IIHUK
Idiopathic Intracranial Hypertension

Weight related conversations in people with IIH

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Why?

IDIOPATHIC INTRACRANIAL HYPERTENSION PRIORITY SETTING PARTNERSHIP

Top 10 Priorities for IIH Research

1 ADDRESSING THE CAUSES, SYMPTOMS AND PROGRESSION

In the individual with IIH; what causes the disease, the symptoms and the progression of the disease?

2 BIOLOGICAL MECHANISMS OF HEADACHE

What are the biological mechanisms of headache in IIH and why in some do headaches continue even after papilloedema has resolved?

3 SAFE TREATMENTS

Can new therapies for IIH be developed which are effective, safe, and tolerable and potentially help with weight loss as well as reducing brain pressure?

4 PREDICTING VISUAL LOSS

What is the biological explanation for the differences between rapid visual loss compared with gradual visual loss in IIH and how can this be predicted?

5 MONITORING VISUAL FUNCTION

What are the best ways to monitor visual function?

6 IIH BIOMARKERS

Can IIH biomarkers (tests in body fluids for example urine, saliva, blood, or brain scans) help diagnosis, predict the risk and guide therapy decisions in IIH?

7 HORMONES

What are the hormonal causes for IIH and why is IIH primarily associated with female sex?

8 SAFE AND EFFECTIVE MEDICATIONS

What medications are effective and safe to treat IIH headaches?

9 WEIGHT LOSS

With regard to weight loss in IIH: how much is needed to treat IIH and how quickly does it work? What is the best, safest and most acceptable method to achieve this in the short and long term? Additionally, does the initial Body Mass Index (BMI) of the patient have an effect?

10 BEST TYPE OF INTERVENTION

Which is the best type of intervention to treat IIH and when should surgery be performed?

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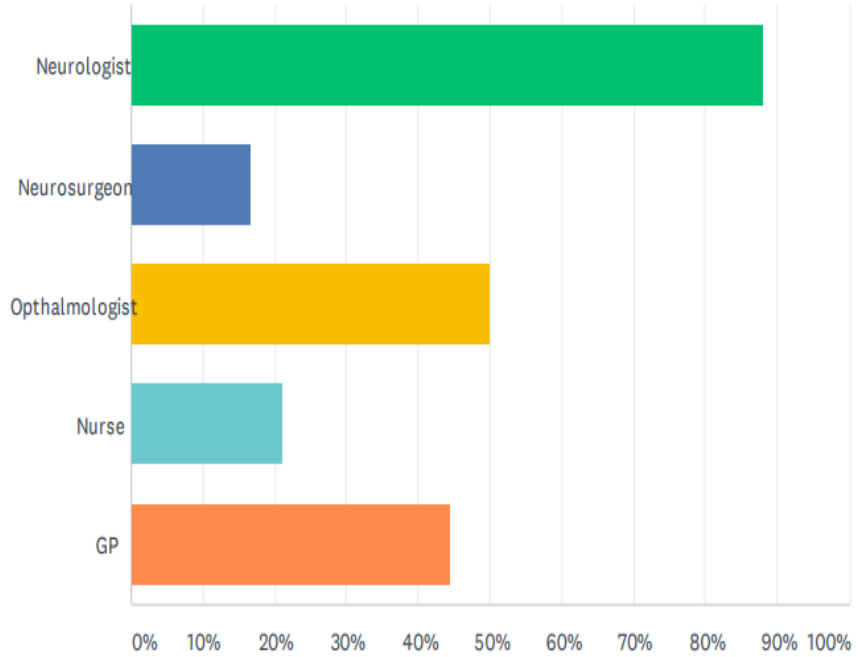
James Lind Alliance Priority Setting Partnerships

IIH PATIENTS AND PROFESSIONALS SETTING RESEARCH PRIORITIES

Q1 Which health care professionals advised you to lose weight? Please check all that apply

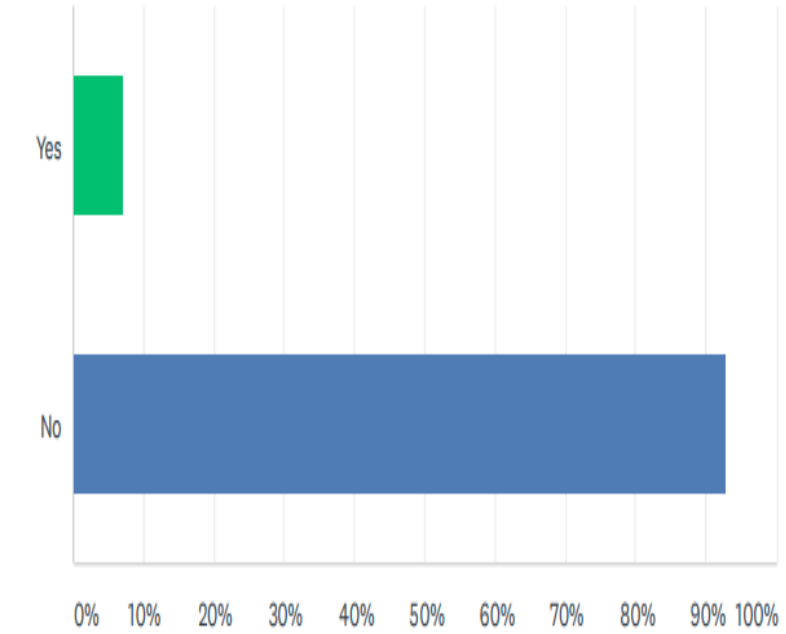
Answered: 617 Skipped: 8



ANSWER CHOICES	RESPONSES	
Neurologist	88.01%	543
Neurosurgeon	16.69%	103
Opthalmologist	49.92%	308
Nurse	21.07%	130
GP	44.41%	274
Total Respondents: 617		

Q2 Did the person who asked you to lose weight ask your permission to discuss your weight with you?

Answered: 625 Skipped: 0



ANSWER CHOICES	RESPONSES	
Yes	7.04%	44
No	92.96%	581
TOTAL		625

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How did the person who advised you to lose weight raise this with you?

- **The Good**

“Weight gain can be a cause for iih, weightloss can help symptoms. Do you need support with this”

“The ……., matter of factly, told me to lose weight as it would improve my symptoms, I wasn't offended by it, I appreciated that ….. wasn't patronising me”

- **The Bad**

“Told me lose weight and it would go away haha”

"To help yourself you need to lose weight, you will not get rid of this until you have"

- **The Ugly**

“You need to lose weight or go blind. That's your choice”

“I have one thing to say “slimming world”

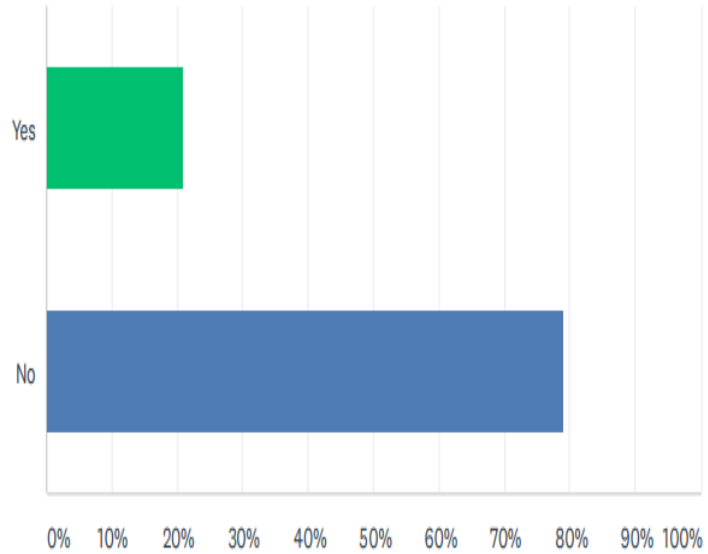
‘This happens to people who like too much cake’

“If you weren’t fat and had some control you wouldn’t be here”

“There’s no way you eat what you say you do, do the exercise you say you do and are as fat as you are”

Q6 Did you find the person who told you to lose weight empathetic and supportive?

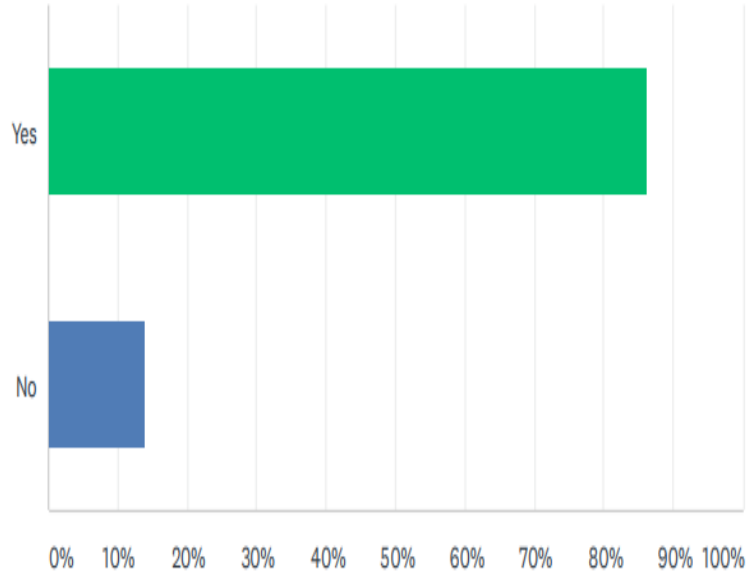
Answered: 624 Skipped: 1



ANSWER CHOICES	RESPONSES	
Yes	20.99%	131
No	79.01%	493
TOTAL		624

Q5 Have you been made to feel that IIH was your fault because of your weight?

Answered: 624 Skipped: 1



ANSWER CHOICES	RESPONSES	
Yes	86.22%	538
No	13.78%	86
TOTAL		624

How did being advised to lose weight make you feel?

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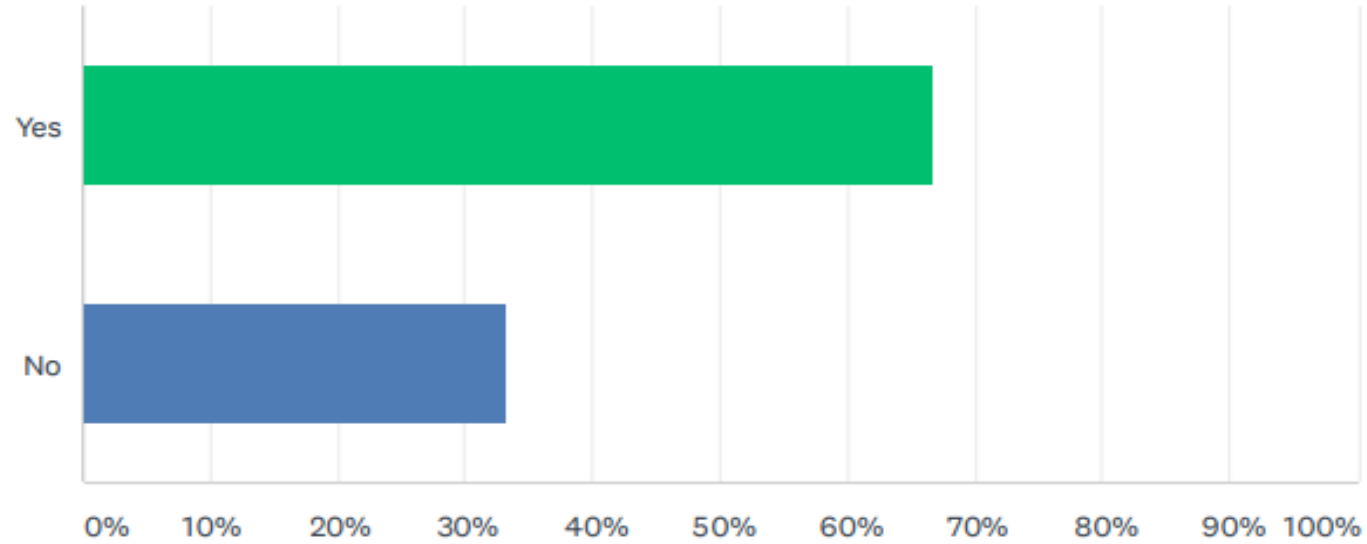
How did being advised to lose weight make you feel?

- “Awful! Like I had caused the issue myself. Like I was wasting time and hospital resources”
- “I knew I had to do it but the amount of times I have been told to do it has had an effect on me and it makes me feel really down about myself”
- “The "walk a mile in my shoes" quote sprang to mind”
- “It gets tiresome and frustrating and makes me distrust the medical people that should be helping me”
- “Fine it was done with sensitivity”

Q10 Do you feel that you have had less favourable treatment because of the link between IIH and obesity?

Answered: 621 Skipped: 4



ANSWER CHOICES	RESPONSES	
Yes	66.67%	414
No	33.33%	207
TOTAL		621

Are there any words or language you would prefer health professionals to use when discussing weight with you?

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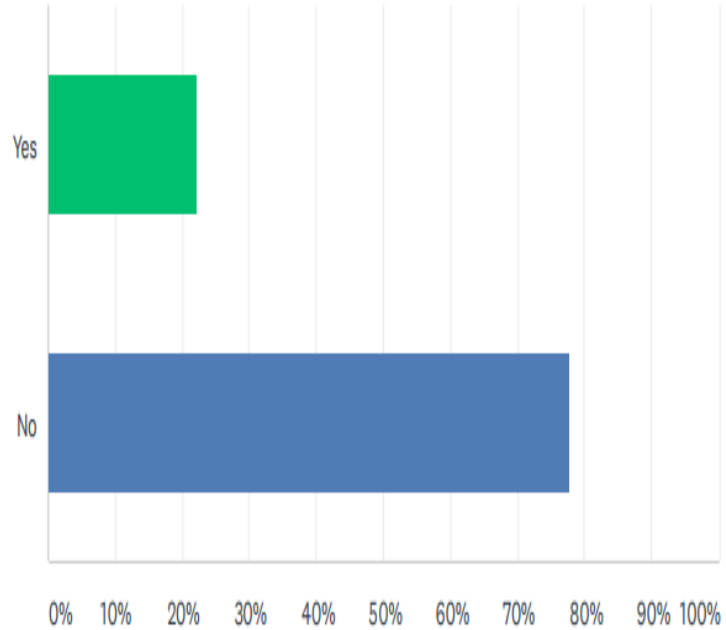
How could the experience of being advised to lose weight be improved?

- “Is it okay if we can discuss the topic of your weight?” “Are you sure?”
- “Let’s explore options to assist you in weight loss and see how this will impact your symptoms and condition”
- “Take blame out of it. Approach it as you would any other medical condition. Here is the problem, here are ways to treat it, here are people/resources that can help you”
- “Overweight is always nicer than obese but understand that is the true medical term on the scale”
- “I wish they’d ditch the “morbidly” or “extremely” as it’s dehumanizing”
- I think that if it's going to be considered such a crucial part of treating the condition, then doctors should take more time to understand potential issues around weight rather than assuming it's a simple case of losing
- I would rather they listen to me. I am desperately trying to lose weight and maybe I need help to manage it? I must do, I am fat. But provide support not judgement.

Q11 When you were advised to lose weight were you offered support to do this?

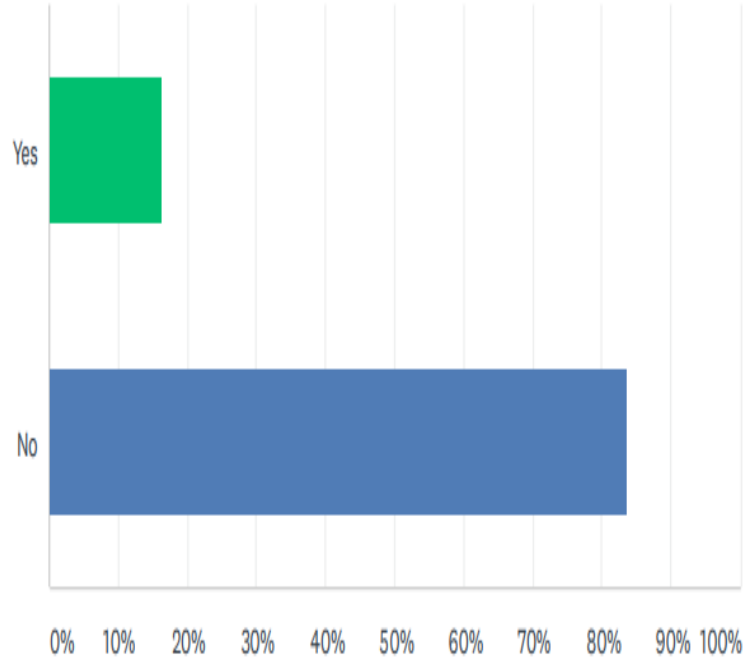
Answered: 624 Skipped: 1



ANSWER CHOICES	RESPONSES	
Yes	22.12%	138
No	77.88%	486
TOTAL		624

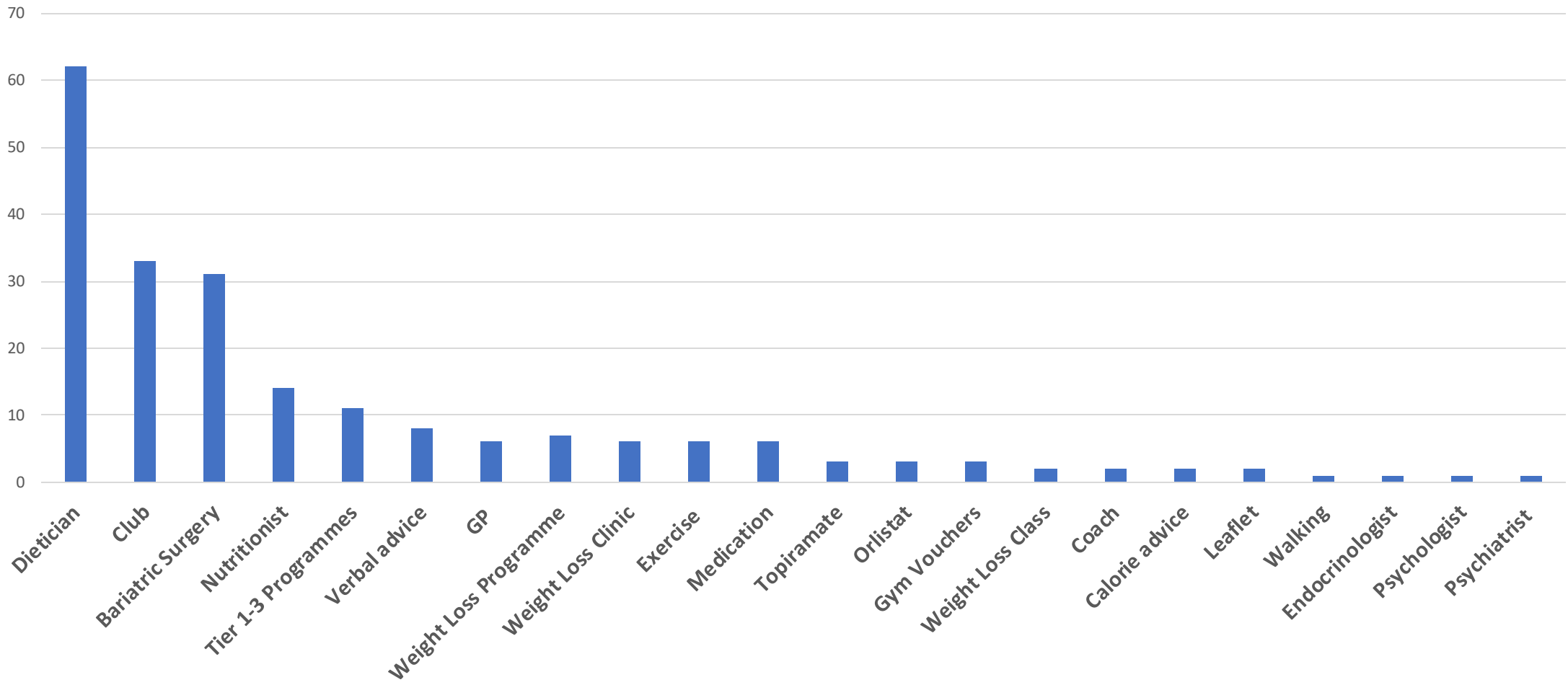
Q13 Was the support offered helpful and appropriate?

Answered: 461 Skipped: 164



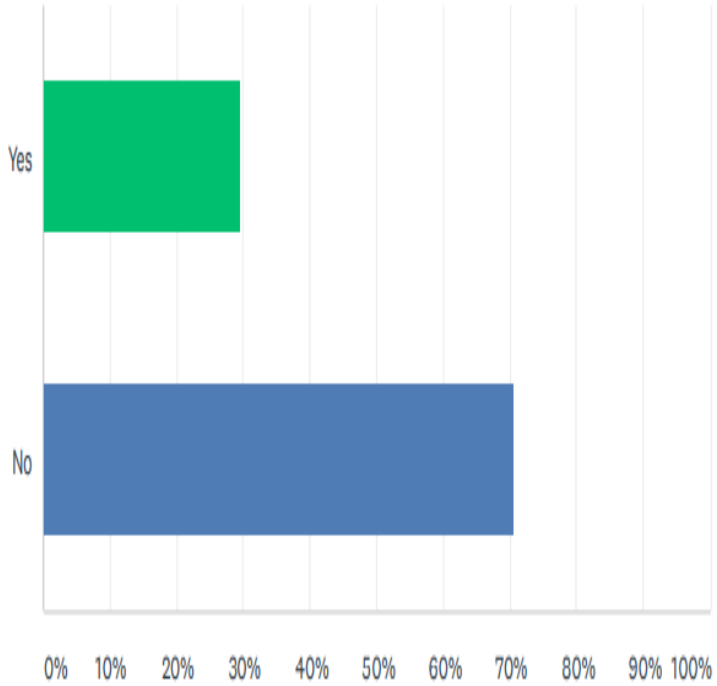
ANSWER CHOICES	RESPONSES	
Yes	16.27%	75
No	83.73%	386
TOTAL		461

If you were offered support to lose weight please detail the support that you were offered?



Q16 If you were advised to lose weight were you given a weight loss goal?

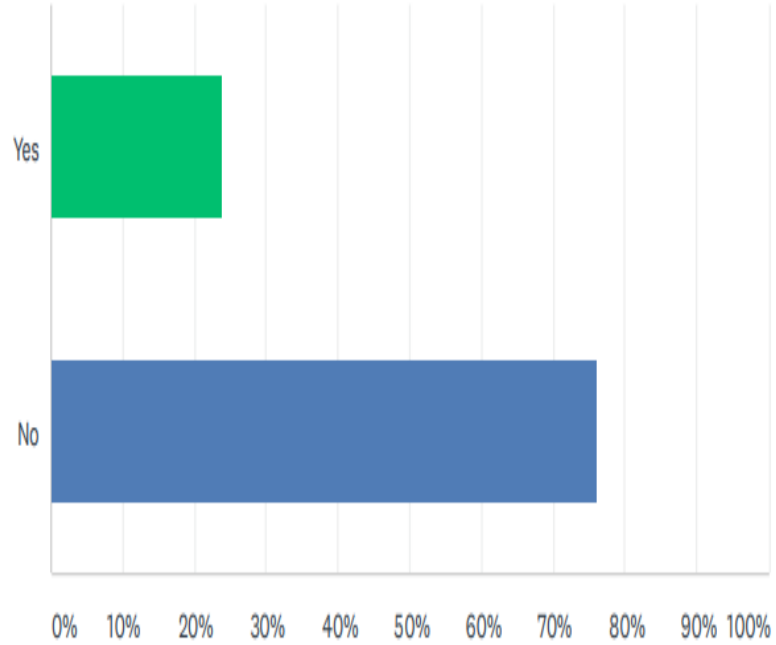
Answered: 610 Skipped: 15



ANSWER CHOICES	RESPONSES	
Yes	29.51%	180
No	70.49%	430
TOTAL		610

Q17 If you were given a weight loss goal did this feel achievable for you?

Answered: 412 Skipped: 213



ANSWER CHOICES	RESPONSES	
Yes	23.79%	98
No	76.21%	314
TOTAL		412

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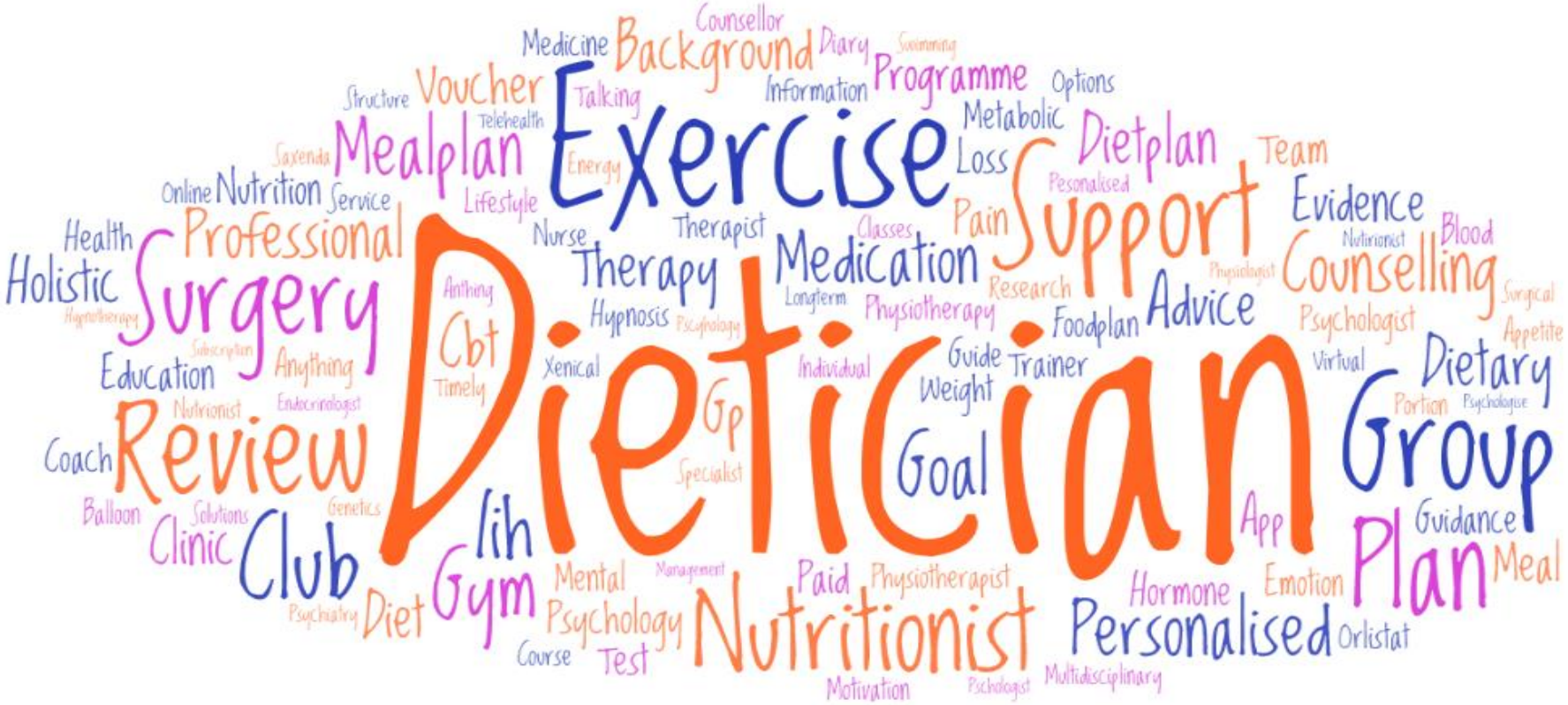
What support would you like the professionals who look after you to offer to help with weight management?



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Take home messages…

- People with IIH are experiencing weight stigma with 86% believing that IIH is their fault because of their weight
- 93% of people with IIH were NOT asked permission to discuss their weight with them despite consensus guidelines
- 78% of people with IIH who were advised to lose weight were NOT offered support in achieving this
- 84% of the 22% offered support with losing weight did not find the support offered helpful and appropriate

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What would pwIIH like to change?

1. Detail the relationship between IIH and weight
2. Individualise care
3. Give Advice
4. Provide Support
5. Adapt Communication

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[Weight management communications in idiopathic intracranial hypertension: challenges and recommendations from the patients' perspective | BMJ Neurology Open]

Open access Original research

BMJ Neurology Open

Weight management communications in idiopathic intracranial hypertension: challenges and recommendations from the patients' perspective

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ABSTRACT

Background Idiopathic intracranial hypertension (IIH) is a neurometabolic condition severely impacting the quality of life of people living with IIH (PwIIH). Most PwIIH are overweight or live with obesity, and weight loss is recommended by healthcare professionals (HCPs) as it is central to disease management. There is currently no research evaluating patient–clinician interactions when discussing weight management in IIH. The aim of this study was to evaluate the patient experience of communication with HCPs regarding weight management from the perspective of PwIIH.

Methods A cross-sectional online survey was developed and distributed by the IIH UK charity via their mailing list and social media network. Eligible participants were adults with IIH who have been recommended to lose weight by their HCP. Descriptive statistics were used to summarise quantitative responses and content analysis was used to inductively draw out themes from open-ended free-text responses.

Results There were 625 respondents. One-fifth of PwIIH (n=127/603, 21%) felt that HCPs were supportive and

WHAT IS ALREADY KNOWN ON THIS TOPIC

⇒ Discussions about weight management are a sensitive topic for patients and evidence shows that healthcare professionals (HCPs) lack confidence in discussing body weight with patients. Priority setting research by the James Lind Alliance highlighted that weight management in the context of idiopathic intracranial hypertension (IIH) is a top research priority for patients and HCPs. To date, there is no published research evaluating the experiences of weight management interactions from the perspective of people living with IIH (PwIIH).

WHAT THIS STUDY ADDS

⇒ This is the first study evaluating the experiences of weight management interactions with HCPs from the perspective of PwIIH. The results of this study demonstrate that PwIIH feel unsupported and experience negative emotions when weight management discussions are initiated by their HCPs. This study also provides unique insights into how HCPs

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