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# Results from the 2016 Pituitary Foundation Survey

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Pituitary Life

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## **Results from the 2016 Pituitary Foundation Patient Satisfaction Survey**

**By Hannah Forrest, Alyson Norman & Sue Jackson**

Last year members of the Pituitary Foundation were invited to take part in a survey to look at the needs of patients with pituitary conditions. This was an update to the patient satisfaction survey that was conducted in 2006. The survey was sent out to 2000 members of the Pituitary Foundation. Of those, 1062 members took part. The survey consisted of a series of questionnaires about patients' conditions, their diagnosis and treatment, how they manage their condition, and membership of the Pituitary Foundation. Respondents were also given the opportunity to give free-text feedback on questions on the key issues they faced and how the Foundation could better support them, the impact of their illness, how the Foundation had helped them, any problems they had getting others to understand their condition and feedback on the digital services provided by the Foundation.

366 of people responding to the survey were male and 683 female (some did not give their gender), and were aged from under 18 years of age to over 65 years, with most people being between 36 and 55 years of age. Men were generally a bit older than women, with more being between the ages of 56-65 years. 861 people lived in England, 70 in Scotland, 30 in Wales and 20 in Northern Ireland. 15 people came from outside the UK. 89% of respondents identified themselves as White British (948 respondents) and 6% identified as "other white" (67 respondents). Thirteen respondents were Asian, 8 were Black British, 3 other Black, 2 Chinese and 9 reported being of other ethnic backgrounds. 94% of respondents identified as being someone with a pituitary condition, with 1% being worried that they may have a pituitary condition but not yet having a diagnosis. 3% of respondents were relatives or friends of someone with a pituitary condition. Of those taking part, half were in paid employment (52% full time, 48% part time), 4.5% were in education and 15% were volunteers.

Two thirds of respondents felt supported by the organisations that they worked within and their managers, with 77% feeling their colleagues were supportive. The survey did highlight that respondents felt they did not get enough information to help them manage their condition at work (72%), with two thirds of people feeling their careers

had suffered as a result of their condition and half stating they had given up work because of their condition. 21% of people reported feeling discriminated against at work because of the pituitary condition.

**Diagnosis:** Respondents reported having a range of different pituitary conditions, with the most common being hypopituitarism (473 respondents). 183 respondents had diabetes insipidus, 170 had a non-functioning tumour, 138 had acromegaly, 123 had prolactinoma, 98 had Cushing's disease, 64 had craniopharyngioma, 367 had hypogonadism and 14 had Sheehan's syndrome.

The most common symptoms reported included fatigue (72%), mood swings (58%), anxiety or depression (57%), changes in appearance following their condition (57%), weight gain (48%) and difficulties concentrating (41%). 43% of respondents reported pain, 39% experiencing low libido, with 8% experiencing impotence, and 36% reduced fertility or infertility. A further 33% of respondents experienced headaches, 29% of respondents reported feeling generally unwell, with 28% experiencing difficulties recovering from minor illnesses. 24% of respondents reported dizzy spells and changes to their appetite. 21% reported changes in their behaviour and 20% reported thin skin.

Respondents were asked how long after they first told their GP about their symptoms they received their diagnosis. Answers ranged from less than 1 week to 40 years, with patients having to wait on average 3-4 years and many (13% visiting their GPs more than 20 times.

Respondents could rate the service they received from healthcare professionals involved with their pituitary care. The top three groups of health care professionals were opticians, neurosurgeons and radiologists. The worst three groups of health care professionals were neurologists, practice nurses and GPs with GPs being rated lowest with only 68% rating them as good or very good.

**Information and Support:** Respondents were asked whether they had been given information about the Pituitary Foundation, or recommended they contact the Foundation by either their GP or endocrine nurse. Worryingly, only 36% of respondents stated that they received this information. Respondents were then asked about the information they received about their condition. 49% agreed or

strongly agreed that they were not told enough about their condition when they were first diagnosed. A further 37% felt they had not been told enough about their condition before treatment and 38% felt that were not told enough about their condition after treatment. 48% agreed or strongly agreed that they had not been given enough written information about their condition.

Information was collected in the survey about things that could make a real difference to the health care of pituitary patients. 75% of respondents stated that there needed to be more information on the impact of pituitary illness on mental health and what support is available and 73% highlighted that better informed GPs and early signposting to the Pituitary Foundation would improve healthcare. 63% agreed that there was a need for more information around different treatment options and 61% felt an online community to discuss pituitary illness and treatment options would be useful.

Generally respondents found the support they received from the Pituitary Foundation useful, with many agreeing that the Foundation helped them to cope with their diagnosis and treatment, helped them feel in control of their life, reduced the fear they felt as a result of diagnosis, and reassured them. Respondents also felt that the Pituitary Foundation helped them to gain a realistic idea of their future, and helped them to make the most of hospital consultations.

**Managing Pituitary Conditions:** Respondents were asked about local support group service. Only 19% stated that they had attended a local support group, with most stating that distance and travel difficulties prevented them from attending. 22% of respondents lived within 30 minutes of local group and 33% within an hour of one. Of those who did attend local support groups, 26% felt that support groups provided them with information, 24% found them useful for meeting like-minded people, 20% gained a sense of belonging and 20% found them useful for learning about different treatment options. A further 18% gained emotional support and found them useful for self-management of their conditions.

The survey highlighted other problems that pituitary patients experience with managing their conditions. 23% were dissatisfied with their ability to get around, 46% were dissatisfied with themselves generally, and 47% were dissatisfied with the

quality of their sleep. Relationships were also affected with 43% feeling dissatisfied with their sex lives, 23% dissatisfied with their personal relationships and 20% feeling that did not get enough emotional support from friends and relatives. 44% of respondents felt their pituitary condition had prevented them from socialising.

**Membership of the Pituitary Foundation:** When asked why respondents joined the Pituitary Foundation, 66% answered that they had done so to gain information about their condition, 54% to support the work it does and 45% to receive the pituitary life magazine. A further 34% joined to feel part of a community and 33% for emotional support. 55% of respondents in the survey felt that the pituitary Foundation made them feel part of a community.

Respondents were asked to state how supportive the Pituitary Foundation had been in aspects of the pituitary care and management. Overall, 70% of respondents were satisfied with the support they received from the Pituitary Foundation. 49% of respondents agreed that the Pituitary Foundation helped them to cope with their diagnosis and 48% agreed they helped them to cope with their treatment.

The survey listed a series of support services offered by the Pituitary Foundation and asked respondents to state whether they were aware of them, had used them, and if so how helpful they had been. The three most helpful services were the information booklets, newsletter and the website. The three least helpful services were the online forum, Facebook and Twitter feeds and the telephone buddies network. This was mainly because most members had not used these services.

As part of the feedback about the Pituitary Foundation, respondents were asked about the Pituitary Life magazine. 59% found the magazine informative, 54% found it easy to read and 49% of respondents enjoyed reading the patient stories. 48% of respondents stated that the medical articles helped them to manage their conditions whilst 29% felt it had engaging content.

Respondents were asked to provide feedback on the type of content they would like to see more of. The three most popular answers were; new treatments (38%), long term conditions (33%) and Hydrocortisone (32%).

**Open questions:** As part of the open comments element of the questionnaires, respondents provided information about the following issues; 1) a lack of awareness of pituitary conditions, 2) managing my condition, 3) personal relationships, 4) “me and the Pituitary Foundation and 5) digital improvements.

**Lack of awareness:** It was identified that there was a general lack of awareness of pituitary conditions, both in the general population and from healthcare professionals. It was felt that there needed to be wider education and awareness-raising campaigns to address this issue. This was linked to the idea of pituitary conditions being a form of “hidden disability” as many of the symptoms are not visible which often leads to a lack of understanding or empathy for patients.

**Managing my condition:** Condition management was generally seen as an issue for respondents, with quality of life being by far the biggest problem for 473 respondents. Patients felt that more information could be provided through the Pituitary Foundation to support these issues. Respondents also highlighted the impact of their condition on their mental health with more information and advice through the Pituitary Foundation needed to support them, and access to counselling.

**Personal Relationships:** 444 people identified that their condition had impacted negatively on their personal relationships. This was put down to a general lack of understanding of pituitary conditions. 65 identified that their condition had put a strain on their relationship with the partner or spouse and 56 stated they their relationship had broken down as a result of their condition. Another 51 noted the strain or breakdown in relations with the wider family network and 51 had identified that they had lost friends or had identified “*who their real friends were*” since diagnosis. This strain on close relationships left many respondents feeling that they did not receive satisfactory emotional support from close friends or relative.

Other respondents commented on the burden that having a pituitary condition puts on the wider family. Participants identified that in some cases, their partners and families had been incredibly supportive but there had been a change in the relationship with them becoming with reliant upon them or it had put an unfair strain on their family.

On a more positive note, 14 people identified that their pituitary condition had led to them becoming closer to their family or partner as a result of their diagnosis.

**Me and the Pituitary Foundation:** 515 respondents felt that the Pituitary Foundation provided an incredibly useful source of support, information and reassurance at diagnosis, during treatment and with long-term symptoms management. 71 patients highlighted that diagnosis of pituitary conditions can be very isolating and the Pituitary Foundation helped them feel part of a community and that they are not alone.

**Digital Improvements:** While many respondents, particularly older patients, preferred more traditional sources of support from the Pituitary Foundation, some wanted more access to digital services and provided recommendations on how to improve these. These recommendations included wanting a closed Facebook group, better use of a coordinator to police the forum and respond to and access to endocrine specialists through the forum via text chats and live chats. Other provided feedback on changes that could be made to the website to make it more usable.

**Conclusions:** In summary the survey has identified several key areas of need for patients with pituitary conditions, including condition management support, better support at the time of diagnosis and ongoing emotional support and understanding. Overall, respondents were satisfied and grateful for the support and information they had received from the Pituitary Foundation, and viewed them as an important source of social support to reduce the fear and isolation associated with their condition.

The survey highlighted that there were issues around diagnosis and treatment with GPs having little knowledge and understanding of pituitary conditions. HCPs were on the whole viewed as helpful and supportive but that at times they could provide better information and emotional support to patients. Problems around long term symptom management need addressing, particularly in relation to symptoms that affect quality of life. These symptoms were often left unaddressed by HCPs and the extent of their effect on patients' lives is not being fully acknowledged. Furthermore, the interaction with other conditions needs to be addressed more adequately in the future.