compliments	81	103	106	80	125	129	107	72	64	65	87	573*
Complaints	12	7	14	10	9	13	11	7	12	9	13	16*
Formal Complaints	2	1	0	0	0	0	0	0	0	1	0	0
Total	112	121	136	115	161	162	143	100	102	97	132	75

Table 1: Breakdown of all feedback – 2017

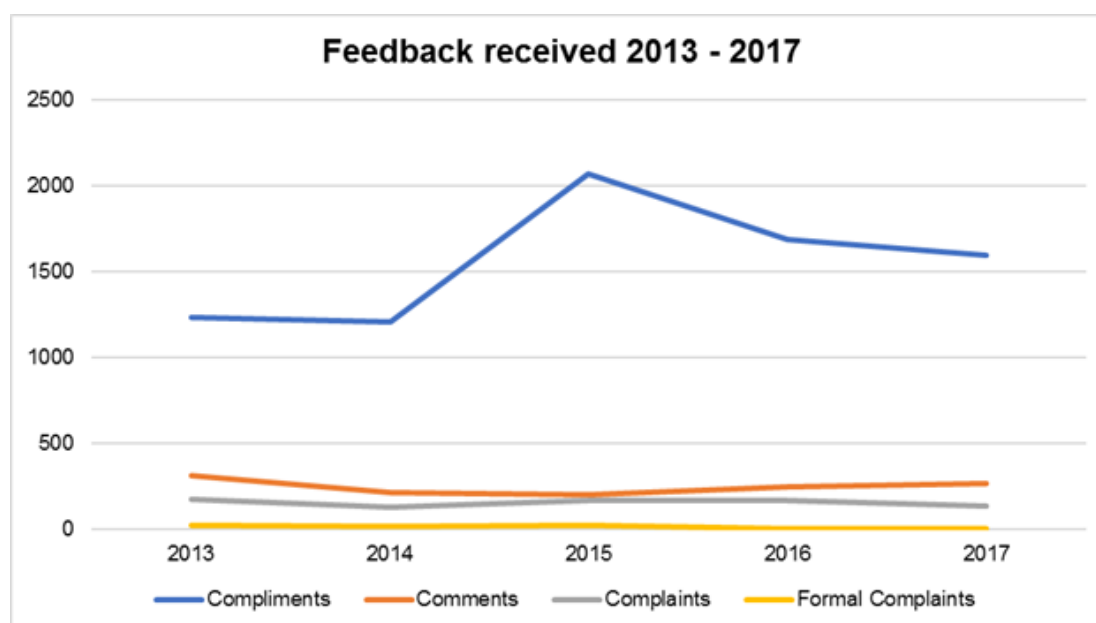
*includes a total of 525 positive and 15 negative survey responses

Comparison to previous years

The total feedback items received (n1996) reduced slightly compared to 2016.

Feedback 2017	2013	2014	2015	2016	2017
Compliments	1233 (71%)	1205 (77%)	2066 (84%)	1684 (80%)	1593 (80%)
Comments	313 (18%)	216 (14%)	199 (9%)	244 (12%)	267 (13%)
Complaints	172 (10%)	131 (8%)	171 (6%)	170 (8%)	136 (7%)
Formal Complaints	26 (1%)	15 (1%)	26 (1%)	4 (0%)	4 (0%)
Total	1744	1567	2493	2102	1996

Table 2: Comparisons to previous years



Graph 1: Feedback received 2013 - 2017

Positive and negative feedback

Removing comments and suggestions (neutral feedback), of the items received, 91% (1593 items) were complimentary and 9% (140 items) were negative (complaints and formal complaints).

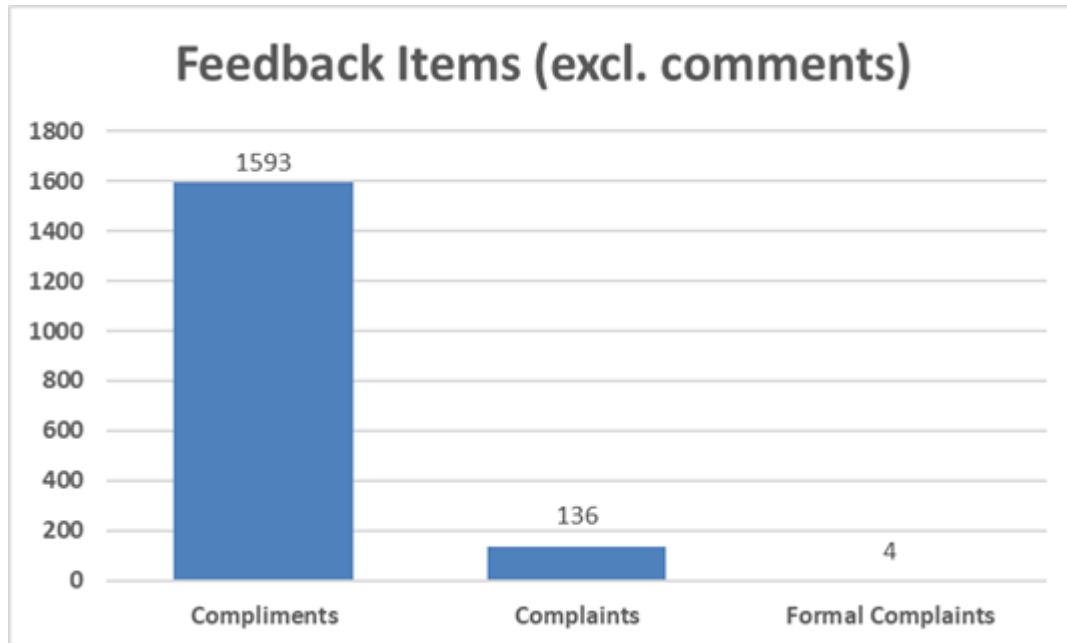


Figure 2: Feedback received in 2017, excluding comments and suggestions

Unsolicited feedback

Within our feedback figures we include some solicited feedback gathered through evaluation surveys, for example. With survey data removed, we received a total of 1456 items of feedback (unsolicited); of these 1456 items 1068 were positive, 121 were negative and 267 were comments or suggestions as shown in Figure 3.

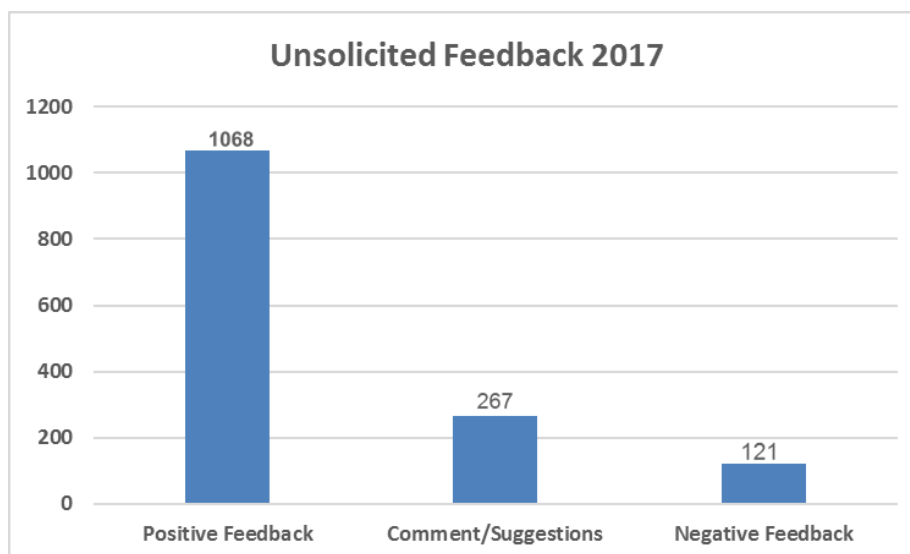


Figure 3: Levels of unsolicited feedback in 2017

When we compare unsolicited feedback in 2017 to previous years, we note that the positive feedback received has continued to increase, whilst negative feedback has decreased.

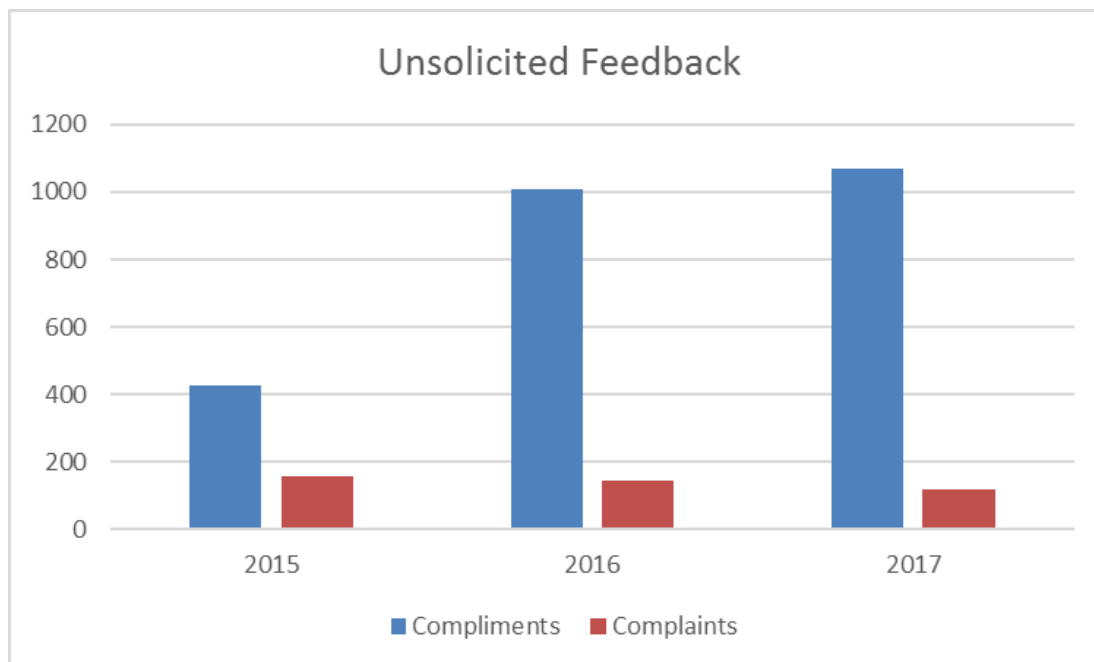


Figure 4: Unsolicited feedback items for positive and negative feedback 2015 to 2017.

Compliments

Compliments were received from across the UK and relating to all areas of the charity. And 2017 saw an elevated level of unsolicited compliments: 1068.

The following areas of the charity received particularly strong feedback during 2017:

Parkinson's Local Advisers

As was the case in previous years, Parkinson's Local Advisers make up most of our unsolicited feedback, with over half of all positive feedback being instances of service users praising their local adviser.

"Parkinson's support has been priceless, with advice and helpful information – not just at the beginning but even when you [just] need to talk" - Q1, 2017

"I had a home visit for help applying for PIP, with which I was successful, without the need of an assessment, which was a great relief. An excellent professional service." - Q4, 2017

Helpline

Feedback in relation to the helpline continued to be strong, with Benefit and Employment Advisers receiving praise for assisting people to navigate the benefits system.

"Found the helpline extremely helpful. Really appreciated the support, encouragement I received." – Q4, 2017

"We used the helpline recently - it's excellent. I spoke to a nurse with 18 years' experience and it was so reassuring" – Q1, 2017

Editorial and Creative

Feedback in relation to our information resources was positive throughout the year, with 91% of respondents saying they answered their questions and 96% saying that they helped them better manage their condition day-to-day.

Additionally, there was praise for our magazines, The Parkinson and Progress.

"I would like to compliment you on all the work that you do [...] I find the magazines very informative and having Parkinson's myself look forward to these coming through my door." – Q1, 2017

Website

The website redesign, particularly the Information and Support section, has received positive feedback from users. Praise has been received regarding the standard and clarity of information, the wide-ranging information available, as well as the inclusion of information for younger people living with the condition.

"Having seen Parkinson's UK take on feedback and react by transforming their whole digital performance is a real feather in their cap. As someone with Parkinson's but still of a working age, it is so important that the charity can communicate on new levels." – Q2, 2017

"I would like to compliment the team who designed your website and all the information contained therein. I found it informative across the whole spectrum of Parkinson's and which is written in a way that is easy to follow, giving a balanced view. Congratulations on a job well done" – Q2, 2017

First Steps programme

"I just wanted to say a huge thank you to Parkinson's UK and the programme facilitators for providing an empowering and positive First Steps programme. I came away yesterday feeling that I can do anything and now I will. That was after day 1. I really hope that people around the country, in my position will be able to access this invaluable course. I look forward to day 2." - Q1, 2017

Policy and Campaigns

The Campaigns team received positive feedback relating to a wide range of activities, from the Personal Independence Payment (PIP) media coverage and presence at political party conferences to supporting people with Parkinson's with benefit claims and advice.

"Thank you for making it easy to be a part of a movement that gives voices to us in a seemingly powerless group." – Q3, 2017

You said, we did 2017

We use feedback to shape how we do things. Based on the views shared by people affected by Parkinson's, here are some of the things that have changed.

Helping you find local activities	
You told us what activities would best help you maintain control and manage your condition. With more and more activities becoming available across the UK, we had to find a way to make this information easily available to you.	Staff and volunteers worked extensively inputting information about activities from all areas of the UK into the database that is now live on our website. With a simple postcode search, you can now find local activities for you.
Taking education further	
Occasionally, we've been unable to provide a training presentation within a care home. This happens when we don't have a volunteer educator available at the time within an area.	We now provide access to online learning modules for care home staff. This solution has resulted in 31 people opting to learn online in 2017. This method also means we can provide training to care homes located in more remote areas of the UK, where volunteer educators are not always available.
Young onset Parkinson's	
You told us that we could do more to represent the needs of younger people affected by Parkinson's.	<p>In 2017 we:</p> <ul style="list-style-type: none"> • we came together with younger people affected by Parkinson's, including those who represent independent charities and networks, under the Younger Parkinson's Alliance, to work collaboratively to take forward a bespoke programme of work • we piloted a tailored online self-management programme • we held First Step sessions younger people who are newly diagnosed • in collaboration with expert clinicians and researchers, the Younger Parkinson's Alliance is developing a consensus statement on the treatment of young onset Parkinson's

Policy and campaigns	
<p>You told us you didn't always know about our campaigns successes or how you could get involved locally.</p>	<p>Our campaigns work relies on you, the Parkinson's community, and we recognise the importance of better engagement and success sharing. So we have updated the campaigns section of our website and you can now find a prominent area showing our successes. We have also produced a flyer on campaigning and how you can get involved.</p> <p>Additionally, new country pages on the website allow you to see information on all our services in Scotland, Wales and Northern Ireland and how to get involved locally with campaigns.</p>
<p>You told us that our policy work didn't address concerns people had about mental health problems associated with Parkinson's.</p>	<p>We reconfigured the team and recruited a staff member to focus on mental health, alongside dementia.</p>
Our website	
<p>You tested our website and gave us feedback on what could work better within our information and support area.</p>	<p>Changes made following your feedback include:</p> <ul style="list-style-type: none"> • improved accessibility • web content is now fully searchable and easier to locate • a new bespoke area dedicated to those with young onset Parkinson's • a new section for people who are concerned they <i>may</i> have Parkinson's – we'd previously not provided for this sort of user • reworked content for newly diagnosed people, answering the top questions you have at point of diagnosis.
Improved care for our members and supporters	
<p>You told us that our donations processing system was slow and frustrating.</p>	<p>So we launched a new credit card processing system, which allows us to take immediate and fuss-free card payments live over the phone with you.</p>
<p>You also said it was frustrating when different members of staff followed up</p>	<p>We now log all communications with an action on a database each time you get</p>

on your donation and membership queries.	in touch with our Support Services Team. Each action makes it clear which member of staff you last spoke to, meaning any further follow-up can happen with the same member of the team.
Helpline	
<p>Sometimes you experienced difficulties contacting your Parkinson's Local Advisers, if they were on long-term absences or where a post was vacant.</p> <p>You said getting through to us wasn't always easy at times when we were experiencing outages in service or staff absences.</p>	<p>Our helpline is now working with other teams to ensure up-to-date details on Parkinson's Local Adviser availability so that we have accurate information quickly available when you call us.</p> <p>We now employ additional helpline advisers who can work on a temporary basis providing cover during busy periods and/or where staff are on leave or sick.</p>
Local group visits to London office	
Local groups visiting the UK office say it's a very positive experience - they gain insight into the work we do here and feel more connected as a result. However, feedback from one volunteer suggested that all visits should include the opportunity to meet the Chief Executive or a Director.	We agree with this valuable feedback and from 2018 all hosted visits to the UK office by volunteers will include the opportunity to meet a senior leadership team member.

Complaints

In 2017 140 complaints were received, making up 7% of all feedback received.

In this final part of the report, we list all complaints received. As expected, a high proportion of complaints fall under the areas where there is the highest activity and interaction with customers. Principal areas of activity include:

- Helpline answered 20,944 phone calls and responded to 3,328 email enquiries.
- Parkinson's Local Adviser service received 11,852 referrals (9,432 new) and had over 25,317 general enquiries;
- fundraising campaigns and activities included
 - Direct Mail: 80,037 pieces
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- Information resources ordered: 310,500
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Formal complaints

There were no recurring formal complaint themes this year - 4 formal complaints were received with 1 being partially upheld.

Complaint Theme	No.	Upheld
No thank you letter after donation	1	-
Concerns about transparency of research and funding	1	-
Non-removal of address from database	1	-
Local group Service level agreement	1	1

Informal complaints

Fundraising Directorate (66)	Complaint Theme	No.
	Poor customer care (<i>New member received slow response from the charity, with first communications received being appeal letters</i>)	1
	Database (<i>1x failure to remove deceased member, 3x discrepancies between head office and local group data lists</i>)	4
	Order had not been received (<i>Christmas order not received as of 9th Jan</i>)	1
	Difficulty making donation (<i>1x difficulty in sending a mixture of cash and cheques following a funeral, 1x confusing direct debit form, 1x website error led to duplicate donation from major donor</i>)	3
	Wrong information on thank you letter (<i>1x member had sent two donations, thank you letter only included</i>)	1

	<i>one amount – second cheque had been cashed separately)</i>	
	Repeated mailings/communication (3x too many fundraising appeals, 1x membership cancelled due to intimidating volume of donation requests)	4
	Events fundraising (1x member had sent cheque with funds for entry to the Great North Run, cheque had not been received so direct debit payment made – cheque later received so second transaction processed)	1
	Staff rudeness (1x customer was disappointed in having to wait over 3 weeks for their membership card. But was most disappointed by the member of staff they spoke to who they felt lacked apparent empathy)	1
	Unsolicited contact (3x member donated but following additional asks for donations, now opted for no further contact from charity)	3
	Delay in receiving membership (1x member had not received membership information 1 month after sending application)	1
	Wasted recourses (1x member incorrectly received a membership renewal form despite already renewing membership, 1x member received multiple membership cards, 1x major donor found appeal letters to be too “flamboyant and gimmicky”)	3
	No thank you letter (1x due to ICO ruling, 1x complainant did not respond to request for details)	2
	In mem letter content 3x members did not like the “loved one”/“much loved” phrasing)	3
	Location of events (Shake with Laughter only available in certain city centres, excluding members living in rural areas)	1
	No reply to correspondence (1x events team replied to email and apologised, 1x no reply following event application, 4x No reply following donation, 1x member emailed SST with no reply, 1x no reply from event team, 1x Major Gifts team re. gift aid)	9
	Disappointed with thank you letter (1x member felt unvalued by charity following generic reply following donation of a substantial amount of money)	1
	CAF charity account payment delay	1
	Direct debit forms (1x supporter put off donating as he did not believe the donation form required the CSC numbers filled out, citing this a fraud risk)	1
	Fundraising materials (1x member felt that fundraising materials were not being used to raise awareness)	1
	Failure to be removed from mailing list (1x member had requested to be removed from mailing list,	3

	<i>continued to receive mails to an altered address, believed that the address had been changed as a loophole to continue sending mail, 1x failure to remove deceased member from mailing list, 1x failure to remove member from list)</i>	
	Garden Gathering Pack (1x disappointed with Garden Gathering Pack contents)	1
	Legacy appeals (1x member joined and first piece of literature she received was a legacy appeal, putting her off supporting the charity)	1
	Insensitive appeal letter (1x appeal letter sent to family whose son-in-law with Parkinson's recently passed away; also felt we could do more for him as a younger person)	1
	Merchandise (1x local group secretary is disappointed with the current range of merchandise, feeling it does not help fundraising)	1
	Legacy donations (1x complaint referred to a property that had been donated as part of a will)	1
	Event e-news (1x complainant is a volunteer who does not want to continue to receive additional fundraising emails as they feel they already contribute, so removed from mailing list)	1
	Partner Company (not upheld) (1x member contacted Supporter Services claiming to have seen a partner organisation on rouge traders and wanted to know what kind of due diligence is carried out by Parkinson's UK – the gentleman was incorrect about the company that appeared on the programme)	1
	Fundraiser rudeness (1x local company emailed to complain of 'rude' volunteer fundraiser, apology was issued. Investigation carried out and local volunteering team made aware)	1
	Christmas card options (1x member based in Wales found it patronising that the only Welsh language card featured a picture of a sheep; also was disappointed at the lack of bi-lingual cards)	1
	Rubbish left following event (1x complaint following rubbish left following event – apology issued but events team believe rubbish was left by external company)	1
	VAT exemption on website (1x member attempted to purchase an item that had been listed on the website as VAT exempt, the website was out of date and the item was no longer VAT exempt)	1
	Lack of support for fundraisers (1x member did not feel supported by fundraising team following changes made to their event, 1x lack of support from charity for fundraising event)	2

	Disappointed with event (1x Spooky Sprint, disappointed with organisation)	1
	Difficulties renewing membership (1x member had sent cheque to renew membership, this was not received, member then made direct debit payment. Cheque later arrived leading to a duplicate payment)	1
	Breach of Data Protection (Not Upheld) (1x member believed that Fundraising team had shared details of a donation with another organisation)	1
	Dave the worm (1x member did not understand the need for Dave the Worm, Dave The Worm no longer in use as a marketing tool)	1
	Database error (1x member address had been changed without his permission – UK Changes, 1x member listed as deceased incorrectly)	2
	Staff rudeness (call to helpline saying they were disappointed by staff member's tone of voice. Call was about a daily living aid so we're unsure who they spoke to – this potentially member of was a shop staff).	1
	Plastic card coverings	1

Support and Local Networks Directorate (22)	Unhappy with local support (1x lack of support in Northern Ireland, member was not aware of support available, 1x admin and governance expectations of volunteers, 1x along with donation member stated he and his wife had not received any support for many years)	3
	Local group network materials (1x too much cyan ink used when printing, 1x late delivery of materials)	2
	Staff behaviour (1x concerns raised by local group regarding behaviour of staff at group meeting)	1
	No reply from helpline (1x no record of phone call or message could be found, member did not want to follow this up)	1
	Parkinson's local adviser advice perceived as unhelpful. (Adviser spoke about the benefits of employment but the client felt unable to work)	1
	Volunteer home visits (1x volunteer disappointed that charity policy does not allow for members to visit housebound members, stating it makes it impossible to 'reach everyone' at a national level)	1
	Local group Chair (1x member of a local group phoned to complain about the newly elected Chair who had been disregarding policy – resolved by local team following meetings with the group)	1
	Lack of support for volunteer educators (1x Volunteer educator believes that the recent change in structure has altered the level of support received by	1

	<i>volunteer educators from the charit, in terms of referrals, raising awareness and general administrative support)</i>	
	Self-Management Toolkit (1x member is concerned that the new self-management toolkit is an alternative to making effort to engage 'difficult to reach groups' such as those who are housebound and cannot attend self-management sessions)	1
	Discrimination (1x member of Skegness group felt he had been discriminated against due to his wheelchair, fully investigated by local team)	1
	Helpline (1x complaint against helpline, team member was 'completely unwilling to help or provide information' – no further information given and no record of call internally Not upheld)	1
	Local group membership lists (2x inaccuracies in local group listings)	2
	Termination of contract (1x local group cancelled contract with exercise class, fully investigated by local team partially upheld)	1
	Branch procedures (1x too much admin left to groups, unhappy with procedures set out by head office)	1
	Working age terminology (1x members felt alienated from events advertised as working age)	1
	Lack of reply/Are you still there (1x Upon investigation member had received replies, not upheld)	1
	Lack of support from charity (1x various issues from a regular supporter)	1
	Kinetics film funding (Local group disappointed they cannot fund a film about Parkinson's through the charity)	1
Research (5)	Brain Bank (1x exchange with Brain Bank operator perceived as uncompassionate, Brain Bank responded to member directly)	1
	Expenses at GDNF event (1x member had requested additional expenses paid following event, including 1 st class upgrade and disabled rail card, all of which fall outside of the expenses policy.)	1
	Virtual Biotech Appeal (1x member had received various pieces of mail about Virtual Biotech but does not understand the purpose of it)	1
	Project Involvement (1x member complained about the selection process for a project, members that had been involved in earlier stages or research were disqualified from later research – upon discussion with research team this was revised)	1
	Negative lecture content (1x member found lecture to be well presented but content was negative and depressing in regard to living with Parkinson's)	1

Organisational Development (4)	No reply following application (<i>volunteering team made contact to discuss application process</i>)	1
	Discrimination (<i>1x Interviewee claimed to have been discriminated against during an interview, has not provided any further details for investigation upon request, not upheld</i>)	1
	No reply following interview (<i>1x Interviewee had received no feedback following interview</i>)	1
	Volunteering (<i>1x local group raised concerns around volunteer retention and abundance of admin</i>)	1
Finance, IT and Performance Directorate (5)	Where your money goes graphic (<i>1x member thought the 'where your money goes' graphic was incorrect and difficult to read</i>)	1
	Charity spending (<i>1x local group had various queries around charity spending, particularly related to staff salaries, role changes and the charities presence at the World Parkinson's Congress</i>)	1
	Delayed expenses payment (<i>1x involvement member had his expenses payment delayed, member also had problems reaching accounts payable (out of date voicemail greetings). Member received payment following conversation with accounts payable</i>)	1
	Incorrect details on database (<i>1x ongoing issue in which members details are altered during database cleanses</i>)	1
	AGM (<i>1x local group felt that voting procedure should be more transparent</i>)	1
Strategic Intelligence and Excellence Directorate (1)	NICE Guidelines (<i>1x member felt that The Parkinson should be used to raise awareness of NICE guidelines and felt disappointed that the charity had not consulted members on the guideline's development</i>)	1
Digital Transformation and Communications Directorate (14)	Parkinson's Awareness Week (<i>1x local groups do not have enough time to plan events, 1x late delivery of materials</i>)	2
	Difficulty donating online	1
	Difficulty completing online registration form (<i>1x member attempted to sign up for an event online, found form kept deleting information repeatedly</i>)	1
	No reply to letter (<i>1x 3 poems and letter unanswered, letters and poems could not be located so apology issued</i>)	1
	Lack of support for advanced Parkinson's – (<i>1x person was referred to the advanced Parkinson's</i>)	1

	<i>section of the website and informed of various pieces of work concerning advanced Parkinson's)</i>	
	Time and location of events (1x complaint was in response to an evening session, marketing explained the reasons behind the later time of the session and the complainant was provided information on corresponding day time sessions)	1
	Website content (1x forum user emailed to request his account be closed as he felt the website is designed solely to fundraise)	1
	Forum privacy (1x forum user is concerned that members are using the forum to gather personal data on other members – forum team assured member that privacy is taken seriously and moderators work to protect this, also reminded members it is their responsibility not to post personal details)	1
	Plagiarism (1x email received accusing the charity of using their idea for an animation teaching children about Parkinson's without credit)	1
	Forum profile closure (1x Member wanted to have their forum profile completely removed as opposed to only being blocked due to privacy reasons, 1x Member requested forum profile to be closed due to disagreements with other members on the forum, member suggests thread authors be given moderation privileges over their own threads to prevent further disagreements)	2
	Impulsive and compulsive behaviour warnings (1x Carer believes that the charity does not do enough to warn people about potential side effects of medication)	1
	2010 Rebrand (1x Gentleman believed that the 2010 rebrand had been a misuse of charity funds)	1

Involvement and Inclusion, 2018