

AWARENESS AND COMMUNICATION:

Improving patient care in
2022 and onwards

Pituitary Patient Care
Survey 2021

The Pituitary Foundation

Registered Charity No: 1058968

The
Pituitary
FOUNDATION



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1. EXECUTIVE SUMMARY

This survey is the most extensive undertaken in the UK. It captures diagnosed pituitary patient's perspective of NHS endocrine care, over the past three years, and at every stage of the patient journey. The startling results highlight some significant issues in the systems that patients navigate. Amongst examples of good, there are many examples where care has fallen below a standard that should be expected, with potentially life-threatening consequences.

There is the need for immediate remedial action and improved communication. The good news is that we believe this to be achievable in the short-term and we would hope this to extend in the longer term.

There is a clear urgency to raise awareness and increase education around pituitary conditions in GP, emergency and non-endocrine settings. Within endocrinology, patient experiences are patchy. It is interesting that this is often due to communication – simple, and arguably easy to remedy.

The survey sought responses for the past three years, pre-dating the pandemic. The impact of covid-19 on patients, as well as on NHS staff is undeniable. However, whilst any survey will enable a bias towards negative experiences, the themes raised in this survey are amplified rather than created by the covid-19 crisis.

The report overwhelmingly reflects unequal care in all settings, with a challenging accent towards negative experiences:

ELEMENT	POSITIVE COMMENT	NEGATIVE COMMENT
GP service	3	75
Endocrine nurse	25	16
Endocrinologist	78	137
Surgery experience	14	19
Ambulance, A&E care	1	47
Education	0	27
Appointments & follow up	0	40
Covid impact	2	34
Diabetes insipidus/adrenal insufficiency	0	73
Centre specific comments	74	14
The Pituitary Foundation	17	0
General comments	26	54

The key themes of the findings are:

Overall patient experience is patchy.

There were negative comments about services in secondary and tertiary centres across the UK.

In some cases, one patient was positive while another was negative about the same centre.

Comments related to endocrine units, as well as A&E and non-endocrine settings.

Communication is vital.

The negative experiences were predominantly around communication.

In some cases, patients were not educated about their condition, in other's they were not listened to by medical staff.

Covid is not all bad.

The pandemic has of course had an impact, but it is not all bad.

If the parity of virtual or face-to-face consultations can be made clear to patients, this flexibility can be a benefit.

There is an urgent need to support GPs.

There is a lack of awareness at GP level that leads to delayed diagnosis and ongoing support for patients.

This will disproportionately affect English second language and lower socio-economic patients.

The common themes resulting in negative comments were:

- Patients experienced delays in care
- There was a perceived, or actual, inexperience of people looking after patients, particularly relating to adrenal insufficiency and diabetes insipidus
- There was poor communication between NHS staff and the patient
- Patients could not access appropriate care if they became unwell, particularly in a crisis situation

Comments on good care were largely due to:

- The patient experienced an efficient service with no significant delays
- NHS staff listened to patients, or understood the pituitary condition
- There was easy access to specialist care when a patient entered the NHS outside of the Endocrinology dept (for example in A&E)

This report summarises the findings of the survey, and gives us a clear call to action with three steps we can all take. We are in a challenging time for the NHS. The commitment of consultants, doctors and nurses is not questioned and we share a common purpose to provide the best care possible for patients. Together we must listen and collaborate, to give patients the experience they need and deserve.

Professor of Endocrinology and Consultant Endocrinologist John Newell-Price, Chair of The Pituitary Foundation medical committee, underlines this, saying:

“This is an urgent call to arms for all of us working in Endocrinology. The Pituitary Foundation, in conversation with NHS health care staff, has outlined three simple steps which we can all take to health-check our services to patients and improve communication.”

We will work with peers and partners to achieve these steps. In particular, we are collaborating with the Society for Endocrinology’s Future of Endocrinology working group, with whom we share common aims and outcomes.

I am confident we will achieve this and look forward to working with peers and partners to do so,

Ren Renwick
CEO
The Pituitary Foundation

2. THREE STEPS TO TAKE

We believe that patient care can be dramatically improved through increased awareness, education and communication. All healthcare settings are encouraged to consider how they could health-check their settings against these steps.

Step 1: Increase Awareness & education of pituitary conditions

An increase of awareness, at an emergency, as well at GP level is vital.

This is especially true around diabetes insipidus and adrenal insufficiency. Existing, excellent resources can be used to support this.

Step 2: Increase awareness of importance of communication

Communication goes two ways; a patient must be informed and educated about their condition, especially around hydrocortisone and sick day rules.

But also, and more often in the case of a less common condition, a patient must be listened to. Endocrine specialists should be contacted routinely if required. Appointments should be provided, where possible, in the format preferred by the patient.

Step 3: Signpost Charities' Support

The pressure the NHS is under is well understood and documented.

The role that The Pituitary Foundation and peer-patient led charities offer is increasingly a vital part of the patient journey, and must be signposted to patients at every stage of their journey.

What The Pituitary Foundation will do:

- We will raise awareness of pituitary conditions.
- We will signpost existing resources at GP, emergency and clinical settings.
- We will work with peers to increase efficacy of the steroid emergency card.

What The Pituitary Foundation will do:

- We will raise the importance of listening to patients who are informed of their condition.
- We will advocate for patients through our Helplines, providing support about how to navigate the NHS system.
- We will seek to work with emergency physicians to develop guidance on safe and realistic timelines for giving steroids, setting standards, and managing expectations.

What The Pituitary Foundation will do:

- We will raise awareness of our patient services in Endocrine units, to support recommendations to patients.
- We will support our network of peer support for patients in communities throughout the UK.
- We will raise awareness of the complementary work of charities at conferences, and regional teaching programmes.

3. THE LANDSCAPE FOR THE SURVEY

The survey was available electronically between August 2021 and December 2021. Instigated by Professor John Wass, the survey was developed by some members of The Pituitary Foundation's medical committee working group and requested anonymised data from diagnosed patients over 18.

The need for a survey was clarified in the Foundations 2021 conference, where standards of care post-surgery or medical treatment were discussed. The conference brought to light the variations in how the patient is informed, ready for discharge, and how or if, information about the patient's ongoing care is related between hospital clinicians, departments and their GP. The lack of emergency care protocols for adrenal insufficient and diabetes insipidus patients were also raised.

This all concurred with the enquiries received to The Pituitary Foundation Helplines where there are regular concerns raised about little or no AI adrenal insufficiency or diabetes insipidus education, nor sick day rules. Poor communication to enable patient to understand. Far longer than expected delays with appointments and tests. Unawareness of AI/DI in A&E and general wards, leaving patients without hydrocortisone and desmopressin for hours, for example the death of Kane Gorney.

A total of 982 survey forms were completed, with 700 providing free text comment. Of those leaving comments, a number of areas of concern for the pituitary patient group. 98% had received NHS endocrine care in the past 3 years.

About The Pituitary Foundation

The Pituitary Foundation is the UK's representative for pituitary patients. Established in 1994, it is recognised as one of the global leaders in its field. We run an Endocrine Nurse Helpline, responding to 900 calls annually from patients unable to get support through the NHS. We have a world class medical committee informing our research and support.

To find out more visit www.pituitary.org.uk or follow us:



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4. SURVEY FINDINGS: PATIENT EXPERIENCE

Key message:

The overall patient experience is patchy.

There is an unacceptable level of poor care, with a concerning perception that endocrinologists do not always understand a patient's condition.

This may often be due to poor communication and HCP learning, leaving the patient unaware of their own needs and opening the door to life-threatening situations.

It is clear that the information and support offered by The Pituitary Foundation is a vital part of patient care, significantly improving their experience and confidence to live well.

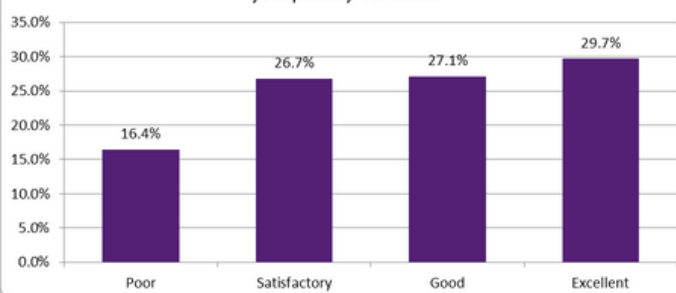
Actions:

- Ensure patients receive full education about hydrocortisone/adrenal insufficiency
- Ensure patients receive full education about diabetes insipidus
- Signpost The Pituitary Foundation to all patients

Key Findings:

- 71% of patients routinely see an endocrine consultant. 16% see a registrar and 13% see a registrar with clear consultant input.
- There is an inequitable spread of experiences for pituitary patients in the UK, with an almost equal spread of experiences from excellent to poor. Most stated that their unsatisfactory experiences pre-dated the pandemic.

What do you feel is the overall quality of care you have received for your pituitary condition?



"I usually leave appointments feeling under heard and disheartened"

"Steroid rescue pack only explained two years ago. Pituitary failed 2002. Collapsed twice without fully understanding sick day rules. Also, no info on dangers of sodium balance with DI.

Thank goodness for your charity! I feel you have literally saved my life."

SURVEY FINDINGS: PATIENT EXPERIENCE

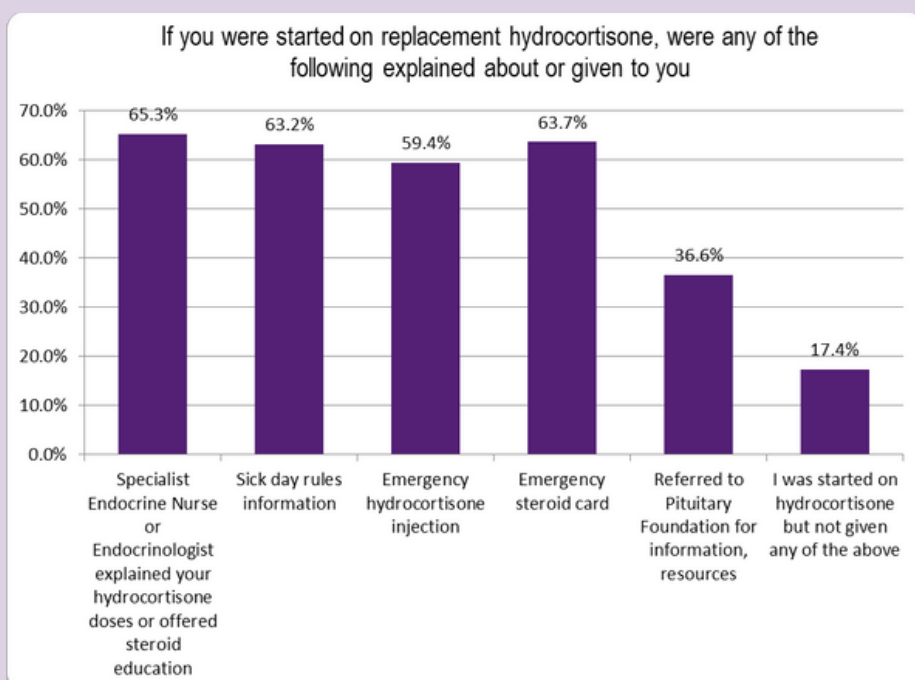
In longer term care of patients, 67% had problems accessing an endocrine consultant or team, however accessing Endocrine nurses was easier, with only 34% having problems accessing a nurse.

Regarding routine follow up appointments, 72% felt that the endocrinologist leading their care understood their condition fully. 28% felt that the endocrinologist did not.

The communication between patient and doctor is especially concerning. 23% of respondents were not warned of potential complications post-surgery (e.g. nasal congestion, blood in mucus and loss of taste or smell).

75.6% of patients with cranial diabetes insipidus were not given written information about desmopressin (e.g. doses, sodium and fluid balance), which can lead to hyponatremia and hospital admission.

Similarly, there is a significant lack of communication around hydrocortisone, with around 40% of patients not receiving information; leading to patients not understanding sick day rules, and prompting of adrenal crises, again with hospital admissions.



"Terrifying Adrenal Crisis 2010. I had the Steroid card, but why was I never warned this could happen?"

"I was unaware of the sick day rule, how it applied to me I found quite a lot of information out by myself. I found The Pituitary Foundation by googling, and that helped me no end."

5. SURVEY FINDINGS: EMERGENCY AND INPATIENT CARE

Key message:

Pituitary conditions are rare, but lack of management and treatment can lead to life-threatening situations.

Overwhelmingly, pituitary patients do not feel their condition is understood, or managed appropriately outside of an endocrine unit.

Endocrine staff are not routinely contacted when a pituitary patient is admitted, leading to life-threatening situations in cases where staff are not aware of steroid and DI precautions.

Aside from the physical risk, this leads to a patient's lack of trust in the hospital and emotional distress.

Actions:

- Raise awareness of DI amongst A&E staff
- Raise awareness of steroid replacement protocols
- Making sure the aims of the national patient safety alert are carried out

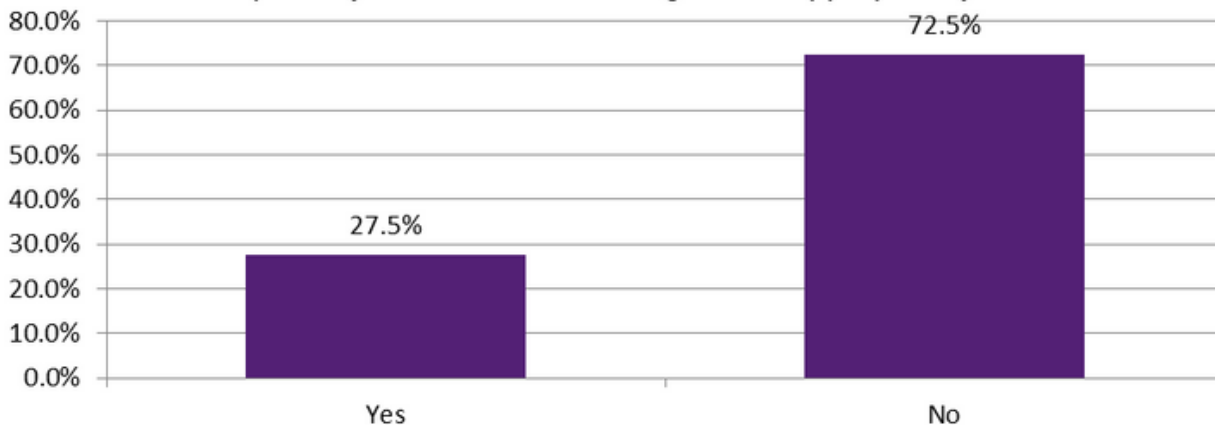
Key Findings:

There is significant concern about experiences of patients when they are in hospital, outside of an endocrine unit.

For those on steroid replacement, or who have cranial diabetes insipidus, who have been an inpatient or in A&E,

72.5% did not feel staff understood their condition or managed it appropriately.

For those on steroid replacement or with cranial diabetes insipidus, did you feel confident that staff in hospital or A&E understood your pituitary condition and managed this appropriately?



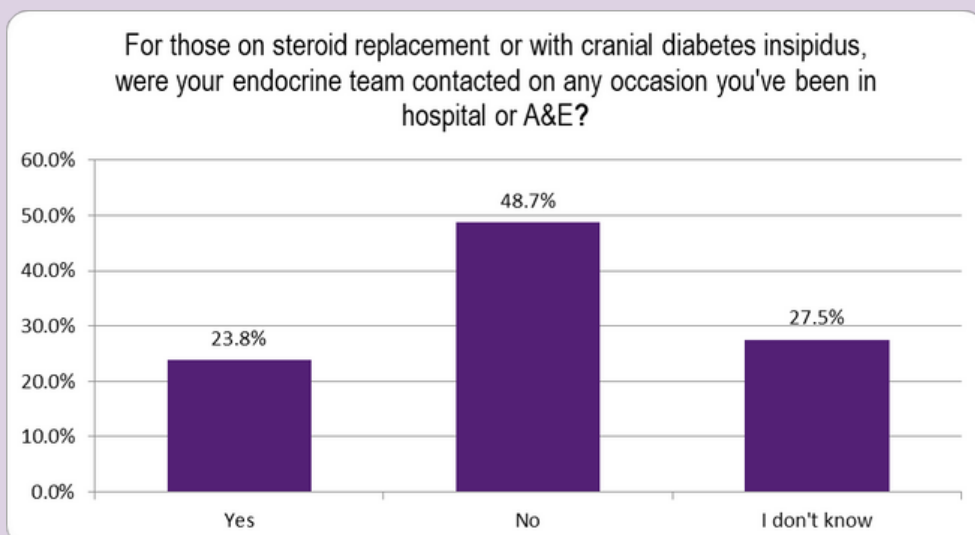
SURVEY FINDINGS: EMERGENCY AND INPATIENT CARE

There is a lack of understanding about pituitary conditions, especially diabetes insipidus which is regularly confused for diabetes mellitus.

This lack of experience leads to physical crises (e.g. an adrenal crisis), and emotional distress for the patient.

48.7% of patients who had been in hospital or A&E had not had their endocrine team contacted. For the 27.5% who didn't know, this could be due to poor communication with HCPs.

As the graph above shows, the arrangement of routine appointments for patients was satisfactory. In comments, a minority felt their appointment schedules unsuitable for their need, with reports of missed and rushed appointments featuring, along with increasing intervals between appointments. A further smaller group, reported a perceived reduction in their care as a result of the Covid-19 crisis.



“I was told on one Emergency Admission to A&E for developing adrenal crisis that the incidence is so rare it wasn't that.”

“Being an inpatient on a ward and in A&E on regular occasions, I find very few nurses if any of them know any information or how life-threatening diabetes insipidus is and how important the medication needs to be given on time.”

“When I went to A&E with adrenal crisis symptoms, with a steroid card and paperwork in my hand, I was still ignored and told to wait in reception. I was only taken seriously when I collapsed and was sick.”

6. SURVEY FINDINGS: APPOINTMENTS

POST-SURGERY ROUTINE APPOINTMENTS

Key Message:

Covid-19 has been a challenge for patients and NHS staff.

The introduction of virtual appointments is here to stay, but patients should be given choice wherever possible to have a face to face appointment.

To note: in the survey, virtual appointments referred to phone or video appointments, with no distinction.

Actions:

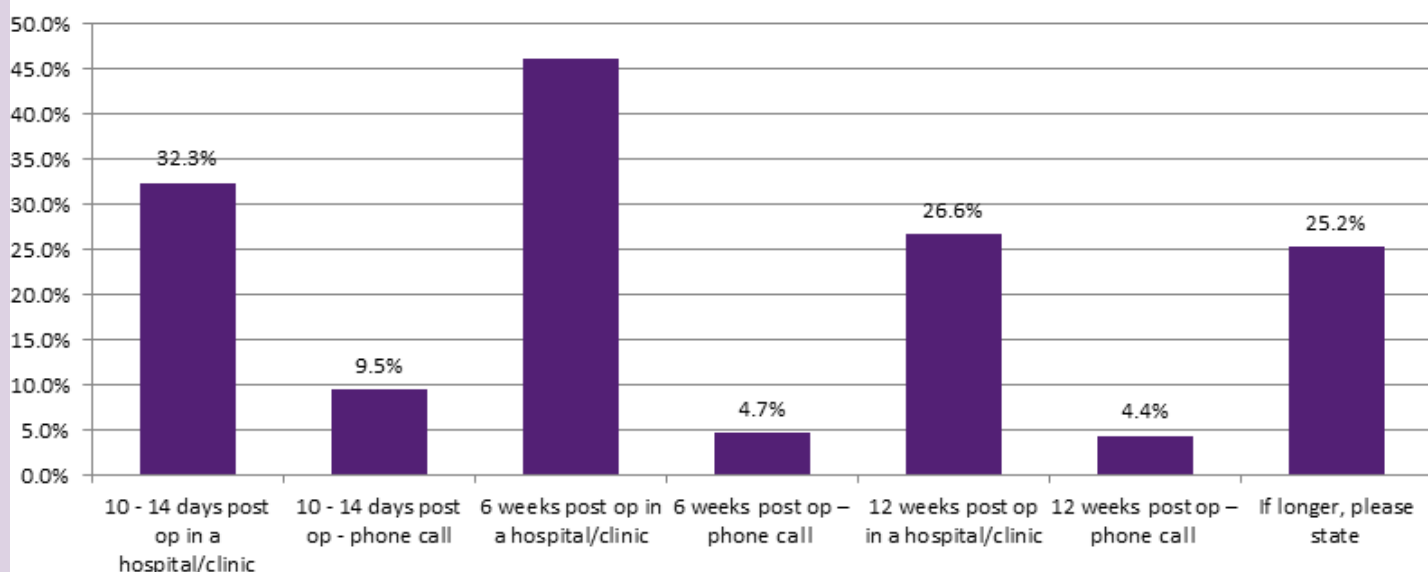
- Demonstrate the parity of virtual and face to face appointments
- Offer patients the choice of virtual or face-to-face appointments wherever possible

Key Findings:

Understandably, 69% of patients said their experience of care had changed since the start of the pandemic, primarily due to the shift in virtual appointments.

57.5% of patients who had had a virtual appointment felt that the quality of management of their condition stayed the same, with 26.5% feeling it had got worse. 6.2% felt it had improved.

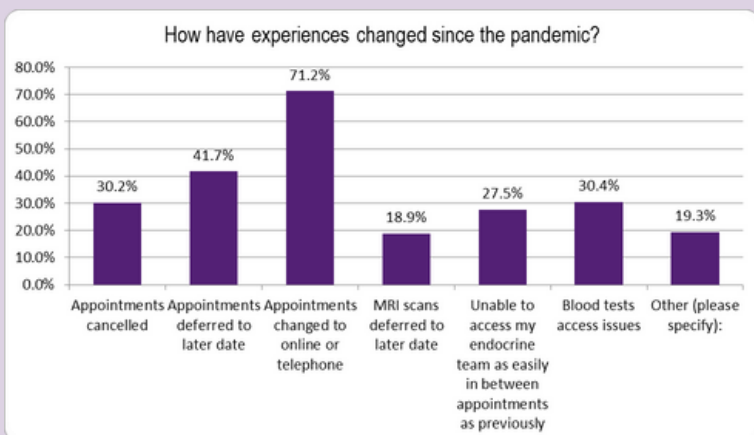
Did the hospital arrange routine appointments following your surgery?



SURVEY FINDINGS: APPOINTMENTS

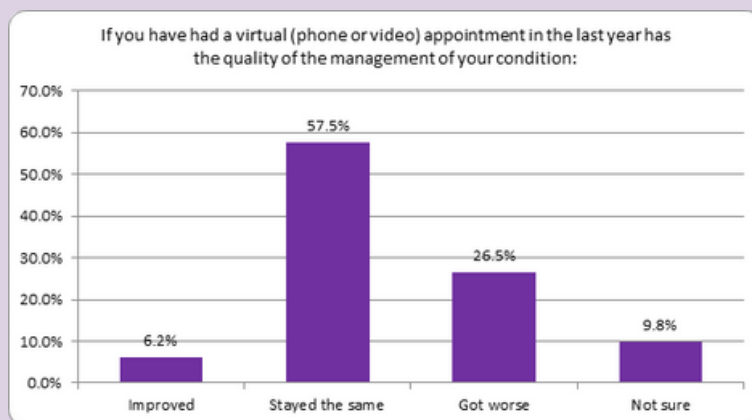
However, challenging this was the fact that of those who had had a virtual appointment, 64.8% felt that they were not as thorough as a face to face appointment.

Long term, 51% of patients would prefer to always have a face-to-face appointment, and 45% would prefer to have a mix of virtual and face to face. Just 4% preferred to have virtual appointments as a default.



"Even before Covid my appointments were always cancelled and changed, each time it was a different registrar and there's no continuity so they don't have time to look at your notes properly."

"Overall the care was good until the pandemic and since then I feel in the wilderness a bit. Always have severe problems when going in as an inpatient with poor understanding of steroid replacement and diabetes insipidus requirements."



"The appointments were too short, the time between appointments sometimes was too long, I waited around 9 months for one appointment when my condition was at its worst, then had a 7 1/2 minute appointment where I was given no time to tell the consultant about the symptoms, so he has no idea about any of it - or how much I was suffering."

7. SURVEY FINDINGS: GP EXPERIENCE

Key message:

Patient experiences were challenging. There is a lack of awareness that leads to delayed diagnosis.

This will disproportionately affect English second language and lower socio-economic patients.

After diagnosis, the lack of understanding leads to delays in prescriptions and referrals, as well as an erosion of trust and care.

"Very often GP's don't understand the effects or indeed what is expected of treatments and the prescriptions required."

"I wish GPs were more aware of pituitary conditions"

Actions:

- Urgently raise awareness of pituitary conditions amongst GPs.
- Urgently detail the patient pathway for diagnosed patients, i.e. communication between patients' endocrinologists and their GPs.
- Reduce delays in prescription alterations, with a target of no more than 3 weeks.

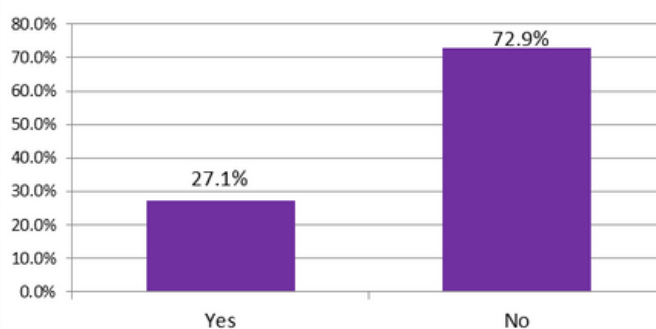
Key Findings:

Once a patient has been seen by (or spoken to) their endocrinologist and has blood tests, these results and review should be sent to their GP, with a copy of this letter to the patient.

This is commonly the only way that a patient has any report and results of their clinic visit.

It is also vital that patients are aware of prescription changes (if any) and that their GP has been told of these.

Your GP should be copied into letters from your endocrine clinic, regarding your condition and prescribed medications.
Have you ever experienced a delay of more than four weeks when trying to alter a prescription



8. CONCLUSION

The survey clearly demonstrates a lack of consistency in the patient pathway through non-specialists, primary care, specialist and surgical care.

The emergency care is particularly fearful for patients.

Endocrine specialist nurses have often, but not always, been a more reliable source of the support for patients.

It is clear that The Pituitary Foundation offers vital, life-changing support for patients who often feel vulnerable outside of this.

The survey reached people who have benefited from the support of The Pituitary Foundation, therefore it is likely that those without this support will have additional problems with care.

We will be working with peers and professionals to take meaningful steps to address the key messages in this report.

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