

Formed question	Contributing uncertainties	Certainty	Reference
<p>A1. (combined with H1, I2, N1, N5) Would an education program for health care professionals and patients with IIH improve care and disease experience for IIH patients??</p>	<p>C 1a). Do GP's lack of experience make it difficult to get a diagnosis of IIH (misdiagnosed migraine)</p> <p>Q1</p> <p>P 14). Why is it difficult to get a diagnosis of IIH</p> <p>Q1</p> <p>F 45). What are the best strategies to ensure that healthcare practitioners including GPs have good knowledge of IIH to enable them to be understanding and provide an</p> <p>Q1</p> <p>F 54). What are the best strategies to ensure that healthcare practitioners including GPs have good knowledge of IIH to enable them to be understanding and provide an</p> <p>Q1</p> <p>P 60a). What are the best strategies to ensure that healthcare practitioners including accident and emergency staff have good knowledge of IIH to enable them to be</p> <p>Q1</p> <p>P 96). What are the best strategies to ensure that healthcare practitioners including GPs have good knowledge of IIH to enable them to be understanding and provide an</p> <p>Q1</p> <p>P 99). Do GP's lack of experience make it difficult to get a diagnosis of IIH, would further training be of benefit (misdiagnosed migraine)</p> <p>Q1</p> <p>P 108b). What are the best strategies to ensure that healthcare practitioners including (GPs, neurologists, etc.) have good knowledge of IIH to enable them to be</p> <p>Q1</p> <p>P 115a). Why is it difficult to get a diagnosis of IIH/to be taken seriously by doctors about symptoms of IIH</p> <p>Q1</p> <p>115b). Do medical staff have an awareness of IIH and how to diagnose it</p> <p>Q1</p> <p>H 130d). How can visual obscurations of IIH be differentiated from migrainous visual loss</p> <p>Q1</p> <p>P 135c). Are neurologists dismissive of patients account of symptoms (other than papilloedema, headache and tinnitus)</p> <p>Q1</p> <p>P 146b). How can awareness amongst medical staff be improved?</p> <p>Q1</p> <p>P 272). Do GP's lack of experience make it difficult to get a diagnosis of IIH, would further training be of benefit</p> <p>Q1</p> <p>P 288). Do doctors have enough training/awareness to dianose IIH</p> <p>Q1</p> <p>P 289c). Is a better awareness of symptoms of IIH needed at primary care level</p> <p>Q1</p> <p>P 295). Is there a variation in standard of care/ability to diagnose manage people with IIH between hositals/trusts/areas</p> <p>Q1</p> <p>P 297). Do doctors have enough training/awareness to dianose IIH</p> <p>Q1</p> <p>P 301). Optician referred not GP, why is it so difficult to get a diagnosis of IIH/how can this be improved</p> <p>Q1</p> <p>P 309b). Should the focus of diagnosing neurologists shift away from weight of patient to avoid misdiagnosis</p> <p>Q1</p> <p>P 331). Could an improvement be made in the awareness of this disease amongst GP's to aid faster diagnosis</p> <p>Q1</p> <p>P 333). Could an improvement be made in the education/awareness of this disease amongst GP's to aid faster diagnosis</p> <p>Q1</p> <p>H 64). What are the best strategies to ensure that healthcare practitioners have good knowledge of IIH and papilloedema to enable them to be understanding and</p> <p>Q1</p> <p>P 266). What are the best strategies to ensure that healthcare practitioners have good knowledge of IIH to enable them to be understanding and provide best care</p> <p>Q4</p> <p>P 278). What are the best strategies to ensure that healthcare practitioners have good knowledge of IIH to enable them to be understanding and provide best care</p> <p>Q4</p> <p>P 280). What are the best treatment strategies for management of headache in people with IIH and are these strategies widely known/used by all those healthcare</p> <p>Q4</p> <p>P 288). What are the best strategies to ensure that healthcare practitioners have good knowledge of IIH to enable them to be understanding and provide best care</p> <p>Q4</p> <p>P 328). What are the best strategies to ensure that healthcare practitioners have good knowledge of IIH to enable them to be understanding and provide best care</p> <p>Q4</p> <p>P 331). What are the best strategies to ensure that healthcare practitioners have good knowledge of IIH to enable them to be understanding and provide best care</p> <p>Q4</p> <p>P 340). What are the best strategies to ensure that healthcare practitioners have good knowledge of IIH to enable them to be understanding and provide best care</p> <p>Q4</p> <p>H 221). What are the best strategies to ensure that GP's have good knowledge of IIH to enable them to support weight loss</p> <p>Q6</p> <p>Q6</p> <p>H 254). How well are GPs informed about IIH?</p> <p>Q6</p> <p>P 114d). What are the best strategies to ensure that healthcare practitioners including (GPs, neurologists, etc.) have good knowledge of IIH to enable them to be</p> <p>Q2</p> <p>P 267). What are the best strategies to ensure that healthcare practitioners have good knowledge of IIH to enable them to be understanding and provide best care?</p> <p>Q2</p> <p>P 289b). What are the best strategies to ensure that healthcare practitioners including (GPs, neurologists, etc.) have good knowledge of IIH to enable them to be</p> <p>Q2</p> <p>P 110). What are the best strategies to ensure that accident and emergency staff have good knowledge of IIH to enable them to be understanding and provide best</p> <p>Q4</p> <p>P 119). What are the best strategies to ensure that healthcare practitioners have good knowledge of IIH to enable them to be understanding and provide best care</p> <p>Q4</p> <p>C 1). What are the best strategies to ensure that GPs have good knowledge of IIH to enable them to be understanding and provide an accurate diagnosis and best care</p> <p>Q6</p> <p>P3). What are the best strategies to ensure that GPs have good knowledge of IIH to enable them to be understanding and provide an accurate diagnosis and best care</p> <p>Q6</p> <p>P 14). What are the best strategies to ensure that healthcare practitioners including (GPs, neurologists, etc.) have good knowledge of IIH to enable them to be</p> <p>Q6</p> <p>P 16a). What are the best strategies to ensure that GPs have good knowledge of IIH to enable them to be understanding and provide an accurate diagnosis and best care</p> <p>Q6</p> <p>P 19). What are the best strategies to ensure that healthcare practitioners including (GPs, neurologists, etc.) have good knowledge of IIH to enable them to be</p> <p>Q6</p> <p>P 20). What are the best strategies to ensure that healthcare practitioners including (GPs, neurologists, etc.) have good knowledge of IIH to enable them to be</p> <p>Q6</p> <p>P 22). What are the best strategies to ensure that healthcare practitioners including (GPs, neurologists, etc.) have good knowledge of IIH to enable them to be</p> <p>Q6</p> <p>P 23). What are the best strategies to ensure that healthcare practitioners including (GPs, neurologists, etc.) have good knowledge of IIH to enable them to be</p> <p>Q6</p> <p>P 26). What are the best strategies to ensure that GPs have good knowledge of IIH to enable them to be understanding and provide an accurate diagnosis and best care</p> <p>Q6</p> <p>P 30b). What are the best strategies to ensure that GPs have good knowledge of IIH to enable them to be understanding and provide an accurate diagnosis and best care</p> <p>Q6</p> <p>P 32). What are the best strategies to ensure that GPs have good knowledge of IIH to enable them to be understanding and provide an accurate diagnosis and best care</p> <p>Q6</p> <p>P 33). What are the best strategies to ensure that healthcare practitioners including GPs and neurologists have good knowledge of IIH to enable them to be</p> <p>Q6</p> <p>P 35). What are the best strategies to ensure that GPs have good knowledge of IIH to enable them to be understanding and provide an accurate diagnosis and best care</p> <p>Q6</p> <p>P 38). What are the best strategies to ensure that accident and emergency staff have good knowledge of IIH to enable them to be understanding and provide an accurate</p> <p>Q6</p>	<p>Known unknown</p>	

Q6	H 182). What are the best strategies to ensure that healthcare practitioners including GPs, neurologists, etc. have good knowledge of IHH to enable them to be
Q6	P189b). What are the best strategies to ensure that healthcare practitioners including GPs have good knowledge of IHH to enable them to be understanding and
Q6	P 200). What are the best strategies to ensure that GPs have good knowledge of IHH to enable them to be understanding and provide an accurate diagnosis and best care
Q6	H 215). What are the best strategies to ensure that general ophthalmologists have good knowledge of IHH to enable them to be understanding and provide an accurate
Q6	P 231). What are the best strategies to ensure that GPs have good knowledge of IHH to enable them to be understanding and provide an accurate diagnosis and best care
Q6	P 237a). What are the best strategies to ensure that healthcare practitioners including (GPs, neurologists, etc.) have good knowledge of IHH to enable them to be
Q6	H 260). What are the best strategies to ensure that healthcare practitioners including (GPs, neurologists, etc.) have good knowledge of IHH to enable them to be
Q6	P 278). What are the best strategies to ensure that GPs have good knowledge of IHH to enable them to be understanding and provide an accurate diagnosis and best care
Q6	P 281). What are the best strategies to ensure that healthcare practitioners including (GPs, neurologists, etc.), carers and the general public have good
Q6	P 282). What are the best strategies to ensure that GPs have good knowledge of IHH to enable them to be understanding and provide an accurate diagnosis and best care
Q6	P 283). What are the best strategies to ensure that GPs have good knowledge of IHH to enable them to be understanding and provide an accurate diagnosis and best care
Q6	P 286). What are the best strategies to ensure that healthcare practitioners including (GPs, neurologists, etc.) have good knowledge of IHH to enable them to be
Q6	P 289a). What are the best strategies to ensure that healthcare practitioners including (GPs, neurologists, eye hospital staff etc.) have good knowledge of IHH to
Q6	P 294). What are the best strategies to ensure that GPs have good knowledge of IHH to enable them to be understanding and provide an accurate diagnosis and best care
Q6	P 296). What are the best strategies to ensure that GPs and other primary care staff have good knowledge of IHH to enable them to be understanding and provide an
Q6	P 297a). What are the best strategies to ensure that GPs have good knowledge of IHH to enable them to be understanding and provide an accurate diagnosis and best care
Q6	P 305). What are the best strategies to ensure that GPs have good knowledge of IHH to enable them to be understanding and provide an accurate diagnosis and best care
Q6	C 307). What are the best strategies to ensure that healthcare practitioners including (GPs, neurologists, eye hospital staff etc.) have good knowledge of IHH to
Q6	P 309). What are the best strategies to ensure that GPs have good knowledge of IHH to enable them to be understanding and provide an accurate diagnosis and best care
Q6	P 315). What are the best strategies to ensure that healthcare practitioners including (GPs, neurologists, eye hospital staff etc.) have good knowledge of IHH to
Q6	P 317). What are the best strategies to ensure that healthcare practitioners including (GPs, neurologists, eye hospital staff etc.) have good knowledge of IHH to
Q6	P 323). What are the best strategies to ensure that healthcare practitioners including (GPs, neurologists, eye hospital staff etc.) have good knowledge of IHH to
Q6	P 324). What are the best strategies to ensure that GPs have good knowledge of IHH to enable them to be understanding and provide an accurate diagnosis and best care
Q6	P 326). What are the best strategies to ensure that healthcare practitioners including (GPs, neurologists, eye hospital staff etc.) have good knowledge of IHH to
Q6	P 327). What are the best strategies to ensure that healthcare practitioners including (GPs, neurologists, eye hospital staff etc.) have good knowledge of IHH to
Q6	P 328). What are the best strategies to ensure that healthcare practitioners including (GPs, neurologists, eye hospital staff etc.) have good knowledge of IHH to
Q6	H 332). Does having a specialist IHH service improve the care of patients with IHH
Q6	P 333). What are the best strategies to ensure that healthcare practitioners including (GPs, neurologists, eye hospital staff etc.) have good knowledge of IHH to
Q6	P 337). What are the best strategies to ensure that accident and emergency staff have good knowledge of IHH to enable them to be understanding and provide an
Q6	P 340). What are the best strategies to ensure that healthcare practitioners including (GPs, neurologists, eye hospital staff etc.) have good knowledge of IHH to
Q6	P 341). What are the best strategies to ensure that GPs have good knowledge of IHH to enable them to be understanding and provide an accurate diagnosis and best care
Q6	P 345). What are the best strategies to ensure that GPs have good knowledge of IHH to enable them to be understanding and provide an accurate diagnosis and best care
Q6	H 347). What are the best strategies to ensure that healthcare practitioners outside of neurology and ophthalmology departments have good knowledge of IHH to enable
Q7	P 14). What are the best strategies to ensure that healthcare practitioners including GPs, neurologists, etc. have good knowledge of IHH to enable them to be
Q7	P 19). What are the best strategies to ensure that healthcare practitioners including GPs, neurologists, etc. have good knowledge of IHH to enable them to be
Q7	P 23). What are the best strategies to ensure that healthcare practitioners including GPs, neurologists, etc. have good knowledge of IHH to enable them to be
Q7	P 26). What are the best strategies to ensure that healthcare practitioners including GPs, neurologists, etc. have good knowledge of IHH to enable them to be
Q7	P 94). What are the best strategies to ensure that healthcare practitioners including GPs and hospital staff have good knowledge of IHH to enable them to be
Q7	P 105). What are the best strategies to ensure that healthcare practitioners have good knowledge of IHH to enable them to be understanding and provide an accurate
Q7	P 114). What are the best strategies to ensure that healthcare practitioners and carers have good knowledge of IHH to enable them to be understanding and provide
Q7	P 119). What are the best strategies to ensure that healthcare practitioners including neurosurgeons have good knowledge of IHH to enable them to be
Q7	H 212). What are the best strategies to ensure that healthcare practitioners including GPs have good knowledge of IHH to enable them to be understanding and
Q7	P 244). What are the best strategies to ensure that healthcare practitioners have good knowledge of IHH to enable them to be understanding and provide an accurate
Q7	H 247b). What are the best strategies to ensure that GPs have good knowledge of IHH to enable them to be understanding and provide an accurate diagnosis and best
Q7	H 262). What are the best strategies to ensure that GPs have good knowledge of IHH to enable them to be understanding and provide an accurate diagnosis and best
Q7	P 317). What are the best strategies to ensure that healthcare practitioners have good knowledge of IHH to enable them to be understanding and provide an accurate
Q1	P 20). Is an improvement in clinician:patient communication required immediately after diagnosis
Q1	P 26). Is better clinician:patient communication about diagnostic testing required
Q1	P 30b). Why do health care providers not always believe patients account of symptoms?
Q1	P 31a). Is an improvement in clinician:patient communication required immediately after diagnosis
Q1	P 244). Is there a need for better clinician:patient communication
Q5	P 231). What are the best strategies for a person with IHH to access help from healthcare practitioners and/or exercise and weight loss experts with their weight

Q4	H 169). What is the effectiveness of patient education (to explain that IIH is a visual disease and that headache is secondary symptom) in reducing medication overuse in
Q4	H 198b). How effective are current patient information strategies for management of headache in people with IIH
Q4	P 348). Do people with IIH fully comprehend the possible consequences of taking symptom relieving medications on a long term basis
Q6	P 31). Are many people with IIH left to self manage their disease without adequate check ups and unsure about how to access help should they feel they need it
Q6	P 108). Would education of people with IIH about their symptoms help guide when to go to A&E
Q6	P 126). Would education of people with IIH help
Q6	P 128). Would education of people with IIH help
Q6	P 166). Would education of people with IIH help
Q7	P 38). What symptoms should cause concern and prompt a person who is self monitoring their IIH to request help and how should they best access this help
Q7	P 78b). What are the best strategies to ensure people with IIH have the information they need about their disease
Q7	H 228). Do people with IIH have a good understanding of their disease
Q7	P 266). What are the symptoms that should prompt people with IIH to seek help from a specialist
Q7	P 268). Can IIH be managed effectively through pregnancy
Q1	P 114). Would better provision of information to patient after diagnosis improve outcome/patient satisfaction
Q4	C 1). What are the best strategies to ensure that healthcare practitioners including GPs have good knowledge of IIH to enable them to be understanding and provide
Q4	P 16). What are the best strategies to ensure that healthcare practitioners have good knowledge of IIH to enable them to be understanding and provide best care
Q4	P 19). What are the best strategies to ensure that healthcare practitioners including neuro-surgeons have good knowledge of IIH to enable them to be understanding
Q4	P 24). What are the best strategies to ensure that healthcare practitioners have good knowledge of IIH to enable them to be understanding and provide best care
Q4	P 25). What are the best strategies to ensure that healthcare practitioners have good knowledge of IIH to enable them to be understanding and provide best care
Q4	P 35c). What are the best strategies to ensure that healthcare practitioners including GP's have good knowledge of IIH to enable them to be understanding and provide
Q4	P 43b). What are the best strategies to ensure that healthcare practitioners have good knowledge of IIH to enable them to be understanding and provide best care
Q4	P 55). What are the best strategies to ensure that healthcare practitioners have good knowledge of IIH to enable them to be understanding and provide best care
Q4	F 86). What are the best strategies to ensure that healthcare practitioners have good knowledge of IIH to enable them to be understanding and provide best care
Q4	P 122). What are the best strategies to ensure that healthcare practitioners have good knowledge of IIH headache to enable them to be understanding and provide
Q4	P 156). What are the best strategies to ensure that healthcare practitioners have good knowledge of IIH headache to enable them to be understanding and provide
Q4	P 158a). What are the best strategies to ensure that healthcare practitioners have good knowledge of IIH headache to enable them to be understanding and provide
Q3	P 20). What are the best strategies to ensure that healthcare practitioners including have good knowledge of IIH to enable them to be understanding and provide best
Q3	P 31). What are the best strategies to ensure that healthcare practitioners including have good knowledge of IIH to enable them to be understanding and provide best
Q3	P 35b). What are the best strategies to ensure that eye departments have good knowledge of IIH to enable them to be understanding and provide an accurate
Q3	P 55). What are the best strategies for supporting patients with vision loss
Q3	P 67a). What are the best strategies to ensure that opticians have good knowledge of IIH to enable them to be understanding and provide best care
Q3	P 72). What are the best strategies to ensure that healthcare practitioners have good knowledge of IIH to enable them to be understanding and provide an accurate
Q3	P81). What are the best strategies to ensure that healthcare practitioners have good knowledge of IIH to enable them to be understanding and provide an accurate
Q3	P 117). What are the best strategies to ensure that healthcare practitioners have good knowledge of IIH to enable them to be understanding and provide best care
Q3	H 201). What are the best strategies to ensure that Ophthalmology departments have good knowledge of IIH to enable them to be understanding and provide best care?
Q3	H 216b). What are the best strategies to ensure that neurologists have good knowledge of IIH to enable them to be able to provide best care?

A4. (combined with N9) Why do people get IIH without papilloedema (IIHWOP) and how should this be treated?

Q1	P 3a). What are the diagnostic criteria for IIH when no papilloedema is present	Known unknown
Q1	P 4). Why is it difficult to get a diagnosis of IIH without papilloedema, do guidelines need to be extended to cover these patients	
Q1	P 15a). Is presence of papilloedema required for diagnosis of IIH	
Q1	P 43a). Is presence of papilloedema required for diagnosis of IIH	
Q1	P 44b). Is presence of papilloedema required for diagnosis of IIH	
Q1	P 56b). Should presence of papilloedema be required for diagnosis of IIH	
Q1	H 77). Should the presence of papilloedema be required for diagnosis of IIH	
Q1	P 89b). Is it possible to have IIH without papilloedema	
Q1	P 148). Can IIH patients have raised CSF pressure without presenting with papilloedema	
Q1	P 160d). Why does papilloedema serve as the main diagnostic indicator for some and not others?	
Q1	H 198a). Is papilloedema required for diagnosis of IIH, and if so should it be	
Q1	P 200). Should presence of papilloedema be necessary for diagnosis of IIH	
Q1	H 248b). Is evidence of papilloedema required for a diagnosis of IIH	
Q1	H 257b). What is the incidence of IIH without papilloedema	
Q1	H 260b). What is the incidence of IIH without papilloedema/ Is presence of papilloedema required for diagnosis of IIH	

		P 286c). Is presence of papilloedema required for a diagnosis of IIH	
Q1		F 318). Do diagnostic criteria allow for correct diagnosis of IIH without papilloedema	
Q1		P 326). Are/should presence of papilloedema and high (CSF) pressure reading be necessary for diagnosis of IIH	
Q1		H 332). Is papilloedema an essential diagnostic criteria for IIH	
Q1		P 345b). Is papilloedema an essential diagnostic criteria for IIH	
Q1		O 202a). Does IIH without papilloedema exist	
Q1		P 179). Are healthcare practitioners aware of the best strategies for treating IIH without Papilloedema	
Q3			

A5. Are cases of IIH missed because the preconception is that all sufferers are overweight females taking c		H 188). Are cases of IIH missed because the preconception is that all sufferers are overweight females taking combined hormonal contraception	Known known	Neuman NJ, Biousse V. (2016) Overdiagnosis
	Q1			

A6. Is IIH commonly misdiagnosed		P 296a). Is IIH commonly misdiagnosed	Known known	Fisayo A, Bruce BB, Newman NJ, Biousse V. (2016) Overdiagnosis of idiopathic intracranial hypertension. Neurology. 86(4):341-
	Q1	P 17). What are the rates of misdiagnosis of IIH as migraine and tension type headache		
	Q4	P 309). Is the headache syndrome often misdiagnosed		
	Q4			

B1. What are the best cut-offs for lumbar puncture (LP) pressure in IIH for normal healthy, for obese healthy and by gender (for men and women)?		P 3b). What are the guideline (lumbar puncture) pressure readings for diagnosis of IIH	Known known	Whiteley W, Al-Shahi R, Warlow CP, Zeidler M, Lueck CJ. (2006) CSF opening pressure: reference interval and the effect of body mass index. Neurology 67(9):1690-1.
	Q1	P 15b). What are the guideline (lumbar puncture) pressure readings for diagnosis of IIH		
	Q1	P 36). What are the MRI/CT/LP tests measuring and what are the guideline values used for diagnosis of IIH		
	Q1	P 39a). Can diagnosis be achieved from lumbar puncture results only		
	Q1	P 41). Are lumbar puncture results the primary diagnostic tool		
	Q1	P 68). What are the guideline lumbar puncture pressure readings for diagnosis of IIH		
	Q1	H 73). What are the diagnostic criteria/cut offs for MRI imaging and CSF pressure		
	Q1	H 75b). What are the (normal) guideline lumbar puncture pressure readings for diagnosis of IIH		
	Q1	H 80). Is IIH diagnosed using lumbar puncture test results		
	Q1	P 89a). What are the guideline pressure readings for diagnosis of IIH and are they used nationally		
	Q1	P 97a). Do cut offs for high pressure differ depending on trust/consultant/clinic visited		
	Q1	P 97b). Is a single cut off for high pressure reading valid for all potential IIH sufferers		
	Q1	P 113b). Is lumbar puncture required for confirmation of IIH diagnosis		
	Q1	H 123). Is lumbar puncture required for confirmation of IIH diagnosis		
	Q1	H 127). Can a normal range of CSF pressure be identified? This is dependent upon multiple variables		
	Q1	P 135a). Why is there variation in the definition of a high pressure reading given by different neurologists		
	Q1	P 153). At which point in the diagnostic process should lumbar puncture be used		
	Q1	H 162b). What are the guideline 'normal' CSF pressure cut offs for normal weight, overweight and obese populations		
	Q1	H 174a). What are the guideline 'normal' ICP cut offs		
	Q1	P 179). Do cut offs for high pressure differ depending on trust/consultant/clinic visited		
	Q1	H 184b). What are the guideline 'normal' LP pressure cut offs for people who are obese		
	Q1	H 184c). What are the guideline 'normal' LP pressure cut offs for people who have IIH with stabile papilloedema		
	Q1	O 190a). What are the guideline 'normal' CSF cut offs		
	Q1	H 198b). In combination with other features of IIH what CSF pressure reading should be considered diagnostic		
	Q1	H 204c). What are the cut offs for normal opening pressure readings		
	Q1	H 217). What are the cut offs for normal opening pressure readings		
	Q1	H 220). What are the cut offs for normal CSF pressure readings and do they vary with gender/abdominal circumference/medication		
	Q1	H 222b). What are the cut offs for normal CSF pressure readings		
	Q1	H 228a). What are the cut offs for normal pressure readings		
	Q1	H 242b). What are the best evidence based cut offs for normal CSF pressure readings		
	Q1	H 243). What are the best evidence based cut offs for normal CSF pressure readings, is there a variation in this with BMI		
	Q1	H 248a). What are the best evidence based cut offs for normal CSF pressure readings		
	Q1	H 252b). Do the cut offs for normal CSF pressure vary with person's (weight) bmi		
	Q1	H 259). What are the best evidence based cut offs for normal CSF pressure readings		
	Q1	H 252a). What is the diagnostic test accuracy of the best evidence based cut off for CSF pressure to diagnose IIH		
	Q1	P 286a). What is the diagnostic test accuracy of the new lumbar puncture opening pressure cut offs compared with previous cut off for detection of IIH		
	Q1	H 306a). What are the guideline cut offs for raised lumbar puncture pressure readings for diagnosis of IIH		
	Q1	H 306b). What is the distribution of pressure readings within the IIH and non-IIH populations		

		H 306c). Can a diagnosis of IIH be given when ICP readings are 'normal'	
Q1		H 308). What are the guideline cut offs for raised lumbar puncture pressure readings for diagnosis of IIH	
Q1		H 321b). What evidence exists for the guideline 'normal' ICP cut offs	
Q1		P 322a). Do guideline diagnostic criteria for opening pressure lumbar puncture readings exist and are they widely used	
Q1		P 328). Do guideline diagnostic criteria for opening pressure lumbar puncture readings exist and are they widely used	
Q1		P 345a). Do guideline diagnostic criteria for opening pressure lumbar puncture readings exist and are they widely used	
Q1		O 202b). What are the normal, borderline and high opening pressure thresholds that should be referred to for diagnosis of IIH	
Q1		H 207b). How does the lumbar CSF pressure relate to intracranial CSF pressure?	
Q7		P 99). What is the best evidence based cut offs for high/normal/low CSF pressure readings	

B2. Does prolonged intracranial pressure (ICP) monitoring improve diagnostic accuracy in IIH compared with lumbar puncture opening pressure (OP)?		H 171c). What is the benefit of ICP monitoring	Known unknown	Partial answer - Neurology Nov 2006, 67 (9) 1690-1691; DOI:10.1212/01.wnl.000242704.60275.e9
	Q1	P 118). What is the test accuracy of single resting pressure measurement compared with monitoring over longer period of normal activity for diagnosing IIH		
	Q1	H 130a). What is the test accuracy of opening pressure measurement, does this vary with ranges 20-25 cm, 25-30 cm, 30-35 cm and 35+ cm		
	Q1	O 170). What is the diagnostic test accuracy of lumbar puncture opening pressure measurements		
	Q1	H 171a). What is the diagnostic test accuracy of lumbar puncture measurements		
	Q1	H 173b). What is the diagnostic test accuracy and safety of ICP monitoring for diagnosis of IIH		
	Q1	H 177). What is the diagnostic test accuracy of lumbar puncture opening pressure for diagnosis of IIH		
	Q1	O 190b). What is the diagnostic test accuracy and safety for Lumbar puncture in IIH		
	Q1	H 228b). What is the diagnostic test accuracy of continual monitoring of pressure over a day compared with a single timepoint pressure reading taken using lumbar		
	Q1	P 241a). Do fluctuations in intracranial pressure reduce the reliability of the lumbar puncture diagnostic test results		
	Q1	H 264a). What is the test accuracy of single resting pressure measurement compared with monitoring over longer period of normal activity for diagnosing IIH		
	Q1	H 298). Is a single timepoint pressure reading from lumbar puncture a reliable indicator		
	Q1	H 316). What is the diagnostic test accuracy of LP opening pressure compared with dynamic CSF pressure measuring/monitoring		
	Q1	P 345c). What is the diagnostic test accuracy of LP opening pressure compared with dynamic CSF pressure measuring/monitoring		
	Q1	H 353). What is the diagnostic test accuracy of LP opening pressure compared with dynamic CSF pressure measuring/monitoring		
	Q1	H 246). Is there a need for new clear evidence based criteria to aid diagnosis (which include MR venography, and dynamic pressure monitoring)		
	Q1	P 16b). What is the diagnostic test accuracy of intracranial pressure monitoring relative to lumbar puncture opening pressure for diagnosis of IIH		
	Q1	H 186c). Are spot (LP) measurements representative of ICP over time for IIH		

B3. Would personalised medicine/ targeted treatment improve IIH care?		H 344). Does the diagnostic criteria used in clinical settings provide the correct basis for targeted treatment	Known Known	Obvious 'Yes' answer
	Q1			

B4. Can technical factors (eg size of LP needle) affect Intracranial pressure (ICP) readings?		H 257a). What factors may cause variation in the CSF pressure readings taken by lumbar puncture, does this technique measure a true representation of actual CSF	Known unknown	Limited evidence - Wright, B.L.C., Lai, J.T.F. & Sinclair, A.J. J Neurol (2012) 259: 1530. https://doi.org/10.1007/s00415-012-6413-x
	Q1	H 198d). Does the type of LP needle used affect opening pressure measurement?		
	Q1	P 135b). What is the diagnostic test accuracy and safety of sedated or X-ray guided LP' compared with unguided LP's		
	Q1	P 176). What is the diagnostic test accuracy and safety of lumbar puncture for IIH when multiple attempts are required before a reading can be taken compared with		
	Q1	H 182b). What is the repeatability of lumbar puncture results between personnel, settings, trusts		
	Q1	H 252d). What is the diagnostic test accuracy, safety and tolerability of ultrasound guided lumbar puncture compared with non guided lumbar puncture for measuring		
	Q1	P 274). Is there variation in patient outcomes/diagnostic test accuracy depending upon the level of training/experience of the practitioner who carries out a lumbar		
	Q1	P 281). Is there variation in patient outcomes/diagnostic test accuracy depending upon the method used to carry out a lumbar puncture		
	Q1	H 303b). What is the inter-operator variability of LP opening pressure measurements		
	Q1	H 304). What is the inter-operator variability of LP opening pressure measurements		
	Q1	H 338b). How can the methods of lumbar puncture pressure measurement be improved to improve reliability and make readings less subject to artifact		
	Q1	H 349a). How can the methods of lumbar puncture pressure measurement be improved to improve reliability and make readings less subject to artifact		
	Q1	H 9b). How does the type of needle used affect manometry and therefore opening pressure readings in lumbar puncture for the detection of IIH		

B5. Is there a single or are there multiple causes for IIH?		P 108). Is there a single or are there multiple causes for IIH	Known unknown	
	Q2			
	Q2	P 148). Is there a single or are there multiple causes for IIH?		
	Q2	H 264e). Is there a single or are there multiple causes for IIH		
	Q2	P 341b). Is there a single or are there multiple causes for IIH		

B6. (combined with C4, N2) Would a diagnostic pathway for IIH improve care?		H 225b). What information should GP's have in order to be able to effectively identify possible IIH and diagnose/refer correctly	Known unknown	Limited evidence- Deborah I. Friedman, Grant T. Liu, Kathleen B. Digre. Revised diagnostic criteria for
	Q1	H 227). IS there a need for easier to follow protocols which focus upon CSF pressure and visual fields to facilitate the diagnosis of IIH		

	H 285a). What symptoms of IIH would make an urgent referral necessary
Q1	H 285b). What symptoms of IIH would make an urgent request for investigations necessary
Q1	H 285c). Who should the person with suspected IIH be referred to for these investigations (GP, Ophthalmologist, neurologist)
Q1	H 303c). What is the best pathway to diagnosis when a case of suspected IIH is identified by a non-neurologist, where should they be referred
Q1	H 330). Can the pathway to diagnosis be improved so that patients see the right specialists and undergo all appropriate tests
Q1	P 340). Can the pathway to diagnosis be improved so that patients see the right specialists, undergo all appropriate tests and receive explanation of the effects and P 342). Is there a standard process for diagnosis of IIH
Q1	H 351). What is the best pathway for people with suspected IIH to reach correct diagnosis, where should they be referred, what tests should they receive
Q1	H 10). Do national guidelines for the diagnosis and early management of IIH need to be developed
Q1	P 294). Could lessons be learned from other countries about how to diagnose and manage people with suspected IIH
Q1	P 156). Could improvements be made to the diagnostic process/criteria to reduce rates of misdiagnosis
Q1	H 136). Who should make the diagnosis - neurologists, ophthalmologists, neuro-ophthalmologists
Q4	H 219). What are the best strategies for management of people borderline IIH pressure measurements (20-25)
Q1	P 2). Why is there a variation in treatment programmes dependent upon the doctor you are treated by
Q4	P 116). How frequently should a person with IIH see a specialist doctor
Q6	H 6). Should people with IIH who do not have visual symptoms be managed by a neurologist
Q6	H 7). Should people with IIH who do not have visual symptoms be managed by a neurologist and ophthalmologist team or ophthalmologist alone
Q6	H 12). What is the best evidenced based care pathway for long term management of people with IIH
Q6	P 16b). Would people with IIH be better managed by an outpatient support clinic
Q6	P 25). Do people with IIH need more regular check ups than they currently receive
Q6	P 29). Do people with IIH receive adequate care for non-vision symptoms of IIH
Q6	P 30a). How often should people with IIH be followed up after having surgery
Q6	P 41). Is there a need for greater communication and knowledge sharing amongst the specialists who are treating people with IIH across the UK
Q6	P 44a). Do people with IIH have to wait too long to see a consultant
Q6	H 53). What are the best evidence based pathways for IIH
Q6	H 77). How should headaches be managed in A&E
Q6	P 97). Would guidelines improve care
Q6	P 109). Would guidelines improve care
Q6	P 115). Would increasing the number of IIH clinics improve care
Q6	P 122). Would increasing the number of IIH clinics improve care
Q6	H 123). Would increased access to weight management clinics improve IIH care
Q6	H 124). Would guidelines improve care
Q6	H 130). Would guidelines improve care
Q6	P 132). Would increasing the number of IIH clinics improve care
Q6	H 133). Would increasing the number of IIH clinics improve care
Q6	H 134). Would guidelines improve care
Q6	H 136). Would guidelines improve care
Q6	H 142). Would increasing the number of IIH clinics improve care
Q6	H 143). Would increased access to weight management clinics improve IIH care
Q6	P 163). How should headache be managed in IIH
Q6	H 171b). Would guidelines improve care
Q6	H 172). Can IIH be managed in primary care
Q6	P 176c). Would increasing the number of IIH clinics improve care
Q6	H 180). Can IIH be managed in primary care
Q6	H 185). Would guidelines improve care
Q6	H 188). Can IIH be managed in primary care
Q6	P 189a). Do people with IIH need better care than they currently receive
Q6	O 190). Should the lead in IIH care be taken by neurologists or ophthalmologists
Q6	H 195). Should the lead in IIH care be taken by neurologists or ophthalmologists
Q6	H 198). What are the best evidence based care pathways for IIH
Q6	H 199c). Is there a role for Managed clinical network for IIH
Q6	H 201). Do people with IIH need better care than they currently receive

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 Deborah I. Friedman, Grant T. Liu, Kathleen B. Digre; Revised diagnostic criteria for the pseudotumor cerebri syndrome in adults and children; Neurology Sep 2013, 81 (13) 1159-1165; DOI: 10.1212/WNL.0b013e3182a55f17

	O 202). What are the best evidence based care pathways for IIH
Q6	H 203). Shoud IIH be managed in outpatient clinic except for when lumbar puncture or therapeutic surgeries are required
Q6	H 204). What are the best evidence based care pathways for IIH
Q6	H 212). Which type of specialists should carry out follow up for people with IIH
Q6	H 218). What type of follow up should people with IIH receive and how frequently should this be done
Q6	H 222). What role should ophthalmologists play in the care pathway of people with IIH
Q6	H 223). Should the lead in IIH care be taken by neurologists or ophthalmologists
Q6	H 226). What type of follow up should people with IIH receive
Q6	H 227). What are the best evidence based care pathways for IIH
Q6	H 229). How frequently should people with IIH be followed up
Q6	H 232). What type of follow up should people with IIH receive for their vision and how frequently should this be done
Q6	H 238). Should the lead in IIH care be taken by neurologists or ophthalmologists
Q6	H 239). Would a dedicated clinical referral pathway be of benefit
Q6	H 240). What are the criteria/symptoms that indicate a person with IIH should be offered bariatric surgery
Q6	P 244). Is there a need for more specialised IIH clinics
Q6	H 245). Who should be responsible for coordinating care for people with IIH
Q6	H 263a). Is an inpatient stay necessary for diagnosis of IIH
Q6	H 264). What is the best evidence based service model for IIH
Q6	H 275). Should people with IIH be treated by specialists doctors
Q6	H 279). What is the safety and efficacy of virtual monitoring clinics for people with IIH
Q6	H 285). What are the best evidence based care pathways for IIH
Q6	P 297c). Do people with IIH need more care than they currently receive
Q6	H 300b). How frequently should people with IIH be followed up
Q6	H 303). How frequently should people with IIH be followed up and by whom
Q6	H 306). How can people with IIH best access the correct care when they experience a worsening in symptoms
Q6	P 311). How can people with IIH best access the correct care when they need support with their symptoms
Q6	H 312). What are the best care pathways for people with IIH
Q6	F 318). Should people with IIH be offered surgery sooner than currently are
Q6	P 322). Should people with IIH receive priority care from accident and emergency departments after a head injury
Q6	H 329). How frequently should people with IIH be followed up and by whom
Q6	H 330). What is the best protocol for follow up and monitoring of people with IIH
Q6	F 335). Do people with IIH need more support than they currently receive
Q6	P 336). Do people with IIH need more frequent follow up then they currently receive
Q6	H 338). Who should be performing lumbar punctures on people with IIH for best outcomes
Q6	P 348). Would better communication between the different specialists involved in treating people with IIH improve care
Q6	H 349). What is the best protocol for follow up and monitoring of people with IIH
Q6	H 353b). Is access to interventions such as shunting or shunt valve adjustment adequate and appropriately targeted to symptoms
Q6	P 356). Do people with IIH need more support than they currently receive
Q7	P 20). Do people with IIH who have well managed papilloedema need more regular check ups and closer management of other symptoms than they currently receive
Q7	P 21c). How should IIH be monitored for relapse (e.g. LP, headache reporting) in a person with IIH in remission
Q7	P 41). Is it very difficult for a person with IIH to contact the right specialist and access necessary healthcare when they have a worsening of their IIH symptoms
Q7	P 43b). Does current guidance recommend that people with IIH and shunts should carry an implant card
Q7	H 77). What are the best methods to determine whether IIH has resolved
Q7	P 78a). What are the treatment options for people with IIH
Q7	P 98). What are the best strategies for self management of symptoms of IIH day to day
Q7	H 124). What are the criteria/symptoms that indicate a person with IIH would benefit from treatment with acetazolamide
Q7	H 141). What is the effectiveness of management of people with IIH through virtual clinics or nurse specialists compared with face to face clinics
Q7	H 172b). What is the effectiveness of management of people with IIH by GP's compared with specialists in secondary care
Q7	H 185). Is there a need for clear guidelines to inform treatment and care pathways for IIH
Q7	H 198a). What is the effectiveness in terms of headache and vision outcomes of people with IIH having access to a dedicated IIH service
Q7	H 226). How frequently or for what reasons should lumbar puncture be carried out post diagnosis of IIH
Q7	P 237b). What extra help should people with IIH receive if they have depression as a co-morbidity

Q7	H 242b). What are the best strategies for managing people with IIH and depression and/or anxiety
Q7	H 258). Do people with IIH need to see an endocrinologist
Q7	P 283). What criteria are used to determine when IIH is in remission, do people need further care after their IIH has gone into remission
Q7	H 300). What is the best evidence based treatment pathway for people with IIH
Q7	P 326a). What are the best treatment options when successful weightloss has failed to relieve symptoms of IIH
Q4	P 83). How should individuals with papilloedema but no headache be treated?
Q1	P 65a). What information should be given at diagnosis?
Q2	P114c). Is there a justification for additional funding for treatment of IIH
Q3	P 348). Do people with IIH have sufficient access to check ups by optometrists
Q4	P 58). Are greater numbers of headache specialist staff required to meet the needs of the IIH population
Q4	P 96a). Are greater numbers of headache specialist staff required to meet the needs of the IIH population
Q6	H 199a). Are there regional variations in quality of care for people with IIH
Q6	H 251). Should people with IIH be managed in a specialist IIH clinic
Q6	H 256). What is the effectiveness in terms of cost and patient outcomes of a two week wait system for referral of people with IIH
Q6	H 258). Is there a need for more specialised IIH clinics
Q6	H 259). Is there a need for more specialised neuro-ophthalmology clinics for people with IIH
Q6	F 277). Is there a regional variation in the types of treatments being offered to people with IIH
Q6	P 297b). Is there a regional variation in the quality of care and types of treatments being offered to people with IIH
Q6	H 339). Are specialist clinics for IIH available
Q6	H 350). Is there a need for specialist clinics
Q7	O 95). Are the waiting times for appointments with IIH specialists too long
Q1	P 39b). What guideline pressure readings exist for prescribing medications to treat IIH
Q7	P 179). Do some regions in the UK need more specialist neurology clinics
Q6	P 51b). Does early conservative management prevent surgery
Q3	P 65c). What is the best route to appropriate healthcare for a person with IIH having concerns about their vision symptoms
Q3	P 85). What is the best route to appropriate healthcare for a person with IIH having concerns about their vision symptoms
Q3	P 119). What effect do long waiting times for ophthalmology appointments have on vision outcomes in IIH
Q3	P 146). What is the best route to appropriate healthcare for a person with IIH having concerns about their vision symptoms
Q3	H 198a). Should all people with IIH be referred to a neuro-ophthalmologist
Q3	H 198d). When should a person with stable IIH be discharged from ophthalmology and visual field follow up
Q1	H 192). Should a lumbar puncture be conducted in the absence of papilloedema
Q1	H 130b). What are the distinguishing features of IIH headache, how can it be differentiated from chronic migraine/MOH
Q1	H 235). What are the symptoms that differentiate between IIH and other headache conditions
Q1	P 271). What are the symptoms/diagnostic test results that differentiate between IIH and other similar conditions
Q1	P 34). How do you differentially diagnose patients without papilloedema that have drusen and IIH, and people with just drusen.
Q1	H 214). Do people with IIH without papilloedema have spontaneous venous pulsation
Q1	P 23b). Is bmi/weight of person a critical factor in arriving at a diagnosis of IIH
Q1	P 43b). What are the best available evidence based diagnostic criteria for IIH
Q1	P 67). What are the full diagnostic criteria for IHH
Q1	P 88). Should lumbar puncture test be carried out first when IIH is suspected
Q1	P 98). What tests are used to diagnose IIH
Q1	H 124). When do you perform further investigations (other than MRI/MRV/LP)?
Q1	P 128). What are the symptoms of IIH, how do they vary between patients
Q1	P 146). At which point in the diagnostic process should lumbar puncture be used
Q1	F 150). What are the full diagnostic criteria for IHH
Q1	P 157). Is the diagnosis of IIH arrived at by exclusion of other possibilities
Q1	P 158). What are the full diagnostic criteria for IHH
Q1	P 164). Is swelling behind the eyes or eye problems a required symptom for diagnosis of IIH
Q1	H 165). What is the process for diagnosis when pressure is borderline
Q1	H 173a). What is the best available method for diagnosis of IIH
Q1	H 174b). Is there an age above which diagnosis of IIH cannot be made?
Q1	H 222d). What symptoms in a patient justify lumbar puncture

	P 251b). Is IIH always symptomatic
Q1	H 257c). What are the best available evidence based criteria for diagnosis of IIH
Q1	H 263c). Do all people with IIH have visual disturbances
Q1	H 264c). Are venograms beneficial for all cases of IIH
Q1	P 289b). Can time with disease be estimated at diagnosis
Q1	H 293). Does an adequate set of criteria for diagnosis of IIH exist and is it widely used
Q1	P 317). Should presence of headaches be an essential diagnostic criteria
Q1	O 320a). What are the standard diagnostic tests for IIH
Q1	P 160c). What are the best evidence based practices for diagnosis and management of IIH and are they widely used
Q1	P 44a). Should people with continuous headache be referred for lumbar puncture earlier in the diagnostic process to confirm/rule out IIH
Q1	H 196). Is venography required for all suspected cases of IIH
Q1	H 206a). Is venography required for all suspected cases of IIH
Q1	H 142). What further tests should be carried out to investigate an atypical case of IIH
Q1	P 79). What are the visual symptoms characteristic of IIH
Q3	P 109). What are the best criteria for distinguishing between IIH headache and migraine headache
Q4	H 129). What are the specific features of IIH headache that enable healthcare professionals to distinguish between it and other types of headache
Q4	H 300a). What are the symptoms/characteristics that define IIH headache
Q4	H 325b). What are the symptoms/characteristics that define IIH headache
Q4	H 300a). What are the best evidence based diagnostic pathway for IIH
Q6	P 44a). Should people at high risk of IIH due to high BMI, who are presenting with severe headache without evidence of papilloedema be given lumbar puncture to
Q7	P 110). What is the best evidence based pathway to diagnosis
Q7	H 229). What are the best evidence based criteria for computed tomographic venography and magnetic resonance venography in IIH
Q1	What are the best evidence based diagnostic criteria incorporating people with IIH with and without papilloedema
Q1	P 289a). Can diagnosis be achieved without an emergency lumbar puncture
Q1	H 312a). Which tests should be carried out to fully diagnose and categorise IIH
Q1	H 239). What additional investigations should be carried out in atypical cases of IIH
Q2	P 113a). What is the test accuracy of the diagnostic process currently in use for IIH
Q1	P 119). What is the test accuracy of the diagnostic process currently in use for IIH
Q1	H 204a). What is the diagnostic test accuracy of current best evidence based criteria for diagnosis of IIH, could these be improved and are they well publicised
Q1	H 205). What are the comparative diagnostic test accuracies for the various diagnostic tests
Q1	H 215). What is the diagnostic test accuracy of standard diagnostic tests for IIH including lumbar puncture compared with standard tests excluding lumbar puncture
Q1	H 221). What is the diagnostic test accuracy of the international headache criteria for IIH, do they need to be improved
Q1	H 225a). Of the battery of tests available for diagnosing IIH which is the most sensitive for identifying the disease
Q1	H 226). What is the best evidence based program for diagnostic work up of suspected IIH
Q1	H 245). The relative contribution/weighting of history, imaging, visual and LP abnormalities for accurate diagnosis
Q1	H 253). What is the diagnostic test accuracy, safety and tolerability of lumbar puncture compared with other diagnostic testing for IIH, is a better test needed
Q1	H 279). Are there any biomarkers for IIH and if so what are the diagnostic test accuracies of these
Q1	H 321a). What is the best (safety, accuracy, tolerability) diagnostic test for measurement of intracranial pressure
Q1	H 349b). What is the best test to confirm the diagnosis of IIH
Q1	P 160a). What is the diagnostic test accuracy of the modified dandy criteria
Q1	H 178). What is the diagnostic test accuracy of confirmation of venogenic problem in combination with other standard testing compared with standard testing alone for
Q1	H 186a). What is the diagnostic test accuracy of modified dandy criteria for IIH
Q1	H 222a). What is the diagnostic test accuracy of standard tests with lumbar puncture compared with standard tests without lumbar puncture
Q1	H 263a). What is the diagnostic test accuracy, safety and tolerability of lumbar puncture compared with other diagnostic testing for IIH
Q1	H 264b). What are the diagnostic test accuracies of presence of empty sella and slit-like ventricles on scans for detecting IIH
Q1	H 303a). What is the diagnostic test accuracy of neuroimaging compared to standard testing (lumbar puncture) for IIH
Q1	C1b). What is the diagnostic test accuracy of lumbar puncture opening pressure alone compared with full battery of diagnostic tests for detecting IIH
Q1	H 7b). What is the diagnostic test accuracy of lumbar puncture in addition to other standard tests compared with other standard tests alone.
Q1	H 9a). What is the diagnostic test accuracy and repeatability of lumbar puncture for detection of IIH
Q3	C 1). What is the diagnostic test accuracy of LP opening pressure alone compared with other classic IIH symptoms including vision problems for detecting IIH
Q7	H 198b). What are the best tests to predict severity of disease at diagnosis
Q1	H 216). What is the diagnostic test accuracy of lumbar puncture for IIH when imaging results are normal

	Q1	P 269). What is the diagnostic test accuracy, safety and tolerability of optical coherence tomography compared with lumbar puncture for detecting IIH	
	Q1-moved from old C3	H 218). What is the diagnostic test accuracy of standard diagnostic tests for IIH with addition of Optical coherence tomography compared with standard tests alone, is it	
	Q1-moved from old C3	H 232). What is the diagnostic test accuracy of the presence of spontaneous venous pulsation for normal intracranial pressure	
	Q1-moved from old C3	H 233). What is the diagnostic test accuracy of non-invasive tests (e.g. ophthalmological sonography), compared with standard testing	
	Q1-moved from old C3	H 265). What is the diagnostic test accuracy and tolerability of presence of spontaneous venous pulsation in the fundi compared with lumbar puncture for	
	Q7	H 174). What is the best diagnostic method to identify that patients with spontaneous CSF leak (e.g. rhinorrhoea) have underlying IIH	

B7. Do all clinicians in the UK use the same diagnostic criteria for IIH diagnosis?	Q1	P 46). Are standard diagnostic criteria used nationally or does a variation exist in patient experience depending on location	Known known	Deborah I. Friedman, Grant T. Liu, Kathleen B. Digre. Revised diagnostic criteria for the pseudotumor cerebri syndrome in adults and children;
	Q1	P 66). Is there local/national variation in criteria used to diagnose IIH		
	Q1	H 121). Do neurologists/ophthalmologists use the most up to date diagnostic criteria		

D1. Are non-invasive intracranial pressure (ICP) measurements accurate and clinically useful?	Q1	O 13). Are there alternative, non invasive, tests to lumbar puncture for measuring intracranial pressure	Known unknown
	Q1	H 140). What is the diagnostic test accuracy, safety and tolerability of lumbar puncture versus alternative diagnostic tests for IIH	
	Q1	H 144). What is the diagnostic test accuracy, safety and tolerability of lumbar puncture versus alternative diagnostic tests for IIH	
	Q1	H 145). What is the diagnostic test accuracy, safety and tolerability of lumbar puncture versus alternative diagnostic tests for IIH	
	Q1	P 151). What is the diagnostic test accuracy, safety and tolerability of lumbar puncture versus alternative diagnostic tests for IIH	
	Q1	P 154). What is the diagnostic test accuracy of alternatives to lumbar puncture for IIH	
	Q1	O 190c). What are the diagnostic test accuracies and tolerabilities of alternative non-invasive methods of measuring cranial pressure compared with lumbar puncture	
	Q1	P 194). What is the diagnostic test accuracy, safety and tolerability of alternative, non invasive, procedures compared with lumbar puncture for diagnosing IIH	
	Q1	H 207a). What is the diagnostic test accuracy of wirelessly readable intracranial pressure reservoirs compared with isolated CSF pressure readings for IIH with	
	Q1	H 210). What is the diagnostic test accuracy of non-invasive tests of intracerebral pressure (e.g. tympanometry) compared with (lumbar puncture)	
	Q1	H 211a). What is the diagnostic test accuracy of non-invasive tests of intracerebral pressure compared with (lumbar puncture)	
	Q1	H 223). What is the diagnostic test accuracy, safety and tolerability of LP opening pressure compared with alternative tests	
	Q1	H 236). What is the diagnostic test accuracy of standard tests including lumbar puncture compared with standard testing without lumbar puncture	
	Q1	P 241b). What is the diagnostic test accuracy, safety and tolerability of lumbar puncture compared with alternative non invasive methods of measuring CSF	
	Q1	H 242a). What is the diagnostic test accuracy of lumbar puncture compared with best diagnostic criteria for IIH, are LP's considered the primary indicator of this	
	Q1	P 251a). What is the diagnostic test accuracy, safety and tolerability of lumbar puncture compared with alternative non invasive methods of measuring CSF	
	Q1	H 252c). What is the diagnostic test accuracy, safety and tolerability of lumbar puncture compared with alternative non invasive methods of measuring CSF	
	Q1	H 247a). What is the diagnostic test accuracy of lumbar puncture for IIH compared with other tests for diagnosis of IIH	
	Q1	H 275). What is the diagnostic test accuracy, safety and tolerability of lumbar puncture compared with alternative non invasive methods of measuring CSF	
	Q1	P 283). What is the diagnostic test accuracy, safety and tolerability of lumbar puncture compared with alternative tests for diagnosis of IIH	
	Q1	P 291). What is the diagnostic test accuracy of available diagnostic testing with lumbar puncture compared to available tests without lumbar puncture for IIH	
	Q1	P 292). What is the diagnostic test accuracy of available diagnostic testing with lumbar puncture compared to available tests without lumbar puncture for IIH	
	Q1	H 300). What is the diagnostic test accuracy of available diagnostic testing with invasive tests such as lumbar puncture compared to available tests without invasive	
	Q1	P 315). What is the diagnostic test accuracy of lumbar puncture compared to alternative non-invasive tests for IIH	
	Q1	H 329). What is the diagnostic test accuracy, safety and tolerability of lumbar puncture compared to alternative non-invasive tests for IIH	
	Q1	H 186b). What are the diagnostic test accuracies of scan and USS methods of ICP measurement compared with lumbar puncture	
	Q3	H 169). Are improvements to shunts in development that would allow the flow through them to be monitored easily and non-invasively	
	Q7	H 10). What are the best methods of measuring intracranial pressure without the use of intracranial bolts	
	Q7	H 143). Is there a more reliable way of measuring intracranial pressure than lumbar puncture	
	Q1	P 18). Are there alternative, non invasive, tests to lumbar puncture for diagnosing IIH	
	Q1	P 28). Are there alternative, non invasive, tests to lumbar puncture for diagnosing IIH in development	
	Q1	P 33). Are there alternative, non invasive, tests to lumbar puncture for diagnosing IIH	
	Q1	P 49). Are there alternative, non invasive, tests to lumbar puncture for diagnosing IIH	
	Q1	P 55a). Are there alternative, non invasive, tests to lumbar puncture for diagnosing IIH	
	Q1	H 133). Are there alternative, non invasive, tests to lumbar puncture for measuring intracranial pressure, e.g. pressure flow, ultrasound, and interferometry compared	
	Q1	P 161). Are there alternative, non invasive, tests to lumbar puncture for diagnosing IIH	
	Q4	P 132). Could non-invasive ICP measurement be reasonably accurate and improve patient experience	
	Q4	H 236). Could non-invasive ICP measurement be reasonably accurate and improve patient experience	
	Q1	P 163e). Are there alternative, non invasive, procedures to lumbar puncture for diagnosing and treating IIH	
	Q1	H 204d). Are there alternative, non invasive, tests to lumbar puncture for measuring intracranial pressure e.g. quantitative MRI	

D2. (combined with 1 qu from N8) How could we improve the patient experience of LP?	Q1	H 12b). Do the (attempts)/tests involved in diagnosis of IIH exacerbate symptoms	Known known	Nomura, J. T., Leech, S. J., Shenbagamurthi, S., Sierzenski, P. R., O'Connor, R. E., Bollinger, M., Humphrey, M. and Gukhool, J. A. (2007), A Randomized Controlled Trial of Ultrasound-Assisted Lumbar
	Q6	H 121). How can LPs be improved to reduce traumatic experience		
	Q6	P 135b). How can LPs be improved to reduce traumatic experience		
	Q6	P 176b). How can LPs be made less traumatic		
	Q6	P 289b). How can LPs be improved to reduce traumatic experience		
	Q1	H 171b). What is the best protocol for carrying out LP in very obese patients (sitting v lateral position; gauge and length of spinal needle; using image intensification;		
D3. (combined with J4) Do lumbar punctures (LPs) have long-term safety complications?	Q1	P 55b). Is lumbar puncture safe	Known unknown	Limited evidence- Evans RW. (1998) Complications of lumbar puncture. Neurol Clin. 16(1):83-105.
	Q3	P 49). What is the safety and efficacy of repeated lumbar punctures to relieve pressure when required for treatment of vision loss in IIH		
	Q3	H 222b). What is the safety and efficacy of urgent lumbar puncture compared with increasing doses of medications for visual failure in IIH		
	Q4	H 332). What is the safety and efficacy of lumbar puncture for treatment of headache in people with IIH		
	Q2	H 134a). How useful is a therapeutic lumbar puncture in the treatment of IIH		
	Q7	H 235). What is the role of ICP monitoring in the diagnosis and management of IIH (and in particular headaches)		
	Q3	H 61). What symptoms of worsening headache/vision indicate the need for lumbar puncture		
	Q3	H 122). When should a person with IIH be referred for therapeutic lumbar puncture		
	D4. What are the diagnostic test accuracies of the presence of unilateral or bilateral tinnitus, visual obscurations and symptom relief post LP	Q1		

Formed question	Contributing uncertainties		Certainty	Reference
E1. Are certain groups of individuals more susceptible to IIH?	Q1	P 42a). What causes IIH	Known unknown	
	Q1	P 87). What causes IIH		
	Q1	P 90). Aside from being overweight, what are the other possible causes of IIH		
	Q1	P 106). Aside from being overweight, what are the other possible causes of IIH		
	Q1	H 195). What risk factors (apart from gender, age and BMI) have been identified for IIH		
	Q1	P 273). What are the risk factors for IIH		
	Q1	P 296b). What causes IIH		
	Q1	O 320c). Are there many different types of IIH?		
	Q2	P 4). What factors in combination with being overweight/obese cause IIH		
	Q2	O 13a). What causes IIH		
	Q2	P 16). Is the cause of IIH known		
	Q2	P 31). Aside from being overweight, what are the other possible causes of IIH		
	Q2	P 34). What causes IIH		
	Q2	P 38b). What causes IIH		
	Q2	P 44b). What causes IIH		
	Q2	P 60a). What causes IIH		
	Q2	H 61a). What causes IIH		
	Q2	P 68). What causes IIH		
	Q2	P 76). What are the characteristics of the population most at risk of IIH and why		
	Q2	P 79). What causes IIH (suggests previous injury or other undiagnosed illness)		
	Q2	H 80). What are the characteristics of the population most at risk of IIH and why		
	Q2	P 81). What are the risk factors for IIH		
	Q2	F 86). What causes IIH		
	Q2	P 87). What causes IIH		
	Q2	P 89). What causes IIH in the healthy weight population		
	Q2	P 99). What causes IIH		
	Q2	P 100a). What causes IIH		
	Q2	P 107). What causes IIH		
	Q2	P 110a). What causes IIH		
	Q2	P 113a). What causes IIH		
	Q2	P 115c). What causes IIH		
	Q2	P 126). Do factors related to bmi, hormone profile, stress, caffeine, allergies contribute towards risk of developing IIH and what is their order of influence		
	Q2	P 132a). What causes IIH		
	Q2	H 133a). Aside from being overweight, what are the other possible risk factors for IIH		
	Q2	H 142). What causes IIH		
	Q2	P 144b). Are there any known triggers for IIH		
	Q2	P 147a). What causes IIH		
	Q2	P 153). Aside from being overweight, what are the other possible causes of IIH		
	Q2	P 156). Aside from being overweight, what are the other possible causes of IIH		
	Q2	P 157a). What causes IIH		
	Q2	P 158c). What triggers onset of symptoms in IIH		
	Q2	P 160b). What causes IIH		
	Q2	P 163). What causes IIH		
Q2	F 167). What causes IIH			
Q2	O 170). What causes IIH			
Q2	H 180a). What causes IIH			
Q2	H 181). What are the relative impacts of the various risk factors for IIH			
Q2	H 188). What causes IIH			
Q2	H 192). What causes IIH			
Q2	H 195). Apart for gender, age and bmi what other risk factors are associated with developing IIH			

Q2	H 205) What are the best evidence based risk factors identified for IIH
Q2	H 215). What is the role of the various risk factors (obesity, gender, hormones) in the development of IIH
Q2	H 223). What causes IIH
Q2	H 226). What are the risk factors for IIH
Q2	H 228a). Aside from gender, age and bmi what are the other risk factors for IIH
Q2	H 234). What are the common characteristics/risk factors for men with IIH
Q2	P 237). What causes IIH
Q2	H 238a). What causes IIH
Q2	H 246). What causes IIH
Q2	P 281). What are the risk factors for development of IIH
Q2	P 289c). What are the risk factors for IIH
Q2	P 291). Adise from being overweight/obese what are the risk factors for IIH
Q2	H 313). What causes IIH
Q2	P 315). What causes IIH in a non-typical sufferer
Q2	O 320b). What are the common risk factors for IIH
Q2	H 332). What causes IIH
Q2	H 338). What are the unknown risk factors for IIH
Q2	P 345a). What causes IIH
Q2	H 346a). What causes IIH
Q2	H 355a). What causes IIH
Q2	H 141). Is this a heterogenous group of disorders with a common endpoint or is there an underlying common pathway
Q1	P 23c). Are women really at greater risk of developing IIH than men and if so why
Q1	H 59). Is risk of disease higher in any specific ethnic group or age group
Q1	P 85). Does IIH occur in men
Q1	H 312b). What is the best way to investigate an atypical patient (eg male or not obese) for unusual causes?
Q2	P 3). Why is IIH more likely to occur in women than in men
Q2	H 9). How are gender and bmi related to pathogenesis
Q2	H 11b). Why is the risk of IIH highest in post pubescent females
Q2	H 12a). Is it age related
Q2	P 110b). Why is IIH more common in women than men?
Q2	H 124). What is the the biological explanation for increased risk of IIH in females of child-bearing age
Q2	H 129). Why is IIH rare in men
Q2	H 140a). What is the biological reason for females being at greater risk of developing IIH
Q2	H 149b). What causes IIH in men
Q2	H 183b). What is the biological reason for the higher incidence rates in women than men
Q2	H 184a). What is the biological reason for the higher incidence rates in women than men
Q2	H 187c). What is the biological reason for the higher incidence rates in women than men
Q2	P 189a). What is the biological reason for the higher incidence rates in women than men
Q2	H 201). What is the biological reason for the incidence of IIH being much lower in men than women
Q2	H 211e). What is the biological reason that IIH has a much higher incidence in women than men
Q2	H 220a). What is the biological reason for the higher incidence of IIH in women than in men
Q2	H 220b). What is the biological reason that the incidence of IIH is higher in younger people
Q2	H 238b). What is the biological explanation for the higher incidence among females age 20-40 yrs
Q2	H 250b).Do the incidence rates of IIH vary with ethnicity
Q2	H 253). What is the biological reason for low incidence of IIH in men
Q2	H 257b). What is the biological reason for the higher incidence rates in women than in men
Q2	H 275). What I the biological explanation for the higher rates of incidence of IIH in women than in men
Q2	P 286c). What is the biological explanation for the higher incidence of IIH in women of child-bearing age
Q2	H 304a). What is the biological explanation for the higher incidence of IIH in women of chidbearing (a certain) age
Q2	H 329b). What is the biological explanation for the higher incidence of IIH In women than men
Q7	P 104). What are the rates of incidence of IIH in men and children compared with in women

Q7	H 220). Does ethnicity play a role in the development and severity of IIH?
Q2	P 30a). Is IIH caused by infant trauma at childbirth
Q2	P 51b). Does long term treatment with hydrocortisone cause an increased risk of IIH
Q2	F 54). Can a blow to the head cause IIH
Q2	P 56). Can IIH be caused by epidural and 6 spinal blocks in single session
Q2	P 65a). What proportion of IIH population connect the onset of their symptoms with a particular incident
Q2	P 67). Could a blow to the head cause IIH
Q2	H 118c). What is the biological explanation for the link between certain drugs and risk of IIH
Q2	P 137b). Do some medications increase the risk of IIH
Q2	P 145). Is IIH stress related
Q2	P 244). Is there a link between the antibiotic nitrofurantoin and IIH
Q2	H 259c). Is IIH drug induced
Q2	H 260b). Which drugs can cause IIH
Q2	H 285b). Is IIH caused by certain foodstuffs?
Q2	H 285f). Is IIH linked to smoking
Q1	F 277). Can tetracycline cause IIH
Q2	P 28d). What medications are linked to increased risk/worsening of symptoms of IIH
Q2	P 26). What is the relationship between Nitrofurantoin and IIH
Q2	P 305). Which medications have an associated increased risk of IIH
Q2	P 322). What evidence exists for the following possible triggers for IIH: back injury, contrast used in myelogram, multisystem body trauma, glandular fever, micro -
Q2	H 262). Is IIH caused by adverse childhood experiences
Q2	P 348). Does spinal or nerve damage cause or contribute towards risk of IIH
Q2	P 146b). Is IIH caused by a physical malfunction in the brain
Q7	P 90). What causes IIH and can it be cured
Q7	P 116). What causes IIH
Q7	P 296). What causes IIH
Q7	H 313). What are the risk factors for IIH
Q7	F 318). What causes IIH
Q2	P 24). Why do healthy weight people get IIH
Q2	P 28a). Why do healthy weight people get IIH
Q2	P 51a). What causes IIH in the healthy weight population
Q2	H 75b). Are there any risk factors for IIH associated with a persons metabolism
Q2	H 198b). What is the biological explanation for the occurrence of IIH in the atypical patient (e.g. healthy weight males)
Q2	O 193). Why do only a small proportion of overweight women suffer from IIH
Q2	H 197). What causes IIH in healthy weight people
Q2	P 230). What causes IIH in healthy weight individuals
Q2	H 250a). What is the biological reason for the higher incidence of IIH in overweight females
Q2	H 250c). What is the biological explanation for low incidence in elderly overweight females
Q2	H 263b). What is the incidence of IIH in the healthy weight population
Q2	H 312). What causes IIH in healthy weight and/or male populations
Q2	P 314). What causes IIH in the healthy weight population
Q2	H 321b). What triggers onset of symptomatic IIH in a person who has been overweight with no recent weight change
Q2	P 324b). What causes IIH in the healthy weight population
Q2	H 350). Do the causes vary between men and women and over weight and healthy weight people with IIH
Q5	P 115). What is the biological explanation for the incidence of IIH in healthy or underweight people and what can they do to relieve symptoms when losing weight is
Q7	P 64). What is the biological explanation for the higher incidence in women than men
Q7	P 153). What causes IIH in healthy weight people who do not experience headaches
Q7	H 204b). What proportion of people with IIH do not fit the expected clinical phenotype
Q5	P 36). What causes IIH in the healthy weight population
Q5	P 89). What is the cause of IIH in people who are underweight
Q5	H 124c). Does lean mass (ie muscle) contribute to the (presumably hormonal) drivers of IIH

Q5	P 147a). What are the rates of incidence of IIH in the healthy weight population	
Q5	P 302). Does weight loss or weight gain influence symptoms/disease progression in those people with IIH who were at a healthy weight when diagnosed	
Q5	F 318). What are the risk factors for IIH besides high BMI	
Q6	H 9). Should greater efforts be made to investigate cause of raised CSF pressure	
Q7	P 108). Has any patient focussed research taken place into the causes and impact of IIH	
Q7	H 303). Do the causes of IIH differ between the females and males and high BMI and normal BMI populations	
Q2	H 259a). What is the metabolic profile of individuals with IIH	

E2. (combined with A2, A3, R3, R4) 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?

Q2	P 21a). How closely is weight correlated with risk of IIH (relapse) compared with other factors	Known Unknown
Q2	H198c). What are the prognostic markers for IIH	
Q2	H 249a). What are the risk factors that correspond to more aggressive form of IIH	
Q2	H 256). What are the risk factors that for sight loss in IIH	
Q2	H 261c). Are there any molecular mechanisms that can serve as potential targets for the development of novel therapies	
Q3	P 109). what is the impact of environmental variables on IIH symptoms e.g. temperature, altitude etc	
Q7	P 62). What is the explanation for the higher incidence of IIH in some regions of the UK than others	
Q7	H 221). What factors predict risk of relapse of People with IIH	
Q2	H 250d). Why do some people get fulminant IIH and some not	
Q7	P 284a). What are the signs/symptoms that people with IIH formerly in remission have relapsed	
Q6	H 11). What are the early signs that IIH is recurring	
Q1	P 17c). Why is it difficult to get a diagnosis of IIH (misdiagnosed drunkenness, tension headache, migraine)	
Q1	P 19). Why is it difficult to get a diagnosis of IIH	
Q1	P 30). Why is it so difficult to get a diagnosis of IIH	
Q1	P 35). Optician identified markers not GP, why is it so difficult to get a diagnosis of IIH/how can this be improved (misdiagnosed dry eyes, migraine)	
Q1	P 65b). Optician identified markers not GP, why is it so difficult to get a diagnosis of IIH/how can this be improved	
Q1	P 72). Optician identified markers, why is it so difficult to get a diagnosis of IIH/how can this be improved	
Q1	P 81). Why is it difficult to get a diagnosis of IIH	
Q1	P 84). Why is it difficult to get a diagnosis of IIH	
Q1	F 86). Why is it difficult to get a diagnosis of IIH	
Q1	P 105). Why is it difficult to get a diagnosis of IIH	
Q1	P 107). Why is it difficult to get a diagnosis of IIH	
Q1	P 108a). Why is it difficult to get a diagnosis of IIH/to be taken seriously by doctors about symptoms of IIH	
Q1	P 117). Why is it difficult to get a diagnosis of IIH (misdiagnosed migraine)	
Q1	P 132). Optician identified markers not GP, why is it so difficult to get a diagnosis of IIH/how can this be improved	
Q1	H 203b). Is IIH overdiagnosed in the overweight people presenting with headache	
Q1	P 230). Why is it difficult to get a diagnosis of IIH despite high pressure readings	
Q1	H 262). How reliable are diagnoses?	
Q1	P 311). Why does it take so long to get a diagnosis of IIH	
Q1	P 319). Why does it take so long to get a diagnosis of IIH	
Q1	O 320b). How long does/should it take to diagnose IIH	
Q1	P 322b). Why does it take so long to get a diagnosis of IIH	
Q1	P 324). Why is it difficult to get a diagnosis of IIH until visual problems are present	
Q1	P 348). Optician identified markers not GP, why is it so difficult to get a diagnosis of IIH/how can this be improved (misdiagnosed dry eyes, migraine)	
Q1	H 130e). What is the incidence of functional overlay in IIH, how can this be differentiated from actual IIH symptoms	
Q4	F 318). Why does IIH take so long to diagnose	
Q1	P 23a). What is the quality and extent of the evidence base for determination of symptoms/used for diagnosis of IIH	
Q1	H 182a). Can the diagnosis process be simplified to avoid the need for multiple specialists' involvement	
Q1	H 184a). Have any biomarkers of disease been identified	
Q1	H 224). Are there any biomarkers for IIH in development?	
Q1	H 249). Could further useful symptomatic evidence be obtained from observing/testing CSF in suspected IIH	
Q1	H 143). Could improvements be made to the diagnostic process to move away from diagnosing by exclusion	
Q1	P 58). Are there alternative tests to lumbar puncture for measuring pressure	

Q1	P 60b). Are there alternative tests to lumbar puncture for measuring pressure
Q1	P 120). Are less painful diagnostic tests available that could replace the current standard tests
Q1	H 180). Are there alternative, non invasive, tests in development which will simplify process of diagnosing IIH
Q1	H 347). Is there a better, less invasive way of measuring intra-cranial pressure than lumbar puncture in development
Q1	H 354). Is there a better, less invasive way of measuring intra-cranial pressure than lumbar puncture
Q2	H 134b). Are there less invasive ways of managing IIH
Q7	H 195). Have any biomarkers of disease been identified which could aid diagnosis and predict disease severity
Q2	H 228c). Is IIH underdiagnosed
Q1	P 43d). Is it likely that IIH is underdiagnosed
Q1	H 211c). To what extent is there an invisible non-symptomatic population with IIH in the community
Q1	H 75c). What is the diagnostic test accuracy of monitoring features such as cough headache, visual obscuration, pulsatile tinnitus for IIH
Q1	P 163d). What is the diagnostic test accuracy and safety of the imaging techniques used to treat IIH
Q1	H 172). What are the diagnostic test accuracy and safety of MRI flow studies and venous imaging for IIH
Q1	H 198c). What is the diagnostic test accuracy of MRI markers of IIH
Q1	H 234). What are the diagnostic test accuracies of brain imaging techniques (small ventricles, optic nerve sheath swelling, empty sella, etc.) for IIH
Q1	H 255). What are the diagnostic test accuracy, safety and tolerability ratings of the various neuroimaging techniques for diagnosing IIH
Q1	H 260a). What are the diagnostic test accuracy, safety and tolerability ratings of the various neuroimaging techniques for diagnosing IIH
Q1	H 263b). What are the diagnostic test accuracy, safety and tolerability ratings of the various neuroimaging techniques for diagnosing IIH
Q1	P 286b). What is the diagnostic test accuracy of standard testing with additional CT or MRI scan compared with standard testing alone
Q1	P 302b). What is the diagnostic test accuracy of MRI/CT scanning compared to standard testing (lumbar puncture) for intracranial pressure measurement
Q1	H 321c). What is the diagnostic test accuracy of MRI scanning compared with other standard tests for IIH
Q1	H 75a). What is the diagnostic test accuracy of MRI imaging for IIH
Q1	H 5). What is the diagnostic test accuracy of optical coherence tomography compared with other available tests for detection of papilloedema
Q1	P 16a). What is the diagnostic test accuracy of CT scan compared with MRI for detection of IIH
Q1	H 57). What is the best evidence based test to detect/rule out optic disc swelling in patients with anomalous discs
Q1	O 190f). What is the diagnostic test accuracy of optical coherence tomography for detection of disc oedema in IIH
Q1	H 199a). What is the average time between symptom onset and diagnosis of IIH
Q1	H 212). What is the average time between symptom onset and diagnosis of IIH
Q3	P 44a). What is the diagnostic test accuracy and between rater reliability of observation using slit lamp compared with imaging techniques for monitoring
Q3	H 242a). What is the accuracy and safety of optical coherence tomography for diagnosis of papilloedema
Q3	H 242b). What is the diagnostic test accuracy of optical coherence tomography for detection of IIH and/or raised CSF pressure
Q6	H 235). Could a diagnostic test for papilloedema be carried out by GP's (retinal pictures using smart phone)
Q1	O 190e). What causes the high rate of false positive diagnoses of papilloedema and how can this be improved
Q1	H 199b). What are the rates of misdiagnosis/overdiagnosis of IIH and papilloedema
Q1	H 260c). How reliable are clinicians in diagnosing papilloedema?
Q1	H 338a). How do you differentially diagnose patients with acquired optic disc swelling due to raised ICP from disc drusen or congenitally crowded discs.
Q3	H 279). Are there better diagnostic markers for papilloedema (biomarkers)
Q1	P 27). What is the prognosis for this disease
Q3	F 45). What is the long term prognosis for vision loss in IIH
Q3	P 50). What is the long term prognosis for vision loss in IIH
Q3	P 58). What is the long term prognosis for vision loss in IIH
Q3	P 60a). What is the long term prognosis for vision loss in IIH
Q3	P 68). What is the long term prognosis for vision loss in IIH
Q3	P 107). What is the prognosis for vision loss in IIH
Q3	H 130a). What is the prognosis for vision in those with IIH without papilloedema
Q3	H 130c). What is the best evidence based prognostic marker for vision loss
Q3	P 158a). What is the prognosis for vision outcomes in people with IIH and papilloedema who have no vision problems currently
Q3	O 190d). What is the lifetime of the disease, do people with IIH go into remission when they reach a particular age
Q3	H 275). What is the long term prognosis in terms of vision outcomes for people with IIH
Q3	P 317). What is the prognosis for vision in IIH
Q3	P 342). What is the prognosis for people with mild papilloedema and IIH

Q6	P 34). What is the prognosis for people with IIH
Q6	H 214). What is the prognosis for people with IIH
Q7	P 21b). What is the prognosis/likelihood of relapse for a person with IIH in remission
Q7	P 33b). What is the prognosis for people with IIH
Q7	P 50). What is the prognosis for people with IIH
Q7	H 139). What is the prognosis for vision of people with raised ICP without papilloedema
Q7	P 145). What is the prognosis for people with IIH
Q7	P 154b). What is the prognosis for people with IIH
Q7	O 190b). What is the long term prognosis for those people with IIH who lose weight compared with those who did not lose weight
Q7	O 190c). What impact does the age of the person with IIH have on their prognosis
Q7	H 205). What prognostic factors of IIH have been identified
Q7	H 257b). What is the prognosis for people with IIH
Q7	P 272). What is the prognosis for people with IIH
Q7	P 292). What is the prognosis for people with IIH
Q7	H 306). What proportion of people with IIH go on to experience complete resolution of all symptoms
Q7	P 322). What is the duration of disease for IIH post menopause
Q7	P 323b). What is the prognosis for people with IIH and multiple stenoses
Q7	P 342). What is the prognosis for people with IIH
Q7	H 256). At what CSF pressure is sight more likely to be threatened?
Q3	P 38). What are the early warning symptoms of vision problems arising from IIH
Q3	P 99). What is the impact of low intracranial pressure on visual outcomes in IIH patients treated with shunts
Q3	H 134). What are the additional risk factors that lead some people with IIH to experience vision loss while others remain stable
Q3	H 182a). What are prognostic factors that could indicate a deterioration of vision in IIH?
Q3	H 232). What are the risk factors and/or symptoms which indicate whether or not a person with IIH will have vision loss
Q3	H 246a). What are the characteristics of the people with IIH in the subset that go on to have loss of vision
Q3	H 303). What are the characteristics/risk factors/symptoms that are predictive of whether or not a person with IIH will experience loss of vision
Q4	H 11). Does the severity of the headaches experienced by a person with IIH relate to the severity of the disease overall
Q7	H 198c). What proportion of people with IIH with normal visual fields at presentation will go on to experience deterioration of vision
Q3	F 86). What is the risk of relapse and vision loss after successful treatment of papilloedema
Q3	H 180b). Which characteristics/risk factors of people with IIH should be considered when making treatment decisions
Q6	H 228). Does poor compliance affect disease outcomes in people with IIH
Q7	O 190d). What is the impact of IIH on pregnancy
Q4	H 260b). Is presence of headache a useful guide to severity/risk of IIH

E3. What is happening in the body of a person with IIH which causes the development of the disease, the symptoms and the progression of the disease?

Q2	H 199b). Are the genes related to steroids (cortico as well as sex hormone) involved?	Known unknown
Q2	P 176). Is IIH related to thyroid function failure	
Q2	H 177). What is the role of intra abdominal pressure	
Q2	H 186c). How does raised ICP lead to papilloedema	
Q2	H 186d). What is the role of glymphatic channels (clear CSF) in IIH?	
Q2	H 198a). What is the key pathophysiological mechanism of IIH	
Q2	H 224). What is the mechanism of disease for IIH	
Q2	H 233). What is the pathophysiology of IIH	
Q2	H 261b). What is the pathophysiology of IIH	
Q2	H 264f). Do people with IIH show histological meningeal changes	
Q2	H 264g). What are the rates of higher than normal inflammatory cell count in CSF, what role does this play in the pathophysiology of the disease	
Q2	H 300a). What is the pathophysiology of IIH	
Q2	H 330). What is the mechanism of disease for IIH	
Q2	H 346c). What is the role of aquaporins (water channels?) in the pathogenesis of the disease	
Q3	P 158b). Does IIH cause brain damage which then results in vision problems	
Q3	H 173). What is the relationship between visual acuity, visual fields and degree of optical nerve swelling	
Q3	P 176). What is the relationship (or lack thereof) between papilloedema and loss of vision/visual disturbances	

	Q4	P 274b). What is the biological explanation for the pain in the arteries in the neck in people with IIH	
	Q4	H 298). What is the biological explanation for the high incidence of migraine in people with IIH	
	Q4	O 320c). What is the biological reason that painkillers worsen headaches in people with IIH	
	Q5	H 208). What is the biological explanation for relief of IIH symptoms for some people with weight loss but not for others	
	Q7	P 120a). Does CSF pressure fluctuate over time	
	Q7	P 120b). What is the biological explanation for the swelling and pain in the eyes in people with IIH	
	Q7	H 121b). What is the relationship between CSF pressure and papilloedema	
	Q7	H 206). What is the biological explanation for the burn out of the condition over time	
	Q7	H 347). What causes raised CSF pressure in people with IIH	
	Q7	P 31b). What is the relationship between blood pressure and intracranial pressure	
	Q2	P 144a). Is IIH present from birth	
	Q7	P 230). For what reason are people with IIH told to avoid blows to the head and air travel	
	Q7	341e). Does IIH have a dormant phase before symptoms occur	
	Q7	341d). What is the explanation for unilateral optic disc swelling in people with IIH	
	Q7	P 160). What causes symptoms associated with IIH	
	Q7	H 162). What is the natural history of IIH	

E5. Is IIH becoming more common?	Q1	H 222c). What is the incidence of IIH without optic disc swelling	Known unknown
	Q7	H 184b). Is the rate of incidence of IIH increasing	
	Q7	H 203). What is the rate of incidence of IIH without papilloedema	
	Q7	H 204a). Is the rate of incidence of IIH increasing	

Ee2. (combined with L3 in part) Besides weight gain what are the lifestyle triggers for IIH?	Q2	O 62). What are the lifestyle risk factors for developing IIH	Known unknown
	Q2	H 63c). What factors other than weight loss can reduce symptoms of IIH	
	Q2	H 228d). Is lower than average mobility a risk factor for IIH	
	Q2	Q2/P 317c). Is prolonged period of inactivity a risk factor for IIH	
	Q3	P 113). Can vision be restored by effective disease management	
	Q3	P 114). What can people with IIH do to prevent loss of vision	
	Q3	H 143). What are the best strategies for management of vision in people with IIH to reduce risk to their sight	
	Q3	P 34). What are the best evidenced interventions/lifestyle changes/actions to be implemented when vision starts to deteriorate	
	Q3	P 98). What treatments/actions/lifestyle changes could help to prevent further symptoms and/or pain in people with IIH	
	Q3	H 240a). What is the efficacy of successful weight loss compared with no weight loss for treatment of vision problems in IIH	

Ee3. Is there a genetic cause of IIH?	Q1	P 91). Are some people genetically more susceptible to developing IIH	Known unknown
	Q1	O 95). Is IIH hereditary	
	Q1	P 309a). Is a research focus on identifying genetic markers for IIH and IIHWOP needed	
	Q2	H 12b). Is it hereditary	
	Q2	P 35a). Is IIH hereditary	
	Q2	P 43b). Is IIH hereditary	
	Q2	P 55). Is IIH hereditary	
	Q2	H 71). Have genetic variants for IIH been identified	
	Q2	P 92). Is IIH hereditary	
	Q2	P 96c). Have genetic variants for IIH been identified	
	Q2	P 119). Is IIH hereditary	
	Q2	P 131). Is IIH hereditary	
	Q2	P 138). Is IIH hereditary	
	Q2	P 147b). Is IIH hereditary	
	Q2	P 166). Is IIH hereditary	
	Q2	H 171b). Have genetic variants for IIH been identified	
	Q2	H 174). Have genetic variants for IIH been identified	
	Q2	H 182b). Is IIH hereditary	

Q2	H 199a). Have genetic variants for IIH been identified
Q2	H 234b). Have genetic variants for IIH been identified
Q2	H 254). Have genetic variants for IIH been identified
Q2	H 255). Have genetic variants for IIH been identified
Q2	H 263a). Is IIH hereditary
Q2	H 264c). Is IIH hereditary
Q2	P 280). Is IIH hereditary
Q2	H 285a). Is IIH hereditary
Q2	H 306c). Is IIH hereditary
Q2	O 320a). Is IIH hereditary
Q2	P 324a). Is IIH hereditary
Q2	H 325a). Is IIH hereditary
Q7	P 21a). Is IIH hereditary
Q7	H 121c). Is IIH hereditary
Q7	H 242a). Is IIH hereditary
Q7	H 275). Is there any genetic predisposition to IIH
Q2	H 199c). Is there a genetic cause of IIH
Q2	H 207). Is there a genetic cause of IIH
Q2	H 208). Is there a genetic cause of IIH
Q2	H 279). Is there an epigenetic cause of IIH
Q2	H 325). Is there an epigenetic cause of IIH

Ee4. (combined with F8) What other conditions / features are associated with IIH (e.g. depression, sleep apnoea, endocrine disorders, cognition, nerve pain)?

Q1	P 17a). Is there a link between auto-immune disorders (lupus, ME, MS) and IIH	Known unknown
Q1	P 21). Is there a link between auto-immune disorders and IIH	
Q1	P 100). Can IIH occur as a symptom of another condition (e.g. ME/CFS/FIBROMYALGIA or Multiple Sclerosis)	
Q1	P 110). Are common co-morbidities considered during diagnosis	
Q1	P 126). Could IIH be a symptom of another underlying condition	
Q1	H 222e). Is migraine a common comorbidity and how should this be managed	
Q1	H 325). What is the incidence of comorbidities such as (OSA) obstructive sleep apnea and anaemia in the IIH population	
Q2	C 1). Is there an increased risk of or association with other conditions	
Q2	P 17). Could IIH be secondary to MS or lupus	
Q2	P 21b). Is uvueitis linked to IIH	
Q2	P 28e). Is there a link between Ehlers-danlos syndrome and IIH	
Q2	P 35b). Is the incidence of IIH higher in the migraine population	
Q2	P 38a). Is there a link between Chiari malformation and IIH	
Q2	P 43e). Is IIH linked to autoimmune disorders, what is the incidence of IIH in the autoimmune disorder population	
Q2	P 85). Is IIH a symptom of another underlying condition	
Q2	P 91b). Is there a link between sinus issues and IIH	
Q2	P 93b). Is IIH linked to any other conditions	
Q2	P 97b). What are the common comorbidities amongst the IIH population	
Q2	P100b). Is IIH linked to any other conditions	
Q2	P 146a). Is IIH secondary to another disease	
Q2	P 146c). Is IIH caused by lupus	
Q2	P 189b). Is risk of IIH related to testosterone levels/polycystic ovary syndrome	
Q2	H 211b). Does a viral infection in the choroid plexus cause the overproduction of CSF that leads to IIH	
Q2	H 219). What is the relationship between IIH and obstructive sleep apnoea	
Q2	H 220d). What is the role of snoring and obstructive sleep apnoea in the aetiology of IIH	
Q2	H 232b). Does sleep apnoea cause raised intra cranial pressure	
Q2	P241c). Is hyperflexibility a risk factor for developing IIH	
Q2	H 243). Is IIH linked to any other headache disorders	
Q2	H 245c). Is IIH linked to polycystic ovary syndrome	

Q2	P 323). What is the rate of incidence of stroke prior to diagnosis of IIH	
Q2	P 333). Is IIH linked to Antiphospholipid (Hughes) Syndrome	
Q4	P 42b). What is the link between IIH and other headache conditions	
Q7	P 56). Is there a higher incidence of depression in people with IIH than in the healthy population and what causes this	
Q7	P 107). What are the rates of incidence of stroke in people with IIH compared with the healthy population	
Q7	P 109). Is IIH linked to diabetes MIDD	
Q7	H 121a). What is the relationship between obstructive sleep apnea and IIH	
Q7	P 159). What are the rates of incidence of IIH as a secondary disease to large cerebral arteriovenous malformation	
Q7	P 284c). Can IIH cause other neurological problems	
Q7	P 284d). Is there a link between IIH and scoliosis	
Q7	341b). Can IIH cause psychosis	
Q7	H 350). What is the relationship between IIH and other abnormal CSF dynamics	
Q2	F 318). What are the co-morbidities for IIH	
Q2	P 340). What are the co-morbidities for IIH	
Q4	P 104). What is the relationship between IIH and migraine	
Q4	H 178). What is the relationship between IIH, Chiari 1 and migraine	
Q4	H 199). What is the incidence of primary headache syndromes in people with IIH compared with the healthy population	
Q2	H 136b). Is IIH associated with insulin resistance/pre-diabetes	
Q1	H 75f). What is the incidence of positive cerebral venous thrombosis (CVT) for sinus thrombosis in standard IIH population	
Q2	H 118b). What is the biological explanation for the link between iron deficiency and risk of IIH	
Q2	P 302). Can viral meningitis cause IIH and if so how	
Q4	P 274a). What is the biological explanation for the common dual diagnosis of IIH and migraine	
Q7	P 58). Does IIH affect memory	
Q7	P 91). Does IIH affect memory and speech	
Q6	P 241). What is the effect of IIH on cognitive function	
Q7	H 247a). What is brain fog	
	P 237a). What is the effect of IIH on memory	
Q7	P 241). What is the effect of IIH on cognitive function	
Q7	P 284b). What is the effect of IIH on cognitive function	
Q7	P 341a). What is the effect of IIH on cognitive function	
Q7	341c). Does IIH or the associated medications cause nerve pain	

Ee5. Are there hormonal causes for IIH and why is IIH associated with the female gender?	Q2	H 191). Is IIH hormone related	Known unknown
	Q1	C 307). Is IIH hormone related	
	Q2	H 10a). Is IIH a hormone related disease	
	Q2	P 15b). Is IIH hormone related	
	Q2	P 28b). Is IIH hormone related	
	Q2	P 41). Is IIH hormone related	
	Q2	P 43c). Is IIH hormone related	
	Q2	P 43d). Are people with excess of some hormones (eg estrogen) at increased risk of IIH	
	Q2	P 44a). Does menopause cause IIH	
	Q2	P 78). Is IIH hormone related	
	Q2	F 82). Is IIH hormone related	
	Q2	P 88). Is there too much focus on high bmi/weight being the cause, could IIH be hormone related	
	Q2	P 96b). Is IIH hormone related	
	Q2	P 97a). What is the role of hormones in raising intra cranial pressure	
	Q2	H 121). What are the roles of hormones generally and androgens specifically in the development of IIH	
	Q2	P 122). What is the roles of hormone in the development of IIH	
	Q2	P 135a). Is IIH hormone related	
	Q2	H 136a). Is IIH hormone related	
	Q2	P 137a). Is IIH hormone related	

Q2	P 146d). Is IIH hormone related
Q2	P 179a). Is IIH hormone related
Q2	P 179b). Is IIH hormone/pregnancy related
Q2	H 182a). What are the hormonal influences that increase the risk of IIH
Q2	H183d). Is IIH hormone related
Q2	H 187b). Is IIH hormone related
Q2	H 236). What is the biological reason for greater incidence of IIH in premenopausal
Q2	P 241b). Is IIH hormone related
Q2	H 258). Is IIH hormone related
Q2	H 263c). Is IIH hormone related
Q2	H 264a). Is IIH hormone related
Q2	P 268). Is IIH hormone related
Q2	P 272). Is IIH hormone related
Q2	P 273). Is IIH hormone related
Q2	P 274b). Is IIH hormone related
Q2	P 278). Is IIH hormone related
Q2	H 285e). Is IIH linked to pregnancy
Q2	H 325c). Is IIH hormone related
Q2	H 339). Which hormones are causally linked to IIH
Q7	P 16). Is there a link between IIH and hormones
Q7	P 268b). Why do periods trigger CSF pressure elevation in women with IIH
Q1	H 258). Do people with IIH have higher than normal levels of androgen
Q2	H 183c). Are there hormonal causes for IIH
Q2	P 19). Can the contraceptive implant cause IIH
Q2	P 28c). What is the effect of the mini-pill on symptoms/progression of IIH and is it safe/effective to use for a person with this disease
Q2	P 115a). What is the biological explanation for the increased risk with birth control
Q2	H 130b). Does pregnancy increase the risk of IIH symptoms in individuals who have previously suffered from the disease
Q2	P 200). What effect does the hrt pill have on risk of developing IIH
Q2	P 241a). Is IIH caused by the contraceptive pill
Q2	P 326). What triggers IIH in a person who has been taking hormones for many years
Q2	P 337). Is IIH linked to prolonged use of the contraceptive pill
Q2	P 341a). Is IIH caused by withdrawing contraceptive pill, if so what is normal time range between stopping pill and symptoms appearing
Q3	H 263b). How do hormones affect visual symptoms
Q3	H 355). What is the role of hormones and metabolism in the progression of vision problems in IIH
Q4	H 263c). Do hormones affect headache
Q2	P 132b). Are symptom flare ups linked to the menstrual cycle
Q2	P 310). Is there a higher incidence of IIH amongst women who have the mirena coil
Q5	P 68b). What role do hormones play in resolving symptoms after weight loss

F1. Why is obesity a risk factor for IIH in women and why is this not the case in men?

Q1	P 25). Does high bmi/obesity cause IIH	Known unknown
Q1	P 42b). Does high bmi/obesity cause IIH	
Q1	P 92). Does high bmi/obesity cause IIH	
Q1	O 95b). Does high bmi/being overweight/obesity cause IIH	
Q1	P 101). Does high bmi/being overweight/obesity cause IIH	
Q1	O 276). Does high bmi/obesity cause/contribute to development of IIH	
Q1	P 282). Does high bmi/obesity cause/contribute to development of IIH	
Q2	H 10b). Why do some people with a given BMI develop IIH while others don't	
Q2	H 11a). Why do only a small proportion of overweight people suffer from IIH	
Q2	O 13b). Why does being overweight/obese cause IIH	
Q2	P 15a). Does being overweight/obese increase risk of IIH	
Q2	P 22). Is it weight related and if so why do some people who are not overweight get it	

Q2	P 25). Is IIH caused by something other than being overweight
Q2	P 27). What evidence exists to suggest that IIH is caused by person being overweight
Q2	P 30b). What causes IIH in the healthy weight population, could this also be the cause in those who are overweight
Q2	P 32). What evidence exists to suggest that IIH is caused by person being overweight
Q2	P 36). Is it weight related and if so why do some people who are not overweight get it
Q2	P 37). Is it weight related and if so why do some people who are not overweight get it
Q2	P 43a). Does being overweight/obese increase risk of IIH
Q2	P 44c). Is it weight related and if so why do some people who are not overweight get it
Q2	P 46). Does being overweight/obese increase risk of IIH
Q2	P 49). Is it weight related and if so why do some people who are not overweight get it
Q2	P 50). Does being overweight/obese increase risk of IIH and are there other contributing risk factors
Q2	P 52). Could the correlation between bmi and risk of IIH be due to confounder such as types of foods consumed by the overweight population
Q2	H 53). What is the relationship between increasing bmi and risk of IIH
Q2	P 65b). What are the bmi/weight measurements at which people become high risk for IIH
Q2	P 65c). What possible confounding factors associated with high bmi/inability to lose weight could contribute to risk of IIH
Q2	P 72). What causes IIH in healthy weight population, is weight a proven risk factor
Q2	H 73). Does being overweight/obese increase risk of IIH
Q2	H 75a). Does being overweight/obese increase risk of IIH
Q2	P 93a). Does being overweight/obese increase risk of IIH
Q2	P 94). Does being overweight/obese truly increase risk of IIH
Q2	P 96a). What is the relationship between obesity and IIH
Q2	P 98). Do factors related to bmi, age or stress contribute towards risk of developing IIH
Q2	P 103). What is the biological explanation for the link between high bmi and risk of IIH
Q2	P 104). Why do only a proportion of overweight people suffer from IIH
Q2	P 106). Is there too much focus on high bmi/weight being the cause, could IIH be hormone/genetics related
Q2	P 114a). Does being overweight/obese cause IIH
Q2	P 115b). What causes IIH in healthy weight population, is weight a proven risk factor
Q2	P 116). What causes IIH in healthy weight population, is weight a proven risk factor
Q2	P 117). What causes IIH in healthy weight population, is weight a proven risk factor
Q2	H 118a). What is the biological explanation for the link between high bmi and risk of IIH
Q2	P 120). What is the physiological reason between high BMI and IIH
Q2	H 123). What is the the biological explanation for increased risk of IIH in overweight females
Q2	H 125a). Why do only a small proportion of overweight people suffer from IIH
Q2	H 127). What additional risk factors do overweight women with IIH have compared with overweight women who do not have the disease
Q2	P 128). Why do only a small proportion of overweight women suffer from IIH
Q2	P 135b). Why do only a small proportion of overweight women suffer from IIH
Q2	H 140b). What is the biological reason for the increased risk in people who are obese
Q2	H 143). Why do only a small proportion of overweight women suffer from IIH
Q2	H 149a). Why do only a proportion of obese women suffer from IIH
Q2	F 150). What evidence is there to show that high bmi/being overweight is a risk factor for IIH
Q2	P 151). What evidence is there to show that high bmi/being overweight is a risk factor for IIH
Q2	P 158a). What evidence is there to show that high bmi/being overweight is a risk factor for IIH
Q2	P 160a). What evidence is there to show that high bmi/being overweight is a risk factor for IIH
Q2	P 161). What is the prevalence of IIH among the overweight and obese population compared with in the healthy weight population
Q2	H171a). What causes IIH, what is the role of obesity
Q2	H 172). Does being overweight really cause an increased risk of developing IIH
Q2	H 173). What is the biological reason for the increased risk of IIH in overweight females
Q2	H 180b). Why do only a small proportion of overweight women suffer from IIH
Q2	H 182c). What is the biological reason for the increased risk of IIH with obesity
Q2	H 182d). At what bmi/weight do individuals become at greater risk of developing IIH
Q2	H 183a). Why do only a small proportion of overweight women suffer from IIH

Q2	H 184b). What is the biological reason for the higher incidence rates in obese people
Q2	H 185). What is the link between obesity and IIH
Q2	H 186a). What is the link between obesity and IIH
Q2	H 187a). Is IIH related to being overweight/obese
Q2	H 211d). If IIH is caused by high bmi/being overweight why do some healthy weight people get IIH
Q2	H 216). Why do only a small proportion of overweight/obese population develop IIH
Q2	H 217). What is the biological reason for obese women being at greater risk of IIH
Q2	H 218). What is the biological reason for obese women being at greater risk of IIH
Q2	H 220c). Why do only a small proportion of overweight/obese population develop IIH
Q2	H 221a). Why do only a small proportion of overweight/obese population develop IIH
Q2	H 228b). Why do only a small proportion of overweight/obese population develop IIH
Q2	P 231). Why do only a small proportion of overweight people develop IIH
Q2	H 240). What is the incidence of IIH in healthy weight population
Q2	H 245a). To what extent does a persons weight contribute towards their risk of developing IIH
Q2	H 248). What is the mechanism by which being overweight causes IIH in women (of a certain age)
Q2	H 252a). What is the biological reason for higher incidence of IIH in the overweight/obese population
Q2	H 259a). What influence does a persons metabolic profile have on the risk of developing IIH
Q2	H 259b). What is the relationship between body weight/changes and risk of developing IIH
Q2	H 260a). What is the biological explanation for the relationship between IIH and weight
Q2	H 261a). What is the role of obesity and insulin resistance in the development of IIH
Q2	H 263d). What is the biological explanation for the relationship between obesity and IIH
Q2	H 264d). Is IIH related to weight change rather than absolute weight
Q2	H 265). Why do only a small proportion of overweight people develop IIH
Q2	P 274a). What is the cause of IIH in healthy weight individuals and could this be the true cause in the overweight population also
Q2	O 276). What is the biological explanation for the increased risk of IIH in the obese population
Q2	P 297). Is IIH caused by being overweight/obese
Q2	H 298). What is the biological explanation for the relationship between weight gain and IIH
Q2	H 300b). What is the relationship between bmi and risk of IIH
Q2	H 303). What is the relationship between weight/bmi and IIH
Q2	H 304b). Is there a upper bmi limit over which IIH does not occur
Q2	H 306a). What is the biological reason for the increased risk of IIH with increasing bmi/obesity
Q2	P 317b). What is the threshold bmi over which people become at higher risk of developing IIH
Q2	H 329a). What is the biological explanation for the association between weight gain and IIH
Q2	P 342). What is the importance of weight as a risk factor for IIH
Q2	H 343). What is the relationship between obesity and IIH
Q2	P 345b). What are the international rates of incidence in relation to the proportion of overweight/obese people in a population
Q2	H 346b). What is the biological explanation for the increased risk with obesity
Q2	H 347). What is the biological explanation for the link between weight and intracranial pressure
Q2	H 351b). What is the biological explanation for the increased risk in the overweight/obese population
Q2	H 353). What is the relationship between obesity and the underlying cause of IIH
Q2	H 355b). What is the biological explanation for the link between obesity and IIH
Q2	P 287). Why do only a small proportion of overweight women get IIH
Q2	P 289a). Can IIH truly caused by being overweight/obese when it exists in the healthy weight population
Q2	H 306b). If IIH is caused by high bmi/obesity why do some healthy weight people hve the disease
Q2	C 307). If IIH is caused by high bmi/obesity why do some healthy weight people hve the disease
Q2	H 308). Why do only a small proportion of overweight women get IIH
Q2	P 328a). Is IIH truly caused by being overweight
Q2	P 328c). Why do only a small proportion of overweight/obese people have IIH
Q2	H 349a). What is the physiopatholy of IIH caused by obesity
Q2	H 285d). Is IIH caudes by being overweight/obese
Q3	P 327). What is the biological explanantion for the improvement in IIH syptoms with successful weight loss

Q5	P 107). What is the biological explanation for the causal link between weight gain and IIH
Q5	P 114). What is the biological explanation for the incidence of IIH in healthy or underweight people and does this cast doubt on the theory that high BMI/being
Q5	P 211b). What is the role of obesity and fat tissue in the pathogenesis of IIH
Q5	H 238). What is the biological explanation for the link between weight and IIH
Q5	P 2). Does weight change (gain or loss) rather than absolute weight cause IIH
Q5	P 23). Is high BMI a symptom or cause of IIH
Q5	P 35b). Does high BMI/being overweight cause IIH
Q5	P 43d). At what BMI/other measure of weight do people become at increased risk of IIH
Q5	P 66). Does high BMI/being overweight cause IIH
Q5	P 67). Does high BMI/being overweight cause IIH or vice versa
Q5	P 68c). Does high BMI/being overweight cause IIH, what triggers the onset of disease in someone who has been overweight for many years without IIH
Q5	P 90). Does high BMI/being overweight cause IIH or vice versa
Q5	H 124b). Which metric (BMI, WHR, fat percentage) most closely correlates with disease activity in IIH
Q5	P 158). Does high BMI/being overweight cause IIH and if so why don't all overweight/obese
Q5	P 160a). Is high BMI/being overweight truly the cause of IIH and if so, why don't all overweight people get it, why don't all people with IIH see relief of their symptoms
Q5	P 160b). What is the prevalence of IIH in the overweight/obese population compared with the healthy weight population and how does this compare with other 'lifestyle
Q5	P 179). Does high BMI/being overweight cause IIH
Q5	P 200). Does high BMI/being overweight cause IIH and if so why do healthy weight and underweight people get the disease
Q5	H 215). What is the relationship between high BMI and incidence of IIH
Q5	H 236). Is there a need for more evidence to support the relationship between obesity and IIH
Q5	H 246). Are there BMI/weight thresholds above which people are at greater risk of developing IIH
Q5	P 274). What are the roles of obesity, fat tissue and poor metabolic function in the pathogenesis of IIH
Q2	H 5). How does obesity affect intracranial pressure
Q2	F 45a). Is the risk of disease greater in overweight women of child bearing age, who take the pill, if so what is the biological explanation for this
Q2	P 58). Why do only a small proportion of overweight people suffer from IIH
Q2	H 61b). What is the role of adipose tissue (body fat) in developing IIH
Q2	H 63a). By what mechanism does increased body weight lead to development of IIH
Q2	H 63b). (linked to 63a-assumed continuation of theme) By what mechanism does increased body weight lead to increased CSF pressure
Q2	H 210c). Does raised intracranial pressure cause increase in body weight
Q2	H 247). What is the mechanism by which being overweight causes IIH in women
Q2	H 257a). What is the biological reason for the higher incidence of IIH in the obese population than the healthy weight population
Q2	H 264b). What is the threshold bmi over which risk of IIH is increased
Q2	P 286b). What is the biological explanation for higher incidence of papilloedema in people who are overweight
Q2	H 211c). Why does only a small proportion of the overweight population have IIH
Q2	H 232a). How significant are intra-abdominal and intra-thoracic pressures as factors contributing to raised intracranial pressure, and how does this relate to obesity?
Q2	H 242). What is the mechanism by which adipose tissue drives the hormonal imbalance to increase CSF pressure
Q7	C 1a). What is the relationship between abdominal pressure caused by obesity and high CSF pressure
Q2	H 169). How does obesity affect brain pressure
Q2	H 211a). How does obesity affect brain pressure
Q2	H 227). How does obesity affect brain pressure

F3. Does obesity with IIH cause long-term secondary health problems?	Q2	H 180c). Do comorbidities associated with obesity have an impact on IIH	Known known	the long-term effects and economic
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Q2/P 20). Are/should other causes of IIH be investigated if a person is considered at risk due to being overweight	Q2	P 20). Are/should other causes of IIH be investigated if a person is considered at risk due to being overweight	Known known	Grant T. Liu, Kathleen B. Digre. Revised
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F4. Is IIH caused by increased production or lack of cerebral spinal fluid (CSF) absorption?	Q2	P 2). Is the increased CSF pressure caused by an increased production of CSF or a failure to drain it away	Known unknown	
	Q2	H 7). Is the increased CSF pressure caused by an increased production of CSF (increased cardiac output) or a failure to drain it away (venous congestion and reduced		
	Q2	P 23). Is the increased CSF pressure caused by an increased production of CSF or a failure to drain away normal production		
	Q2	H 174). What is the relationship between venous outflow and IIH		
	Q2	P 35c). What causes the increased CSF pressure in IIH		
	Q2	P 91a). What causes raised CSF pressure associated with IIH		

	Q2	P 158b). What causes the build up of excess CSF in IIH	
	Q2	H 210b). Are people with IIH anatomically different in terms of their CSF outflow routes	
	Q2	H 186b). Is IIH caused by increased production or lack of cerebral spinal fluid (CSF) absorption	
	Q2	H 235). By what mechanism does the brain control CSF pressure	

F5. Is cerebral venous stenosis the cause or consequence of IIH?	Q2	P 28f). Is Venous sinus stenosis a cause or symptom of IIH	Known unknown
	Q2	H 70). Are the appearance of dural venous sinus stenosis a cause or symptom of IIH	
	Q2	H 75d). Are the appearance of venous stenoses a cause or symptom of raised (CSF) pressure	
	Q2	P 84). Can venous sinus stenosis be present from birth	
	Q2	H 204). Does functional or congenital stenosis/compression of the sigmoid sinuses play any role in development or perpetuation of IIH.	
	Q2	H 210a). What is the rate of CSF outflow into the venous system in people with IIH compared with that in healthy people	
	Q2	H 213a). Does venous sinus stenoses cause IIH	
	Q2	H 213b). Does venous sinus stenoses produce the features of IIH	
	Q2	H 214). What role do venous anomalies play in the development of IIH	
	Q2	H 245b). What is the (relevance) role of cerebral venous stenoses in the development of IIH	
	Q2	H 251). Is IIH caused by chronic venous obstruction	
	Q2	H 252b). What is the relationship between weight/bmi and venous sinuses	
	Q2	H 252c). Does venous sinus thrombosis cause IIH	
	Q2	P 286a). What is the rate of incidence of restricted venous outflow or stenosis in the IIH population	
	Q2	H 351a). Is a problem with venous drainage responsible for causing IIH	
Q2	H 203). Is stenosis the cause or consequence of IIH		

F6. Why does IIH without papilloedema occur? - seems to have become 'what is the relationship between papilloedema and IIH' and labelled 'not a question' need reference or better articulation of reason for being out of scope.	Q3	P 103). What is the biological explanation for papilloedema occurring in some people with IIH but not others	Not a question
	Q2	H 75c). Why do some people with IIH present with papilloedema and some do not	
	Q2	H 125b). Why do some people with IIH present with papilloedema and some do not	
	Q3	F 318). Why do people get IIH without papilloedema	
	Q3	P 145). What is the relationship between papilloedema and IIH	
	Q3	P 328). What is the incidence of IIH without papilloedema and are healthcare practitioners sufficiently aware of this condition to provide best care	

F7. What are the biological mechanisms of headache in IIH and why in some do headaches continue even after papilloedema has resolved?	Q3	P 43a). What is the biological explanation for persistent papilloedema and vision loss in people with IIH who have successfully reduced ICP through shunting	Known unknown
	Q4	P 76). What is the biological explanation for the persistence of headache after a ventriculoperitoneal shunt	
	Q4	P 89b). What is the biological explanation for IIH headaches occurring after pressure has been controlled	
	Q3	H 203). What is the relationship between gravity and impact of headache and visual outcomes	
	Q4	P 99a). What are the risks associated with low pressure headache compared with those associated with high pressure headache and how does this impact on treatment	
	Q4	P 42a). What is the biological explanation for the continuation of headache symptoms after CSF pressure is deemed to be under control	
	Q4	P 106). Is there more than one 'type' of headache caused by IIH	
	Q4	H 125). What is the biological explanation for the higher than average rate of incidence of other headache phenotypes in the IIH population	
	Q4	P 137b). Are the headaches experienced by people with IIH migraine headaches	
	Q4	H 171a). What is the relationship between ICP and headache in people with IIH	
	Q4	H 181b). What proportion of headache experienced by people with IIH is caused by medication overuse	
	Q4	H 184f). Are exacerbation in headaches in IIH from the same trigemino-vascular activation seen in migraine?	
	Q4	H 187). What causes headache in people with IIH	
	Q4	H 214). What is the relationship between low levels of raised intracranial pressure and migrainous headache in people with IIH	
	Q4	H 216). Why do some people with IIH have refractory headache	
	Q4	H 220a). What is the biological explanation for continuation of headache symptoms after normalisation of CSF pressure in people with IIH	
	Q4	H 235a). What proportion of patients develop a migrainous headache superimposed on the pressure headache	
	Q4	P 241). Why do some people with IIH not suffer from headaches	
	Q4	H 251). How do we distinguish headache related to high pressure from a headache of musculoskeletal origin	
	Q4	H 252). What is the biological explanation for persistent headache after treatment of raised CSF pressure through shunting	
Q4	H 255). What is the biological explanation for persistent headache after successful treatment of raised CSF pressure		
Q4	P 272). What is the biological reason that not all people with IIH suffer from headaches		

	Q4	H 300b). What is the biological reason for and rate of incidence of headaches that persist de		
	Q4	P 315). What is the biological explanation for persistent headaches in people with IIH for whom raised ICP is seemingly resolved (though untested)		
	Q4	P 343) What proportion of people with IIH suffer from headaches		
	Q4	H 347a). What is the biological explanation for the headaches experienced by people with IIH		
	Q4	H 353). What causes persistent headache in people with IIH whose vision has been 'saved' by shunting		
	Q4	P 157). What is the best evidence based first line treatment for headache pain in people with IIH whose papilloedema has been resolved		
	Q4	H 141b). What are the best strategies for managing headache in people with successfully managed IIH (in terms of papilloedema and CSF pressure)		
	Q2	P 44d). What causes headaches in IIH with treated papilloedema		

F9 (combined with F10, F11) Is there a relationship between visual problems and headache?	Q3	P 155c). Why don't vision problems and headaches occur simultaneously	Known unknown	
	Q4	H 245). Why is the link between headache and visual symptoms so variable		
	Q4	H 260a). What is the relationship between headache and visual impairment in people with IIH		
	Q3	H 125). What is the biological explanation for transient visual obscurations and how do they progress		
	Q3	P 36). What is the biological explanation for he transient blurring of vision		
	Q3	H 171a). What is the biological explanation for the fact that vision loss occurs in some people with IIH but not others		

F12. What is the biological explanation for the fact that transient visual obscurations (blackouts of vision) occur and permanent vision loss occurs, in some people with IIH but not others?	Q3	H 210). What is the biological explanation for the differences between the effects of fulminant IIH on vision compared with non-fulminant IIH	Known unknown	
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F13 (combined with R5, R6) 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?	Q3	H 350). What is the biological explanation for the pattern of loss of vision early in disease or not at all in people with IIH	Known unknown	
	Q7	H 234). Can grossly impaired vision in IIH be reversible		
	Q4	H 195a). Do optic discs return to normal after the intracranial pressure normalises		
	Q3	H 9c). What are the long term effects of IIH on the optic disc		
	Q3	P 268). How quickly can vision be lost with IIH and how often is this loss permanent		
	Q3	P 326). What are the symptoms that indicate a person with IIH is at high risk of vision loss		

F14. What measures of weight and obesity are most useful for predicting IIH and monitoring IIH?	Q2	Q2/H 130a). What is relative accuracy of absolute weight, bmi, waist/hip ratio and level of weight gain for determining risk of IIH	Known unknown	
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F15. What are the triggers for periods of high CSF pressure in people with IIH?	Q4	P 107). What are the triggers for periods of high CSF pressure in people with IIH	Known unknown	
	Q7	P 200). What are the triggers for high CSF pressure fluctuations in people with IIH		

R1. Is IIH a lifelong condition?	Q1	P 163f). Is anybody working on a cure	Known unknown	
	Q7	P 60). Can IIH be cured, does it resolve itself or is it a condition that must be managed life-long		
	Q7	P 154a). Can IIH be cured		
	Q7	P 157). Can IIH be cured		
	Q7	P 22). Can IIH be cured		
	Q7	F 54). Can IIH be cured		
	Q7	P 289). Can IIH be cured		
	Q4	P 230). Will a person with IIH be on pain killers for the rest of their life to manage headache		
	Q4	H 339). Are the effects of IIH reversible with effective treatment		

R2. What are the diagnostic implications of abnormalities on imaging for IIH and does this guide treatment	Q1	P 17b). What effect does an empty sella have on the progression of disease in IIH	Known known	John Holbrook, Amit M Saindane. (2017) Imaging of Intracranial Pressure Disorders. Neurosurgery, Volume 80, Issue 3, 1 March 2017, Pages 341–354,
	Q7	P 68). What is the cause of narrow veins and the prognosis for a person with IIH and narrow veins		
	Q1	H 206b). What is the significance of venous sinus stenosis/thrombosis to the diagnosis of IIH		

R7. (combined with H5) How big is the impact of headache in IIH (how severe are headaches, how often do they occur, how many years do they continue for and how do they impact patient's quality of life)?	Q4	H 141a). What proportion of people with successfully managed IIH (papilloedema and CSF pressure) will continue to suffer from headache symptoms and what type of	Known unknown	Partial answer - Mulla Y, Markey KA, Woolley RL, Patel S, Mollan SP, Sinclair AJ. (2015) Headache determines quality of life in idiopathic intracranial hypertension. J Headache Pain. 16:521. doi: 10.1186/s10194-015-0521-9.
	Q4	H 196). What is the risk that a person with IIH will transition into migraine		
	Q4	P 284). Does the headache resolve after a certain amount of time		
	Q4	H 325a). What is the prognosis for headache in people with IIH before and after resolution of papilloedema		
	Q4	H 123). Why does the headache continue after ICP has normalised		
	Q4	P 66). What is the headache phenotype in individuals with IIH		
	Q4	H 73c). What is the headache phenotype in individuals with IIH		

Q4	P 155a). What are the defining characteristics of IIH headaches and what symptoms indicate that a person with IIH such seek medical help for an additional headache
Q4	H 264c). What are the best strategies for management of persistent chronic headache unrelated to pressure in people with IIH
Q4	H 209a). What is the incidence of headache in people with successfully treated papilloedema and what type of headaches do they experience
Q4	H 210). What is the incidence of headache in people with successfully treated papilloedema and what type of headaches do they experience
Q4	H 222d). What is the incidence of non-pressure related headache in people with IIH
Q4	H 232b). Are headaches that persist after the resolution of raised ICP related to high or low pressure in any way
Q4	H 265). What is the biological explanation for the chronic headache experienced by many people with IIH after CSF pressure has been normalised who had not previously
Q4	P 179). What is the relative impact on quality of life of the side effects of effective headache pain treatments compared with that of the headache pain itself in people
Q4	P 44c). What is the impact of headache pain on the quality of life in people with IIH
Q4	P 282b). What is the impact of headache on the quality of life of people with IIH
Q4	P 356). Is the impact of headaches on people with IIH under appreciated
Q4	P 160a). What is the effect of unmanaged headache pain on the quality of life of people with IIH
Q4	P 286). Is headache under-managed/treated and if so what is the effect on the quality of life of people with IIH
Q4	P 297). Is headache under-managed/treated and if so what is the effect on the quality of life of people with IIH
Q7	P 165). What is the long term impact of medication overuse and corresponding rebound headache compared with untreated IIH headache pain

Formed question	Contributing uncertainties		Certainty	Reference
S1. Are there any preventative screenings or actions which could reduce the risk of IIH?	Q2	F 45b). What is the effectiveness and safety of screening at risk women for early indicators of disease and treating before symptoms appear	Known unknown	
	Q2	P 113b). What can be done to prevent at risk people from developing IIH		
	Q2	P 158d). What is the efficacy of possible preventative actions that could be taken by people at risk of IIH		
	Q2	H 221b). Are there any tests that predict vulnerability to IIH		
	Q2	P 296). What is the safety and efficacy of preventative measures for the at risk population for IIH		
	Q2	H 344). What is the effectiveness of preventative interventions for people at risk of IIH		
	Q3	P 126). What are the best evidence based preventative measures that can be taken against vision loss		
	Q3	P 163). What are the best evidence based preventative measures that can be taken against vision loss		

Formed question	Contributing uncertainties	Certainty	Reference
<p>G1. (combined with H2 in part and with P1) What medications are effective and safe to treat IIH headaches?</p>	<p>H 7). What is the safety and efficacy of analgesics compared with acetazolamide for treatment of headache pain in IIH</p> <p>Q4</p> <p>H 12). What is the effectiveness of the current standard treatment compared with placebo for headache pain relief in people with IIH</p> <p>Q4</p> <p>O 13). What are the relative efficacies of the available medications for treatment of headache pain in IIH</p> <p>Q4</p> <p>P 15). What are the relative safeties of standard analgesics for treating headache pain in IIH</p> <p>Q4</p> <p>P 20). What are the relative safeties and efficacies of analgesics e.g. paracetamol and ibuprofen for treatment of headache pain in IIH</p> <p>Q4</p> <p>P 22). What are the safeties and efficacies of the two treatment available for treating headache in IIH compared with each other and with placebo</p> <p>Q4</p> <p>P 33a). What are the long term safeties and efficacies of analgesics indicated for use in treatment of IIH headache</p> <p>Q4</p> <p>P 33b). What is the safety and efficacy of Diamox for treating headache pain in people with IIH</p> <p>Q4</p> <p>P 44b). What are the efficacies of the available medications for treatment of headache pain in IIH</p> <p>Q4</p> <p>P 47). Are the best strategies of pain management providing adequate relief from headache caused by IIH</p> <p>Q4</p> <p>P 56b). What is the safety and efficacy of lumbar peritoneal shunt for treatment of headache pain in people with IIH</p> <p>Q4</p> <p>P 67). What are the relative safeties and efficacies of the various pain relief medication options for treating headache pain in people with IIH</p> <p>Q4</p> <p>P 68). Does Diamox cause increased risk of headache pain when taking the medication and/or headaches upon withdrawal of the medication</p> <p>Q4</p> <p>H 71). What is the efficacy and safety of topiramate for headache pain in people with IIH who have been unable to lose weight</p> <p>Q4</p> <p>H 73a). What are the relative safeties and efficacies of the various medications available for treatment of headaches in people with IIH</p> <p>Q4</p> <p>H 75a). What is the safety and efficacy of stenting for treatment of headache in people with IIH and stable vision</p> <p>Q4</p> <p>H 75c). What is the safety and efficacy of Botox® for treatment of headache in people with IIH</p> <p>Q4</p> <p>P 84). What are the relative safeties, efficacies and tolerabilities of the various treatment options for headache pain in IIH compared to therapeutic lumbar</p> <p>Q4</p> <p>P 86). What is the safety and efficacy of Oramorph compared to standard treatment for headache in people with IIH</p> <p>Q4</p> <p>P 88). What are the relative safeties and efficacies of the various medications for treatment of headache in people with IIH</p> <p>Q4</p> <p>P 89a). What are the best evidence based treatment options when Diamox, shunts and paracetamol have failed to relieve symptoms</p> <p>Q4</p> <p>P 90). Which treatments target the raised ICP cause of II headaches rather than the symptoms and how effective are they</p> <p>Q4</p> <p>P 94). What are the relative safeties and efficacies of the various medications, including analgesics, for treatment of headache in people with IIH</p> <p>Q4</p> <p>P 97). What is the safety and efficacy of surgical intervention for people with IIH headache but no vision loss</p> <p>Q4</p> <p>P 99b). Which analgesic medications, other than paracetamol and ibuprofen, are safe to use, i.e. do not raise ICP, for people with IIH</p> <p>Q4</p> <p>P 115). What is the maximum safe and therapeutic dose of Diamox that should be taken for treatment of headache in people with IIH</p> <p>Q4</p> <p>P 120). What is the full list of interventions that are efficacious for treatment of headache pain in people with IIH</p> <p>Q4</p> <p>P 126). What is the best evidence based treatment for headache pain in people with IIH</p> <p>Q4</p> <p>P 128a). What are the best evidence based oral medications for treatment of headache pain in people with IIH</p> <p>Q4</p> <p>H 130b). What is the safety and efficacy of combining topiramate and acetazolamide therapy for treatment of headache pain in IIH</p> <p>Q4</p> <p>H 130c). If topiramate and acetazolamide fail to relieve headache pain in IIH what is the best third line therapy option</p> <p>Q4</p> <p>P 87). Which treatments effectively reduce pain experienced as a symptom of IIH</p> <p>Q1</p> <p>P 4). What are the efficacies of novel medications compared with conventional pain relief medications for treatment of headache pain in IIH</p> <p>Q4</p> <p>P 101). What is the safety and efficacy of analgesics for the treatment of headaches in people with IIH</p> <p>Q4</p> <p>H 134a). What are the safeties and efficacies of anti-migraine therapies for treatment of headache pain in people with IIH</p> <p>Q4</p> <p>H 136). What is the safety and efficacy of topiramate compared with alternative headache treatment for headache pain in people with IIH</p> <p>Q4</p> <p>P 138). What is the safety, efficacy and tolerability of co-codamol for treatment of headache pain in people with IIH</p> <p>Q4</p> <p>H 140). What are the safeties and efficacies of the available medications for treating headache pain in people with IIH</p> <p>Q4</p> <p>P 144a). What is the safety of long term use of paracetamol or codeine for treatment of headache pain in people with IIH</p> <p>Q4</p> <p>P 158b). Is there an effective and safe treatment for headache pain in people with IIH</p> <p>Q4</p> <p>P 160b). What is the safety and efficacy of analgesics for headache pain in people with IIH</p> <p>Q4</p> <p>H 168). Aside from ICP lowering techniques what are the best medications for treatment of acute exacerbations of headache in people with IIH</p> <p>Q4</p> <p>H 171c). What are the best treatments and/or strategies for managing headaches in people with IIH</p> <p>Q4</p> <p>H 172a). What are the best evidence based treatments for headache pain in people with IIH</p> <p>Q4</p> <p>H 172b). What is the safety and efficacy of opiates for treatment of headache pain in people with IIH</p> <p>Q4</p> <p>H 182b). What is the safeties and efficacies of pharmacological treatment for headache pain in people with IIH</p> <p>Q4</p> <p>H 184a). What are the safeties and efficacies of the medications available for the treatment of headache pain in people with IIH</p> <p>Q4</p> <p>H 184b). What are the safeties and efficacies of preventative medications for treatment of headache pain in people with IIH</p> <p>Q4</p> <p>H 184c). What are the safeties and efficacies of acute medications for treatment of headache pain in people with IIH</p> <p>Q4</p> <p>H 198a). What are the best evidence based oral medications for treatment of headache in IIH are they safe and tolerable</p> <p>Q4</p> <p>H 198c). Which oral headache treatments are not suitable for use in people with IIH</p> <p>Q4</p>	<p>Known unknown</p>	

Q4	H 201). What is the safety, efficacy and optimum dose of acetazolamide alone compared with acetazolamide in combination with furosemide for treatment of
Q4	H 206). What is the safety and efficacy of non-surgical management of headache in IHH when no other symptoms are present
Q4	H 207b). What is the safety and efficacy of topiramate for treatment of headaches in people with IHH
Q4	H 212). What are the best evidence based treatment options for headache pain in people with IHH
Q4	H 215). What is the safety and efficacy of acetazolamide for treatment of headache pain in people with IHH
Q4	H 217). What are the most effective oral medications for treatment of headache in people with IHH
Q4	H 218a). What are the comparable safety and efficacies of available drug treatments for headache pain in IHH
Q4	H 218b). What are the comparable safety and efficacies of available injection therapies for headache pain in IHH
Q4	H 227). What is the safety and efficacy of Frusemide compared with Acetazolamide for treatment of headache in people with IHH
Q4	H 237). What are the comparative safety and efficacies of the various oral headache medications for treatment of headache in people with IHH
Q4	H 243b). Is there any role for acetazolamide
Q4	H 249). What is the safest and most effective analgesic for headache in people with IHH
Q4	H 254). What is the safest and most efficacious medications for headache in people with IHH
Q4	H 256). What is the safest and most efficacious medications for headache in people with managed IHH
Q4	H 258). What is the safest and most efficacious analgesics for headache in people with IHH
Q4	H 259b). What is the safest and most efficacious medications for headache in people with managed IHH
Q4	H 263b). What is the safety and efficacy of treating headaches without the use of analgesics compared with using analgesics in people with IHH
Q4	P 267b). What is the safety, tolerability and efficacy of paracetamol compared with alternative treatments for headache in people with IHH
Q4	P 268). What are the relative safety, efficacy and tolerability of suitable over the counter medications for headache in people with IHH
Q4	P 273). What is the safety, efficacy and tolerability of acetazolamide compared with alternative therapies for treatment of headache in people with IHH
Q4	P 274c). What is the safety, efficacy and tolerability of aspirin for treatment of headache in people with IHH and does this justify aspirin desensitisation for people with IHH
Q4	H 275). What is the safest and most efficacious treatment for headache in people with IHH
Q4	P 289). What is the safest and most effective pain relief therapy for headache in people with IHH and is it offered to sufferers when needed
Q4	P 291). What is the safety and efficacy of cortisone injections for treatment of headache in people with IHH
Q4	P 292). What is the safest and most effective medication for treatment of headache in people with IHH
Q4	P 294). Which treatments are safe and effective for relieving headache in people with IHH who have programmable shunts
Q4	H 303b). Which are the safest and most efficacious analgesics for use in headache in people with IHH
Q4	H 303c). What is the safety and efficacy of diamox for treatment of headache in people with IHH
Q4	P 310). What are the best evidence based new treatments (apart from topiramate and ibuprofen) for headache in people with IHH
Q4	H 312). What is the safety and efficacy of topiramate or amitriptyline for headache in people with IHH
Q4	P 317). What is the safety, efficacy and tolerability of acetazolamide for treatment of headache in IHH
Q4	H 329). What is the safety and efficacy of diamox compared with topiramate for treatment of headache in people with IHH
Q4	H 330). What are the safest and most efficacious medications for treatment of headache in people with IHH
Q4	P 341). Which painkillers can cause rebound headache with long term use in people with IHH
Q4	P 345). What are the comparable efficacies of the pain relief treatments recommended for use in IHH headache
Q4	H351c). What is the efficacy of medication for headache in people with IHH
Q7	P 97a). What are the best evidence based treatments for daily migraines associated with IHH
Q7	P 287). What are the best strategies for management of pain in IHH and are they working
Q4	H 191). What is the safety and efficacy of greater occipital nerve injections for treatment of headache pain in IHH
Q5	H 209). What is the safety and efficacy of the medical management for headache in IHH
Q4	P 164). What medications are available to treat headache pain in people with IHH
Q4	H 204b). What is the role of topiramate and/or zonisamide
Q5	H 186b). What is the role of GLP-1 agonists in the management of headache in IHH
Q4	P 40). What is the safety, particularly in terms of mental health outcomes, and efficacy of topiramate for use in headache pain in IHH
Q4	H 259a). What is the safety, efficacy and tolerability of prescribed weight loss alone compared with prescribed weight loss with medical treatment for headache in
Q4	P 60). What is the safety and efficacy of standard pain relief medications compared with IHH specific interventions for treatment of headache pain in people with IHH
Q4	H 61). What are the relative efficacies and safety of the various treatment options for headache pain relief for people with IHH
Q4	H 64). What is the safety and efficacy of acetazolamide for treatment of headache pain in people with IHH
Q4	P 155b). What is the best evidence based first line treatment for headache pain in people with IHH
Q4	H 180). What are the best treatment strategies allowing for individualised patient care for headache pain in people with IHH
Q4	H 181a). What are the best evidence based strategies for treatment of medication overuse headache in people with IHH
Q4	O 190). What is the effectiveness of using chronic migraine treatment pathways for people with IHH who have their CSF pressure controlled but continue to have

Q4	H 198g). What is the effectiveness of successful control of ICP for long term treatment of headache pain in people with IIH
Q4	H 226). What is the safest and most effective treatment for headache in people with IIH
Q4	P 231). Is there an alternative to standard chronic headache causing painkillers that are efficacious in treating headache in people with IIH e.g. cannabalooids, BOTOX
Q4	H 243a). What are the best evidence based preventative treatments for headache in people with IIH
Q4	H 308). What is the best second line treatment when acetazolamide fails to treat headache in people with IIH
Q4	H 338). What are the safeties and efficacies of ICP-lowering treatments compared with alternative strategies for headache in people with IIH
Q4	H 355). What is the safest and most efficacious treatment for headache in people with IIH
Q1	P 160b). Is pain undertreated in IIH
Q4	P 43a). What alternatives are there to migraine medications, shunting, narcotics, and gabapentins to be used when all of these treatment options fail to manage
Q4	P 44a). Should people with IIH see headache specialists to optimise their treatment plans for management of headache pain
Q4	F 45). What are the best strategies for optimising and /or monitoring CSF pressure to prevent excess lowering of pressure causing low pressure headaches
Q4	P 46). What are the best and safest strategies for long term management of headache pain in IIH
Q4	P 50). What are the best evidence based strategies for an individual with IIH to self manage headache pain in the home
Q4	P 56a). Are the best strategies of pain management providing adequate relief from headache caused by IIH
Q4	P 65a). What are the best evidence based strategies for managing a high pressure headache
Q4	P 65b). Is there enough guidance for GP's on managing high and low pressure headaches?
Q4	H 74a). What is the best evidence based strategies for treating headaches in people with IIH whose high pressure has been resolved
Q4	H 74b). What are the best evidence based strategies for people with headache following shunt insertion
Q4	H 77). What are the best non-invasive strategies to differentiate between migraine headache and IIH headache to determine the most effective treatment
Q4	P 100). What are the best strategies for management of headache in people with IIH when they have been advised against taking 'pain killers'
Q4	P 112). What are the best strategies for management of headache in people with IIH
Q4	P 114). What are the best evidence based strategies for controlling pain in people with IIH
Q4	H 124). What is the first line treatment for headache pain in IIH in the absence of migrainous features
Q4	H 130a). Is topiramate the first line therapy for treating headache pain in people with IIH
Q4	H 134b). What are the best strategies for treating chonic headache which persists after active IIH has been treated successfully
Q4	H 143). What are the best strategies for managing headache pain in people with IIH
Q4	P 145). What are the remaining options for treatment of headache pain in people with IIH if ventriculoperitoneal shunts fail to relieve symptoms
Q4	P 146b). What are the best evidenced based criteria/tests to differentiate between migraine and IIH headache to enable best treatment options to be recommended
Q4	P 159). What are the best evidence based strategies for management of headache pain in people with IIH form whom acetazolamide has failed to relieve symptoms
Q4	H 171d). What are the best strategies for management of medication over use in people with IIH headache
Q4	H 185). What are the best strategies for managing headache pain in people with IIH
Q4	H 197). What are the best strategies for management of headache pain in IIH when preventative treatments have failed
Q4	H 198e). Are people with IIH advised to eliminate medication and caffeine overuse for treatment of headache
Q4	H 228a). What is the best evidence based strategy for treatment of headache in people with IIH
Q4	H 232a). What are the best strategies for management of people whose headaches persist, though signs of raised ICP have resolved
Q4	H 233). What is the best strategy for management of headache in people with IIH
Q4	H 263a). What are the best strategies for management of headache in people with IIH
Q4	P 274d). What options are there for people with IIH and refractory headache
Q4	P 299). What are the best strategies for management of headache in people with IIH and shunt when shunt is fully open
Q4	H 304). What are the best strategies for management of headache in people with IIH
Q4	P 305). What are the best strategies to reduce the pain of headaches for people with IIH
Q4	H 313). What is the based evidence based treatment pathway for people with IIH headache for whom Diamox has failed
Q4	O 320a). What are the best therapies for relieving headache symptoms in people with IIH
Q4	P 324). What is the most effective strategy to manage headache in people with IIH and prevent overused of acute medications
Q4	P 326). What are the treatment options for people with IIH and refractory headache
Q4	P 333b). What are the best strategies for management of ice-pick headaches in people with IIH
Q4	H 349b). What are the best strategies for management of people with IIH who have shunts but are still experiencing headache
Q4	H 351a). What are the best strategies for management of headache in people with IIH
Q4	P 189). What are the safest and most efficacious treatments for headache pain in people with IIH who have had weightloss surgery (states cant take NSAIDS or
Q4	H 228c). What are the key symptoms which indicate a need for a change in management of headache in people with IIH
Q4	H 133). Which medications used in the treatment of IIH symptoms will cause headaches
Q4	P 137a). Do people with IIH need more help to manage headache pain than they currently receive

Q4	P 147). Do people with IHH need more help to manage headache pain than they currently receive
Q4	P 161). Are current best strategies for management of headache pain in people with IHH adequately relieving symptoms
Q4	O 202a). Do we over treat IHH
Q4	H 239). What are the best strategies for management of headache in people with IHH and can these be formalised into a protocol
Q4	P 267a). Are headache symptoms undertreated/ignored by healthcare practitioners
Q4	P 282a). Is headache generally well managed in people with IHH
Q1	P 163a). Development of safe and effective pain relief medications for IHH
Q4	P 96b). Are medications in development which target the specific needs of people with IHH headache
Q4	P 103). Are medications in development which target the specific needs of people with IHH headache
Q4	P 108). Are non-addictive medications in development that specifically target IHH headache without causing 'rebound headaches'
Q4	P 117). Is there new research occurring to develop new therapies for pain relief specifically targeting IHH headache pain
Q4	H 224). Is there a need to develop and evaluate the treatment strategy for headache in people with IHH
Q4	H 247). Are there any trials in headache in IHH
Q4	F 277). Is there a need for treatments which specifically target the IHH headache symptoms and causes
Q4	P 333a). Are there any novel treatments for headache in people with IHH

G2. (2 qu's from N8) Can IHH headaches be treated without medication?	Q4	P 14). What are the best evidence based treatments for headache pain in IHH	Known unknown
	Q4	P 18). What are the best evidence based alternatives to analgesics, to be used when analgesics fail to adequately control pain, for treatment of headache pain in IHH	
	Q4	P 34). What are the best evidence based treatment for headache pain experienced by people with IHH and lumbar peritoneal shunts	
	Q4	P 35a). What are the best strategies for treating headache pain in IHH	
	Q4	P 35b). What is the long term safety of analgesic use in IHH	
	Q4	P 36). What are the best evidence based treatment strategies for headache pain in IHH	
	Q4	P 38). What are the best evidence based treatment strategies for headache pain in IHH	
	Q4	P 41b). What is the safety and efficacy of marijuana for treatment of headache pain in IHH	
	Q4	P 43c). What is the quality and extent of the evidence base for alternative therapies (e.g. acupuncture, chiropractic treatment, TENS, homeopathy) for treatment of	
	Q4	P 49). Are the best treatment options for pain management providing safe and adequate relief from headache caused by IHH	
	Q4	H 75d). What are the efficacies and safeties of Gammacore and Cefaly devices for treatment of headache in people with IHH	
	Q4	P 78). What are the best evidence based treatments, excluding lumbar puncture, for headache in people with IHH	
	Q4	P 79). Do any of the treatment options for headache in IHH provide adequate relief of symptoms	
	Q4	F 82). Do any of the treatment options for headache in IHH provide adequate relief of symptoms	
	Q4	P 91). What are the safety and efficacies of 'natural' treatment methods for headache in people with IHH	
	Q4	P 43d). What is the safety and efficacy of marijuana for treatment of headache pain in IHH	
	Q4	P 128b). What are the symptoms/characteristics that indicate therapeutic lumbar puncture for headache pain in people with IHH	
	Q4	P 148). What are the best evidence based treatments for headache pain relief in people with IHH	
	Q4	H 182a). What are the best strategies for management of headache in people with IHH	
	Q4	H 192). What is the effectiveness of weight loss compared with manipulation of CSF pressure for treatment of headache pain in IHH	
	Q4	P 194). Besides acetazolamide and topiramate what are the most efficacious and safe treatments for management of headache pain in people with IHH	
	Q4	H 198d). What is the safety and efficacy of non-invasive stimulation therapy (gammacore or cefaly) compared with standard oral medications for treatment of	
	Q4	H 198f). What is the efficacy of weight loss alone for management of headache in people with IHH	
	Q4	H 205). What are the best evidence based treatments for headache in people with IHH	
	Q4	H 248). What are the safest and most effective therapies for headache in people with IHH	
	Q4	H 253). What is the safest and most efficacious treatment for headache in people with IHH	
	Q4	H 257a). What is the safest and most efficacious treatment for headache in people with IHH	
	Q4	H 262a). What is the safety and efficacy of body work approaches like yoga, mindfulness, relaxation and positive mental training for treatment of headache in	
	Q4	P 269). What is the safety and efficacy of health support such as sacral massage or diet plans for treatment of headache in people with IHH	
	Q4	P 274e). What is the safety and efficacy of medical cannabis for treatment of headache in people with IHH	
	Q4	P 274f). What is the safety, efficacy and cost effectiveness of complimentary therapy for treatment of headache in people with IHH	
	Q4	P 93). How do you treat IHH headache non-medically in IHH	
Q4	P 302). What is the safety, efficacy and reliability of alternative therapies to shunting, which can fail and need frequent replacements, for treatment of headache		
Q4	P 333c). What are the best therapies for relieving headache pain for people with IHH		
Q4	P 113). What are the best non-invasive, strategies for managing headache pain in people with IHH that do not involve taking oral medications		
Q4	H 135). What is the effectiveness of successful weight loss for treating headache/migrainous symptoms in people with IHH		

	Q4	H 188). What is the safety and efficacy of successful weightloss for the treatment of headache pain in IIH	
	Q4	H 207a). What is the safety and efficacy of shunts compared with bariatric surgery for treatment of headache in people with IIH	
	Q4	H 211b). What is the long term safety and efficacy of Ventriculoperitoneal shunts for treatment of headache in IIH	
	Q4	P 21). What are the environmental/lifestyle/dietary triggers that increase the chance of experiencing a headache in IIH and can a clear protocol for avoidance of these	
	Q4	P 39). What are the best evidence based strategies for an individual with IIH to self manage headache pain in the home	
	Q4	H 73b). What are the symptoms/characteristics of people with IIH who should be referred for neurosurgical treatment for their headaches	
	Q4	H 222a). What are the criteria to determine whether or not a person with IIH should receive therapeutic lumbar puncture	
	Q4	H 235b). Is it necessary to optimise CSF pressure (with a shunt procedure if necessary) to be able to improve the migrainous headache	
	Q4	C 307). What can be done to manage pain in people with IIH headache that is refractory to treatment	
	Q6	H 184b). Are regular LP's effective?	
	Q4	P 144b). What are the best non-medical strategies for management of headache pain in people with IIH	

G3. What is the best way to monitor headaches in IIH?	Q4	P 26). What is the effectiveness of headache diaries to aid analysis and effective treatment of headaches in people with IIH	Known unknown
	Q4	H 285). How frequently should headache symptoms be checked in people with IIH, by whom, and what actions should they take	
	Q4	P 290). What are the best routes to healthcare provision for a person with IIH who is struggling to cope with their headaches	
	Q4	P 319). What is the best route to appropriate healthcare for a person with IIH and unmanaged headache	
	Q4	H 213). What are the best strategies for identifying true raised pressure headaches in people with IIH who are also frequently experiencing other types of headache and	
	Q4	H 257c). What is the best strategy for determining whether headache is migraine or high pressure headache without intracranial monitoring	

J5. What degree of reduction in intracranial pressure (ICP) is needed to induce remission in IIH?	Q3	H 9b). Does successful lowering of ICP translate to recovery of visual function	Known unknown
	Q4	H 222c). Are lumbar punctures necessary to check CSF pressure has been successfully reduced	

L1. (combined with L2, L4, L5, L7, L8, M1, M2, M3) 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?	Q4	H 240). What is the efficacy of successful weightloss for treatment of headache in people with IIH	Known unknown
	Q4	H 262c). What is the effectiveness of successful weight loss for treatment of headache in people with IIH	
	Q4	H 303a). What is the effect of successful weight loss on headache in people with IIH	
	Q5	P 337). Can weight loss trigger symptoms of IIH	
	Q5	F 54). What is the relationship between weight management and IIH symptoms/progression	
	Q1	H 7a). Does weight loss lead to resolution of IIH	
	Q2	P 14). If a person is not overweight when they become symptomatic but subsequently put on weight, will losing weight improve their symptoms	
	Q2	P 18). If a person is not overweight when they become symptomatic but subsequently put on weight, will losing weight improve their symptoms	
	Q2	P 39). What is the safety and effectiveness of weight loss for treating IIH in the healthy weight population	
	Q2	P 99b). What is the safety and efficacy of weight loss for treatment of IIH	
	Q2	P 154). What is the efficacy of successful weight loss for treating IIH	
	Q2	P 157b). What is the efficacy of successful weight loss for treating IIH	
	Q2	P 311). What is the efficacy of successful weight loss for treatment of IIH	
	Q2	P 328b). What is the safety and efficacy of successful weight loss for treatment of IIH	
	Q3	P 295). What is the efficacy of successful weight loss compared with other treatments for vision outcomes in people with IIH	
	Q5	P 3). Is there conclusive evidence to support the general opinion of health care practitioners that weight loss will cure IIH and/or relieve its symptoms in all	
	Q5	H 12a). Can weight loss completely resolve IIH	
	Q5	P 41). What is the safety and efficacy of successful weight loss for people with IIH	
	Q5	P 42). What is the safety and efficacy of successful weight loss for people with IIH	
	Q5	P 43a). What is the efficacy of successful weight loss for improvement of symptoms in people with IIH	
	Q5	P 50). What is the safety and efficacy of successful weight loss for people with IIH	
	Q5	P 51). What is the safety and efficacy of successful weight loss for healthy weight people with IIH	
	Q5	P 65b). What is the efficacy of successful weight loss for improving symptoms of IIH and how much needs to be lost	
	Q5	H 70). What is the safety and efficacy of successful weight loss in all types of people with IIH	
	Q5	P 85). What is the safety and efficacy of successful weight loss in people with IIH and how quickly should the weight be lost	
	Q5	P 91). What is the safety and efficacy of successful weight loss for people with IIH who have well managed symptoms	
	Q5	P 104). What is the safety and efficacy of successful weight loss for treatment of all types of people with IIH	
	Q5	P 106). What is the safety and efficacy of successful weight loss for treatment of people with IIH who were at a healthy weight at disease onset	
	Q5	P 110). What is the safety and efficacy of successful weight loss for treatment of all types of people with IIH	
	Q5	P 113). What is the safety and efficacy of successful weight loss for treatment of healthy weight people with IIH	

	P 144). What is the safety and efficacy of successful weight loss for treatment of IIH
Q5	
	P145a). What is the safety and efficacy of successful weight loss for treatment of IIH
Q5	
	P 151). What is the safety and efficacy of successful weight loss for people with IIH
Q5	
	P 156). Do healthcare practitioners rely too heavily on weight management as the treatment for IIH when other causes/treatments should be explored
Q5	
	H 192). What are the symptoms/criteria of the people with IIH who will benefit from weight loss
Q5	
	P 155). Are the symptom relieving effects of successful weight loss temporary and if so, why
Q5	
	P 160c). Is there conclusive evidence to support the general opinion of health care practitioners that weight loss will cure IIH and/or relieve its symptoms in all
Q5	
	P 165). Is there conclusive evidence to support the general opinion of health care practitioners that weight loss will cure IIH and/or relieve its symptoms in all
Q5	
	H 178a). What is the safety and efficacy of successful weight loss for people with IIH and a BMI >30 and without rapidly deteriorating vision
Q5	
	H 187). Is there conclusive evidence to support the general opinion of health care practitioners that weight loss will cure IIH and/or relieve its symptoms in all
Q5	
	H 213b). What is the safety and efficacy of successful weight loss for people with IIH
Q5	
	H 239). What is the safety and efficacy of successful weight loss for people with IIH
Q5	
	H 240a). What is the safety and efficacy of successful weight loss for people with IIH
Q5	
	P 244). Is there conclusive evidence to support the general opinion of health care practitioners that being overweight causes IIH and that weight loss will cure IIH
Q5	
	H 245a). Is there conclusive evidence to support the general opinion of health care practitioners that weight loss will cure IIH and/or relieve its symptoms in all
Q5	
	P 286). Is there conclusive evidence to support the general opinion of health care practitioners that being overweight causes IIH and that weight loss will cure IIH
Q5	
	P 287). What is the safety and efficacy of successful weight loss for people with IIH and how much weight needs to be lost
Q5	
	P 288). What is the safety and efficacy of successful weight loss for people with IIH
Q5	
	P 289). Is there conclusive evidence to support the general opinion of health care practitioners that being overweight causes IIH and that weight loss will cure IIH
Q5	
	H 293). What is the safety and efficacy of successful weight loss for people with IIH who are overweight but not clinically obese (BMI 25-30)
Q5	
	P 296). What is the safety and efficacy of successful weight loss for people with IIH
Q5	
	P 311). Is there conclusive evidence to support the general opinion of health care practitioners that being overweight causes IIH and that weight loss will cure IIH
Q5	
	P 322). What is the safety and efficacy of successful weight loss with shunts compared to successful weight loss without shunts for people with IIH
Q5	
	P 326). What is the safety and efficacy of successful weight loss for people with IIH who are not overweight
Q5	
	P 341). Is there conclusive evidence to support the general opinion of health care practitioners that being overweight causes IIH and that weight loss will cure IIH
Q5	
	P 356). What is the safety and efficacy of successful weight loss for people with IIH, is this affected by the BMI of the individual
Q5	
	H 57). What type of health care practitioner should be responsible for management of weight in people with IIH
Q5	
	H 186a). What level of weight management services should individuals with IIH have access to and should this be standardised across hospitals
Q5	
	P 241). Is there conclusive evidence to support the general opinion of health care practitioners that being overweight causes IIH and that weight loss will cure IIH
Q5	
	H 245b). What are the most cost effective methods of promoting/supporting weight loss in people with IIH
Q5	
	H 339). What are the safety and efficacies of medical weight loss treatments in people with IIH
Q5	
	P 31a). Do healthcare practitioners rely too heavily on weight management as the treatment for IIH when other causes/treatments should be explored
Q7	
	P 31b). Is the focus on high bmi/obesity justified/helpful immediately after diagnosis
Q1	
	H 249b). How much weight needs to be lost before a clinically meaningful improvement in CSF pressure is seen
Q2	
	P 22). What is the safety and efficacy of successful weight loss for people with IIH and how much weight needs to be lost
Q5	
	P 97). What proportion of people who have IIH and successfully lose weight with or without bariatric surgical intervention see an improvement or resolution of
Q5	
	H 124). What are the rates of remission/symptom control at differing weight reduction levels
Q5	
	P 137). What is the safety and efficacy of successful weight loss for people with IIH and how much weight needs to be lost before this can be ruled out
Q5	
	F 150). What is the safety and efficacy of successful weight loss for people with IIH and how much weight needs to be lost
Q5	
	H 174). What is the safety and efficacy of successful weight loss for people with IIH and how much weight needs to be lost
Q5	
	P 189). How much weight needs to be lost to improve symptoms and can enough weight loss result in total cure
Q5	
	H 248a). Are there BMI/weight thresholds below which people must remain to avoid recurrence of IIH
Q5	
	H 249). What kg weight loss would correspond to 5cmCSF improvement
Q5	
	H 253). How much weight needs to be lost to save vision in people with IIH
Q5	
	H 256). How much weight needs to be lost before there will be a meaningful difference to symptoms experienced by people with IIH
Q5	
	H 257c). How much weight needs to be lost before there will be a meaningful difference to symptoms experienced by people with IIH
Q5	
	H 259). How much weight needs to be lost before there will be a meaningful difference to symptoms experienced by people with IIH
Q5	
	H 263a). What is the safety and efficacy of successful weight loss for people with IIH and how much weight needs to be lost
Q5	
	O 276). How much weight needs to be lost before there will be a meaningful difference to symptoms experienced by people with IIH
Q5	
	P 278). What is the safety and efficacy of successful weight loss for people with IIH and how much weight needs to be lost
Q5	
	H 300). How much weight needs to be lost before there will be a meaningful difference to symptoms experienced by people with IIH
Q5	
	H 306a). How much weight needs to be lost before there will be a meaningful difference to symptoms experienced by people with IIH
Q5	

Q5	P 319). What is the safety and efficacy of successful weight loss for people with IIH and how much weight needs to be lost
Q5	P 342). How much weight needs to be lost before there will be a meaningful difference to symptoms experienced by people with IIH
Q5	H 351). What is the safety and efficacy of successful weight loss for people with IIH and how much weight needs to be lost
Q5	H 355). How much weight needs to be lost before IIH will go into remission
Q6	P 274). Is there conclusive evidence to support the general opinion of health care practitioners that being an overweight female causes IIH and that weight loss will
Q6	P 292). Is there conclusive evidence to support the general opinion of health care practitioners that being an overweight female causes IIH and that weight loss will
Q7	P 146). Is there conclusive evidence to support the general opinion of health care practitioners and the IIH community that being overweight causes IIH and that
Q5	C 1). What are the best strategies to help people with IIH who cannot exercise to effectively lose weight
Q5	H 7). What are the best strategies to help people with IIH to effectively lose weight
Q5	O 13). What are the best strategies to help people with IIH to effectively lose weight
Q5	P 15). What are the best strategies to help people with IIH who cannot exercise to effectively lose weight
Q5	P 20). What are the best strategies to ensure that healthcare practitioners have good knowledge of weight loss in IIH to enable them to be understanding about the
Q5	P 24). What are the best strategies to help people with IIH to effectively lose weight
Q5	P 35a). What are the best strategies to help people with IIH to effectively lose weight
Q5	P 37a). What are the best strategies to ensure that healthcare practitioners have good knowledge of weight loss in IIH to enable them to be understanding about the
Q5	P 38a). What are the best strategies to ensure that healthcare practitioners have good knowledge of weight loss in IIH to enable them to be understanding about the
Q5	P 44b). Do people with IIH need more support than they currently receive to aid weight loss
Q5	P 46). Do people with IIH need more support than they currently receive to aid weight loss
Q5	P 49). Do people with IIH need more support than they currently receive to aid weight loss and should this be put in place immediately following diagnosis
Q5	P 52). Do people with IIH need more support and better tailored advice than they currently receive to aid weight loss
Q5	P 55). Do people with IIH need more support and better tailored advice than they currently receive to aid weight loss
Q5	P 65a). Can GP's provide more support and better tailored advice for people with IIH to aid weight loss
Q5	P 68a). What are the best strategies for weight loss for people with IIH and chronic headaches, and how much weight needs to be lost to have an effect
Q5	H 73). What are the best strategies for weight loss in people with IIH, how much weight should they lose and how quickly
Q5	F 82). What are the barriers to successful weight loss for overweight people with IIH
Q5	P 87). Do people with IIH need more support and better tailored advice than they currently receive to aid weight loss
Q5	P 92). Do people with IIH need more support and better tailored advice than they currently receive to aid weight loss
Q5	P 93). Is there an evidence based set of dietary guidelines specifically for people with IIH to promote weight loss without aggravation of raised CSF pressure
Q5	P 94). Do people with IIH need more support and better tailored advice than they currently receive to aid weight loss
Q5	O 95). Is there an evidence based set of dietary guidelines specifically for people with IIH to promote weight loss without aggravation of symptoms
Q5	P 98). Do people with IIH need more support and better tailored advice than they currently receive to aid weight loss
Q5	P 99). What are the barriers to successful weight loss for people with IIH
Q5	P 101). What are the barriers to sustainable weight loss for people with IIH
Q5	F 102). What are the best strategies for supporting and encouraging weight loss in people with IIH
Q5	P 117a). Do people with IIH need more support and better tailored advice than they currently receive to aid weight loss
Q5	P 119). What are the barriers to sustainable weight loss for people with IIH
Q5	P 120). What are the best strategies for weight loss for people with IIH managed using drugs with weight gain side effects
Q5	H 121). What are the best strategies/interventions to help people with IIH to effectively lose weight
Q5	H 123). What are the best strategies/interventions to help people with IIH to effectively and sustainably lose weight
Q5	P 126). What are the best strategies for weight loss in people with IIH who experience a worsening of symptoms when exercising
Q5	P 128). What are the treatment and/or support options for weight loss in people with IIH
Q5	P 135). What are the barriers to successful weight loss for overweight people with IIH
Q5	H 143). What are the best strategies/interventions to help people with IIH to effectively lose weight
Q5	H 149). What are the best strategies to help people with IIH to effectively lose weight and sustain weight loss
Q5	P 154). What are the barriers to successful weight loss for people with IIH
Q5	P 157). Do people with IIH need more support than they currently receive to aid weight loss
Q5	P 161). Do people with IIH need more support than they currently receive to aid weight loss
Q5	H 168). Who should be responsible for managing weight loss support for people with IIH
Q5	P 164). What are the barriers to successful weight loss for people with IIH
Q5	H 169). Do people with IIH need more support than they currently receive to aid weight loss
Q5	P 176). What are the barriers to successful weight loss for people with IIH
Q5	H 180a). What are the best strategies to help people with IIH to effectively lose weight

Q5	H 184c). What are the best strategies to help people with IIH to effectively lose weight
Q5	P 194). Do people with IIH need more support than they currently receive to aid weight loss
Q5	H 195). What are the barriers to successful weight loss for people with IIH compared with non-diseased people who are overweight/obese
Q5	H 197a). How frequently should people with IIH have their weight monitored
Q5	H 198a). What are the best strategies to help people with IIH to effectively lose weight
Q5	H 213a). What are the best strategies to help people with IIH to effectively lose weight
Q5	H 216). Is there a need for a clear goal directed step wise pathway for management of weight in people with IIH
Q5	H 217). What are the best strategies to help people with IIH to effectively lose weight
Q5	H 220b). What are the barriers to successful weight loss for people with IIH
Q5	H 223). What are the best strategies to help people with IIH to effectively lose weight
Q5	H 224). What are the best strategies to help people with IIH to effectively lose weight and maintain their weight loss
Q5	H 226). What are the best strategies to help people with IIH to effectively lose weight
Q5	P 230). What are the best strategies for people with IIH to effectively lose weight
Q5	H 234). What are the best strategies for people with IIH to effectively lose weight
Q5	H 235). What are the best strategies for people with IIH to effectively self manage weight loss
Q5	P 237). What are the best strategies for people with IIH to effectively lose weight
Q5	H 242a). What are the best strategies for people with IIH to effectively lose weight
Q5	H 247). What are the best strategies to help people with IIH to effectively lose weight and maintain weight loss
Q5	H 254). What is the best evidence based sustainable dietary advice to aid weight loss for people with IIH
Q5	H 257a). What are the best strategies to help people with IIH to effectively lose weight
Q5	H 260). What are the best strategies to help people with IIH to effectively lose weight
Q5	H 261a). What are the best strategies to help people with IIH to effectively lose weight
Q5	H 262). What are the best strategies to help people with IIH to effectively lose weight
Q5	H 263b). What are the best strategies to help people with IIH to effectively lose weight
Q5	H 265). What are the best strategies to help people with IIH to effectively lose weight and can they be better implemented through the NHS
Q5	P 266). Should people with IIH who are overweight or obese be immediately referred to a dietitian and weight loss team upon diagnosis
Q5	P 267). Do people with IIH need more support than they currently receive to aid weight loss
Q5	P 268). What are the best strategies to help people with IIH and raised CSF pressure to effectively lose weight
Q5	P 269a). Do people with IIH need more support than they currently receive to aid weight loss
Q5	P 281). Do people with IIH need more support than they currently receive to aid weight loss
Q5	P 283b). What are the barriers to successful weight loss for people with IIH
Q5	H 285). Who should be responsible for managing weight loss support for people with IIH and how frequent should check ups be
Q5	P 292). What are the best strategies to ensure that healthcare practitioners have good knowledge of weight loss in IIH to enable them to be understanding about the
Q5	P 294). Do people with IIH need more support than they currently receive to aid weight loss
Q5	P 295). What are the best strategies to ensure that healthcare practitioners have good knowledge of weight loss in IIH to enable them to be understanding about the
Q5	P 297). What are the best strategies to ensure that healthcare practitioners have good knowledge of weight loss in IIH to enable them to be understanding about the
Q5	H 298). What are the best strategies to help people with IIH to effectively lose weight
Q5	H 303). What are the best strategies to help people with IIH to effectively lose weight
Q5	H 304). What are the best strategies to help people with IIH to effectively lose weight
Q5	P 305). Do people with IIH need more support than they currently receive to aid weight loss
Q5	H 308). What are the best strategies to help people with IIH to effectively lose weight
Q5	H 313). What are the best strategies for people with IIH to effectively lose weight and maintain weight loss long term
Q5	P 317). Do people with IIH need more support than they currently receive to aid weight loss
Q5	P 324). What are the best strategies to ensure that healthcare practitioners have good knowledge of IIH to enable them to be understanding about the non-weight
Q5	H 325a). What are the best strategies to help people with IIH to effectively lose weight
Q5	H 325b). Should people with IIH who are trying to lose weight be offered appointments with a dietitian and/or health psychologist
Q5	P 328). Do people with IIH need more support than they currently receive to aid weight loss
Q5	H 330). What are the best strategies to help people with IIH to effectively lose weight and maintain weight loss
Q5	H 332). What are the barriers to successful weight loss for people with IIH
Q5	F 335). What are the barriers to successful weight loss for people with IIH
Q5	H 338). What are the best strategies to help people with IIH to effectively lose weight
Q5	P 340). What are the barriers to successful weight loss for people with IIH

Q5	H 344). What are the best strategies to help people with IIH to effectively lose weight and maintain weight loss
Q5	H 347). What are the best strategies to help people with IIH to effectively lose weight
Q5	P 348). What are the best strategies to help people with IIH to safely, effectively and sustainably lose weight
Q5	H 349). What are the best strategies to help people with IIH to effectively lose weight
Q5	P 352). What are the best strategies to help people with IIH to effectively lose weight
Q5	H 111). How much weight needs to be lost, how quickly and does this depend on initial bmi of the person with IIH, to show benefits for symptoms/prognosis of IIH
Q5	H 191). How much weight should people with IIH lose and how quickly
Q5	O 193). How much weight needs to be lost to improve symptoms
Q5	H 196). How much weight needs to be lost to improve symptoms
Q5	H 201). How much weight do people with IIH need to lose and what is the best measure or indicator of successful weight loss
Q5	H 202a). How much weight do people with IIH need to lose
Q5	H 214). How much weight do people with IIH need to lose
Q5	H 222a). How much weight do people with IIH need to lose to go into remission
Q5	H 248b). Are there biomarkers that correlate with weight loss that can guide therapy - to let the patient know that they are 'nearly there'
Q5	H 232). How much weight do people with IIH need to lose to go into remission and does rate of loss have any impact
Q5	H 329). How quickly should weight be lost to safely and effectively relieve symptoms in people with IIH
Q4	H 262b). What are the best strategies/techniques to aid successful weight loss in people with IIH
Q2	P 292). What is the efficacy and safety, specifically in terms of mental health outcomes, of advising weightloss for treatment of IIH in the overweight/obese
Q2	H 321a). What is the effectiveness of weightloss compared with raised physical activity levels for treatment of IIH
Q3	H 180c). What is the effectiveness of weight loss interventions for treatment of IIH
Q5	P 20b). What is the safety, efficacy and cost effectiveness of specialised exercise groups to help with weight loss for people with IIH
Q5	P 38b). What are the safeties and efficacies of the various diet plans proposed for use by people with IIH
Q5	P 43c). What are the best evidence based diet strategies for weight loss without aggravation of symptoms in people with IIH
Q5	P 44a). What is the safety, efficacy and cost effectiveness of specialised diet support groups to help with weight loss for people with IIH
Q5	P 65c). What are the best evidence based exercises for aiding weight loss without aggravating raised pressure and other symptoms for people with IIH
Q5	P 100). What is the safety and efficacy of graded exercise therapy for people with IIH who experience pain during gentle movement
Q5	P 103). Is there an evidence based set of dietary guidelines specifically for people with IIH to promote weight loss without aggravation of symptoms
Q5	P 108). What are the best evidence based exercises for people with IIH which will not aggravate symptoms and will aid weight loss
Q5	P 109). What are the best evidence based exercises for people with IIH which will not aggravate symptoms and will aid weight loss
Q5	P 117b). What is the cost effectiveness of providing/discounting portion controlled healthy meals for people with IIH
Q5	P 132). What are the best strategies for supporting a person in remission from IIH to sustain weight loss
Q5	H 139). What is the long term effectiveness of support from a dietician or personal trainer (PT?) on weight loss in people with IIH
Q5	H 141). What are the most effective interventions in terms of patient health and cost to the NHS for management of weight in people with IIH
Q5	P 146). What are the best evidence based treatment options for relieving symptoms in people with IIH during the weight loss process
Q5	P 166). What is the safety, efficacy and cost effectiveness of specialised exercise groups to help with weight loss for people with IIH
Q5	H 180c). What is the safety and efficacy of increasing physical activity in people with IIH
Q5	H 198b). What is the safety, efficacy and cost effectiveness of specialised diet support groups to help with weight loss for people with IIH
Q7	H 325). What are the best strategies to help people with IIH to effectively lose weight and maintain weight loss
Q5	H 185). What level of weight management services should individuals with IIH have access to and should this be standardised across hospitals
Q5	H 212). What are the best treatments to help people with IIH to effectively lose weight
Q5	P 272). What are the best evidence based exercises for aiding weight loss without aggravating raised pressure and other symptoms for people with IIH
Q5	P 273). What are the best evidence based exercises for aiding weight loss without aggravating raised pressure and other symptoms for people with IIH
Q5	H 275). What is the long term effectiveness of dietary advice given to people with IIH
Q5	O 320). What are the best evidence based diets/eating plans for weight loss in people with IIH
Q5	P 333). What are the best evidence based exercises for aiding weight loss without aggravating raised pressure and other symptoms for people with IIH
Q6	H 248). What is the effectiveness of unsupported self management of weight loss in people with IIH
Q7	P 67a). What are the best evidence based exercises for aiding weight loss without aggravating raised pressure and other symptoms for people with IIH
Q6	P 302). What are the best strategies for nutrition and exercise for people with IIH post-surgery
Q3	H 214). What is the safety and efficacy of gastric banding compared with weight loss drugs for vision outcomes in people with IIH
Q3	H 240b). What is the effectiveness of bariatric surgery compared with other weight loss interventions for reducing bmi in people with IIH
Q1	P 138). What is the safety and efficacy of weight loss surgery compared with other weight loss interventions and no weight loss intervention for IIH
Q5	H 9). What is the long term safety and efficacy of bariatric surgery for people with IIH

Q5	H 10). What are the safeties and efficacies of behavioural techniques, systemic medicines and bariatric surgery for controlling symptoms and for prognosis in people
Q5	P 18a). What is the safety and efficacy of weight loss surgery for all people with IIH
Q5	P 19). What is the safety and efficacy of weight loss surgery for all overweight people with IIH
Q5	P 43b). What is the safety and efficacy of weight loss surgery compared with shunts and optic nerve sheath fenestration for treating symptoms of IIH
Q5	P 56). What is the safety and efficacy of weight loss surgery for all overweight people with IIH
Q5	H 75). What is the cost effectiveness of bariatric surgery for treatment of vision in people with unstable vision due to IIH, and in treatment of other symptoms for
Q5	P 81). What is the safety and efficacy of weight loss surgery for people with IIH
Q5	F 86). What is the safety and efficacy of weight loss surgery for all overweight people with IIH
Q5	H 118). What is the safety and efficacy of bariatric surgery compared with dietary advice for people with IIH
Q5	H 125). What is the safety and efficacy of weight loss surgery for all overweight people with IIH
Q5	H 127). What is the safety and efficacy of weight loss surgery for all people with IIH
Q5	H130b). What is the safety and efficacy of weight loss surgery for all people with IIH
Q5	P 131). What is the safety and efficacy of weight loss surgery for all people with IIH
Q5	H 136). What is the safety and efficacy of gastric band surgery compared with best medical therapy for management of obesity in people with IIH
Q5	H 183). What is the safety and efficacy of weight loss surgery for all people with IIH
Q5	H 184b). What is the safety and efficacy of weight loss surgery for all people with IIH
Q5	H 202b). What is the safety and efficacy and cost effectiveness of bariatric surgery for all overweight people with IIH
Q5	H 206). What is the safety and efficacy of weight loss surgery for people with IIH at risk of vision loss
Q5	H 211a). What is the safety and efficacy of liposuction for treatment of people with IIH
Q5	H 218). What is the safety and efficacy of bariatric surgery for people with IIH
Q5	H 220a). What is the safety and efficacy of gastric banding for people with IIH
Q5	H 222b). What is the safety and efficacy of bariatric surgery for people with refractory IIH
Q5	H 240b). What is the safety and efficacy of bariatric surgery compared with other methods of weight loss for people with IIH
Q5	H 242b). Does bariatric surgery have more benefits in IIH, other than just sustained weight loss
Q5	H 251). What is the safety and efficacy of gastric surgery for treatment of IIH
Q5	H 255). What is the safety and efficacy of gastric banding for people with IIH
Q5	H 264). What is the safety and efficacy of bariatric surgery compared with other weight loss interventions/strategies for people with IIH
Q5	P 283a). What is the safety and efficacy of weight loss surgery for all overweight people with IIH
Q5	P 310). What is the safety, efficacy and cost effectiveness of bariatric surgery for people with IIH who require help with weight loss
Q5	P 345). What is the safety and efficacy of bariatric surgery compared with shunting for long term outcomes in people with IIH
Q5	H 353). What is the safety and efficacy of immediate referral to bariatric surgery for people with IIH and BMI >35
Q5	H 354). What is the safety and efficacy of bariatric surgery compared with other surgical options for people with IIH
Q5	H 250). What type of weight reduction surgery is safest and most efficacious for individuals with IIH
Q5	O 190). What is the safety and efficacy of drugs for weight loss (newer antidiabetics e.g. Glucagon-like peptide 1, Qsymia -phentermine and topiramate extended-
Q5	H 220c). What is the safety and efficacy of drugs for weight loss (Glucagon-like peptide 1, liraglutide) for people with IIH
Q5	P 58). What are the best evidence based weight loss targets for people with IIH
Q5	P 88). What are the best evidence based exercises for aiding weight loss without aggravating raised pressure and other symptoms for people with IIH
Q5	H 130a). What are the weight loss targets that have proven impact on symptoms or progression of IIH
Q5	H 133). What are the weight loss targets that have proven impact on symptoms or progression of IIH
Q5	P 147b). What are the weight loss targets for effective symptom relief in people with IIH
Q5	H 180b). How much weight needs to be lost to save vision and improve headaches
Q5	H 182). How much weight needs to be lost to improve symptoms
Q5	H 184a). How much weight needs to be lost to improve symptoms
Q5	P 4). Should people with IIH have access to a dietitian to support weightloss
Q5	H 12b). Should/Do people with IIH have access to a dietitian to support weight loss
Q5	P 14). Do people with IIH receive enough support for weight loss
Q5	F 45). Should people with IIH have access to a dietitian to support weight loss
Q5	H 71). Should every person with IIH have access to support from a dietitian
Q5	P 96). Which types of people with IIH would benefit from referral to a dietitian and/or a bariatric specialist
Q5	P 148). Do people with IIH need more support than they currently receive to aid weight loss
Q5	H 197b). Should/do people with IIH have access to support from a dietitian
Q5	H 228). Are people with IIH better at losing weight than non-disease overweight and obese people

<p>M4. (combined with N3, N4) Are multidisciplinary clinics (joint clinics of neurology, ophthalmology, neurosurgery, dietetics and specialist nurses etc.) clinically and cost effective for the management of IIH and would they improve patient experience?</p>	Q5	H 204). What is the effectiveness in terms of patient health and cost of a joint dietetics, ophthalmology, neurology and personal training clinic for people with IIH	<p>Known unknown</p>
	Q4	O 320b). What is the effectiveness of holistic treatments for people with IIH	
	Q4	P 166). What is the effectiveness of treating individual symptoms of IIH compared with holistic treatment of person with IIH	
	Q5	H 69). What is the effectiveness in terms of patient health and cost of a joint dietetics and ophthalmology clinic for people with IIH	
	Q6	H 10). What is the effectiveness of regional networks comprising ophthalmologists, headache specialists, weight loss endocrinologists, and bariatric surgeons in terms of	
	Q6	P 18). What is the effectiveness, in terms of patient outcomes and cost, of multidisciplinary teams assessing people with IIH in a single clinic, would this result	
	Q6	H 73). Would IIH MDT clinics be of benefit	
	Q6	H 75). Would IIH MDT clinics be of benefit	
	Q6	P 117). Would IIH MDT clinics be of benefit	
	Q6	H 118). Would IIH MDT clinics be of benefit	
	Q6	H 140). Would IIH MDT clinics be of benefit	
	Q6	H 146). Would IIH MDT clinics be of benefit	
	Q6	F 150). Would IIH MDT clinics be of benefit	
	Q6	H 156). Would IIH MDT clinics be of benefit	
	Q6	H 168). Would IIH MDT clinics be of benefit	
	Q6	H 171a). Would IIH MDT clinics be of benefit	
	Q6	H 178). Would IIH MDT clinics be of benefit	
	Q6	H 184). Would IIH MDT clinics be of benefit	
	Q6	H 186). Would IIH MDT clinics be of benefit	
	Q6	H 192). Would IIH MDT clinics be of benefit	
	Q6	H 211). Would IIH MDT clinics be of benefit	
	Q6	H 224). Would IIH MDT clinics be of benefit	
	Q6	H 236). Would IIH MDT clinics be of benefit	
	Q6	P 237b). Would IIH MDT clinics be of benefit	
	Q6	H 242). Would IIH MDT clinics be of benefit	
	Q6	H 246). What are the best evidenced based multidisciplinary strategies for providing best care for people with IIH	
	Q6	H 247). Would IIH MDT clinics be of benefit	
	Q6	H 325). What is the best strategy to providing effective MDT care inclusive of dietetics and health psychology	
	Q6	H 353a). Would IIH MDT clinics be of benefit	
	Q7	P 53). What is the effectiveness, in terms of patient outcomes and cost, of multidisciplinary teams assessing people with IIH in a single clinic, would this result	
	Q7	P 331). Would better communication between healthcare professionals and people with IIH improve outcomes and patient experience	
	Q6	H 243). Should specialist centres deal with individuals with IIH?	
	Q6	P 44b). What needs to be done to improve the post-surgery care of people with IIH	
	Q6	H 187). Would clinical nurse specialists in the community improve care for IIH	
	Q6	H 216). Would specialist IIH nurses improve care for people with IIH	
	Q6	H 217). Would specialist IIH nurses improve care for people with IIH	
	Q6	H 200). Would specialist IIH nurses improve care for people with IIH	
	Q7	P 67b). Do people with IIH need more support to enable them to access the best medications for treatment of their symptoms	
	Q7	P 111). Do people with IIH need more support for managing their symptoms than they currently receive	
	Q7	P 269). Do people with IIH need more support to manage their symptoms and better care than they currently receive	
	Q7	F 335). Do people with IIH need more support than they currently receive	
	Q6	P 2). What is the effectiveness in terms of cost and patient outcomes of a nurse specialist	
	Q6	P 331). Is there a need for more specialist nurses	

Formed question	Contributing uncertainties	Certainty	Reference
H3. Does venous stenting treat IIH?	Q4	Known unknown	
	Q4		
	Q4		
	Q4		

I4. (combined with L6) Is bariatric surgery effective in IIH and at what point in the disease should it be performed?	Q7	H 240). What criteria/syptoms indicate a person with IIH should be offered bariatric surgery according to current guidelines		
	Q3	H 240c). What is the threshold bmi over which bariatric surgery is justified in people with IIH		
	Q3	O 276). What are the symptoms/risk factors that indicate bariatric surgery is needed in a person with IIH		
	Q3	P 244). What are the best strategies to ensure that healthcare practitioners including (GPs, neurologists, etc.) have good knowledge of IIH to enable them to be		
	Q3	H 256). What risk factors/symptoms indicate a need for urgent intervention to preserve vision		
	Q3	P 289). What are the best strategies to ensure that ophthalmologists have good knowledge of IIH to enable them to be understanding and provide an best care		
	Q3	P 309). What are the best strategies to ensure that ophthalmologists and neuro-surgeons have good knowledge of IIH and related vision problems to enable them to		
	Q3	P 311). What are the best strategies to ensure that specialist nurses have good knowledge of IIH and related vision problems to enable them to be understanding,		
	Q3	P 322b). What are the best strategies to ensure that healthcare practitioners including neuro-ophthalmologists have good knowledge of IIH to enable them to be		
	Q3	H 347). What are the characteristics/symptoms/risk factors that indicate a person with IIH requires treatment to prevent loss of vision		
	Q3	H 353c). What are the characteristics/symptoms/risk factors that indicate a person with IIH requires shunt surgery for treatment of vision problems		
	Q4	H 75a). What are the characteristics/symptoms that indicate stenting should be carried out to treat loss of vision in people with IIH		
	Q4	O 276). What are the symptoms/criteria that indicate bariatric surgery is required for treatment of headache in people with IIH		
	Q5	P 40). When should weight loss surgery be used		
	Q5	H 64). Which people with IIH should be offered gastric band surgery to aid weight loss		
	Q5	H 77). Should bariatric surgery be offered to all people with IIH who are struggling to lose weight and whose symptoms cannot be managed		
	Q5	P 138). Which people with IIH should be offered weight loss surgery		
	Q5	H 171). Which types of people with IIH should be considered for bariatric surgery		
	Q5	H 173). Which types of people with IIH should be considered for bariatric surgery		
	Q5	H 197c). What are the symptoms/criteria of the people with IIH who will benefit from bariatric surgery		
	Q5	H 198c). What are the symptoms/criteria of the people with IIH who will benefit from bariatric surgery		
	Q5	H 221). Which symptoms/criteria indicate that bariatric surgery is necessary for a person with IIH		
	Q5	H 257b). What is the role of weight loss surgery for treatment of IIH		
	Q5	H 258). How soon and for whom should bariatric surgery be used to treat IIH		
	Q5	H 312). What are the symptoms/criteria that indicate bariatric surgery would be beneficial for treatment of people with IIH		
	Q5	H 334). What are the symptoms/criteria that indicate bariatric surgery would be beneficial for treatment a person with IIH		
	Q5	H 343). What are the symptoms/criteria that indicate bariatric surgery would be beneficial for treatment of a person with IIH		

K1. (combined with C3, I3, K2) What are the best ways to monitor visual function?	Q3	P 14). How regularly should people with IIH have appointments to monitor vision problems	Known unknown	
	Q3	P 16a). How regularly should people with IIH have appointments to monitor vision problems		
	Q3	P 28). How often should visual field and other vision testing be carried out in a person with IIH		
	Q3	P 30a). Which department should monitor vision problems in people with IIH		
	Q3	P 30c). How often should a person with IIH and vision problems be seen in an ophthalmology clinic or by an optician		
	Q3	P 33). What are the best strategies for enabling effective self monitoring of visual health and ensuring people with IIH know which symptoms to report to a healthcare		
	Q3	P 35a). Should all people with IIH have their vision continually monitored by a healthcare professional after diagnosis		
	Q3	P 43b). How frequently should visual field tests, papilloedema screening and dilated eye screening be carried out in someone with stable IIH		
	Q3	P 44b). How frequently should people with IIH see an ophthalmologist		
	Q3	H 75b). How frequently should people with IIH be seen in an ophthalmology clinic		
	Q3	H 77a). How frequently should people with IIH be seen by an ophthalmologist		
	Q3	F 82). What is the effectiveness of regular check ups with ophthalmologist compared with symptom led referral to ophthalmologists for vision loss in IIH		
	Q3	P 88). What treatment/monitoring strategies are required for people with IIH without papilloedema		
	Q3	P 93). How frequently should vision be checked in people with IIH and which tests should be carried out		
	Q3	P 100). How frequently should vision be checked by an optician in people with IIH		
	Q3	P 101a). How frequently should vision be checked in people with IIH		
	Q3	P 110). How frequently should vision be checked in people with IIH, by whom, and which tests should be carried out		
	Q3	H 123). What are the best evidence based methods for monitoring vision loss in IIH		
	Q3	P 137a). How frequently should vision be checked in people with IIH		

Q3	P 144). How frequently should vision be checked in people with IIH, and which tests should be carried out
Q3	P 152). How frequently should vision loss/papilloedema be tested for in a person with long history of IIH diagnosed without papilloedema
Q3	P 154). How frequently should a person with IIH be seen by a doctor to monitor disease progression
Q3	P 155b). How frequently should visual field tests be carried out in someone with IIH
Q3	P 160a). How frequently should vision be checked by a neuro ophthalmologist in a person with IIH
Q3	H 186a). What is the role of optical coherence tomography in follow up of vision in IIH
Q3	P 189). How frequently should people with IIH have their vision checked
Q3	H 197). How frequently should a person with stable IIH receive check ups for their vision
Q3	H 216a). How frequently should people with IIH have a check up for their vision
Q3	H 222a) What are the best evidence based criteria for assessing vision in IIH and how frequently should these assessments be carried out
Q3	H 228). How frequently should vision be checked in people with IIH
Q3	P 241). How frequently should vision be checked in a person with IIH with papilloedema in remission
Q3	H 251). How frequently should visual fields be tested in people with IIH
Q3	H 252a). How frequently should visual fields be tested in people with IIH
Q3	H 252b). What length of follow up of visual fields should be carried out after the resolution of IIH
Q3	H 254). How frequently should vision be checked in people with IIH and could a protocol for this be disseminated
Q3	H 258). How frequently should a person with IIH have neuro-ophthalmology consultation
Q3	P 269). How frequently should vision be checked in people with IIH
Q3	H 300). How frequently should vision be checked in people with IIH and which assessments should be carried out
Q3	H 312). How frequently should people with IIH have their vision checked
Q3	P 322a). How frequently should people with IIH be seen by a neuro-ophthalmologist
Q3	P 337). How frequently should field tests for vision problems be carried out in people with IIH who have been discharged
Q3	H 339). How frequently should people with IIH be monitored to check for vision problems
Q3	H 343). What are the best strategies to ensure people with IIH get regular follow up with visual fields undertaken
Q3	H 353d). How frequently should people with IIH have their vision monitored and should this change following medical or surgical intervention
Q6	H 210). How frequently should people with visually asymptomatic IIH be monitored to check for onset of vision problems
Q7	H 243). When should a clinician not worry about sight issues
Q1	O 190h). What are the best set of parameters to monitor vision and visual loss
Q1	O 190i). What is the best method for detecting functional visual loss
Q3	P 2). What are the best evidence based tests for monitoring vision in IIH and how often should they be carried out
Q3	H 7). What is the best evidence based test in terms of accuracy, safety and tolerability for monitoring optic disc changes
Q3	H 8a). What is the best evidence based test in terms of accuracy, safety and tolerability for monitoring visual changes
Q3	H 8b). What is the role of optical coherence tomography in monitoring vision in IIH
Q3	H 9a). What are the relative accuracies of kinetic and static perimetry for detection/monitoring of vision problems in IIH
Q3	P 53). What is the safety and accuracy of field testing compared with optical coherence tomography for monitoring changes in vision in people with IIH
Q3	H 77b). What is the safety accuracy and tolerability of Goldman visual field exam compared with Humphrey field exam for monitoring visual problems in IIH
Q3	P 87). What strategies for recognising onset of vision problems are in place and how effective are they
Q3	P 137b). What is the accuracy of goldmanns visual field tests for monitoring vision loss in IIH
Q3	H 139). What is the accuracy of visual field tests for IIH and how frequently should they be carried out
Q3	H 149). What is the accuracy of visual field testing combined with and compared with optical coherence tomography for monitoring vision in IIH
Q3	H 171b). What is the role of optical coherence tomography for monitoring vision in IIH
Q3	H 195). Which tests for vision problems should be carried out by ophthalmologists/neurologists when reviewing people with IIH
Q3	H 198b). What is the accuracy, safety and tolerability of retinal angiography compared with standard fluorescein angiography for identifying papilloedema in
Q3	H 199). What is the best evidence based visual field assessment method for use in primary, secondary and tertiary care
Q3	P 200). What tests should be used to fully assess transient vision problems experienced in IIH
Q3	H 204c). What is the accuracy of retinal or optic nerve imaging for stratifying risk of vision problems in IIH
Q3	H 207). Can OCT and visual fields be used to standardise visual function assessment
Q3	H 209). How frequently should vision be checked in people with IIH, by whom, and which tests should be carried out
Q3	H 211a). What are the best evidence based methods of measuring visual function to monitor disease progress
Q3	H 213). What is the best evidence based and most practical way of carrying out routine visual field assessment
Q3	H 221a). What are the best evidenced based methods for accurately assessing vision in people with IIH
Q3	H 221b). Are there any tests that predict vulnerability in IIH to vision loss

Q3	H 238). What are the most accurate tests to monitor vision problems in IIH
Q3	H 247). What is the accuracy and safety of optical coherence tomography, and which parameters should be used to optimize this accuracy, for monitoring papilloedema
Q3	H 249). What is the accuracy and safety of fundoscopy for monitoring papilloedema diagnosed with other techniques
Q3	H 257). What are the best methods to monitor vision and what is the best schedule over which they should be used
Q3	H 259). What are the most accurate tests for monitoring vision
Q3	H 260). Which is the best variable for monitoring vision problems in IIH
Q3	O 320b). What are the standard tests for monitoring vision problems in IIH
Q3	H 325). What are the best strategies for monitoring vision in people with IIH
Q3	H 329). What are the relative accuracies of the visual parameters that are measured in people with IIH for predicting permanent loss of vision
Q3	H 338). What is the accuracy of the various measurable objective optic disc parameters for predicting risk of vision loss in people with IIH
Q3	H 349). What are the relative accuracies of the various objective tests available to detect deterioration of vision requiring intervention in people with IIH
Q3	H 9d). Which visual monitoring is best
Q3	H 75a). Which visual monitoring technique is best
Q3	H 130b). Which visual monitoring is best
Q3	H 211b). Which visual monitoring is best
Q3	H 242c). Which visual monitoring is best
Q3	F 150). What is the effectiveness of current vision management strategies in the UK
Q3	P 161). What is the effectiveness of current vision management strategies in the UK
Q3	H 171d). What are the best strategies for management of vision in people with IIH to reduce risk to their sight
Q3	H 198c). Should all major ophthalmology and neurology departments have access to optical coherence tomography and optical coherence tomography angiography?
Q3	H 204a). What is the best evidence based guidance for management of vision in IIH and is it effective
Q3	H 218a). What is the effectiveness of combined neurology/ophthalmology follow up compared with other strategies for treating vision problems in people with IIH
Q3	H 219). What is the best evidence based guidance for management of vision in IIH and should both neurology and ophthalmology clinics be involved
Q3	P 274). What are the best strategies for management of vision in terms of a reasonable schedule of appointments for people with IIH to attend
Q3	F 277). Should people with IIH receive interventions to preserve vision before vision problems occur
Q3	P 281). What are the best strategies for management of vision problems, both vision loss and transient vision problems, to reduce impact on quality of life of people with IIH
Q3	H 285). What are the best strategies for management of vision to ensure that people with IIH are seen at the right frequency by the right healthcare professional in order
Q3	H 308). What are the best strategies/treatments for managing vision problems in pregnant women with IIH
Q3	P 78). What is the effectiveness, safety and tolerability of Diamox compared with alternative treatments for vision loss in IIH
Q3	P 89). What is the effectiveness, safety and tolerability of Diamox compared with alternative treatments for vision loss in IIH
Q3	H 127). Are further trials of treatments for IIH needed to create a robust evidence base
Q1	H 75d). What is the diagnostic test accuracy of OCT compared with monitoring for IIH
Q1	H 75e). What is the diagnostic test accuracy of non invasive retinal arteriograms for IIH
Q1	H 162a). What is the best diagnostic test for detection of papilloedema and differentiation between this and blurred disc margins
Q1	H 203a). What is the diagnostic test accuracy of the standard test for papilloedema
Q1	H 203c). What are the comparative diagnostic test accuracies, safety and tolerabilities of fundoscopy (by expert), fluorescein angio and OCT for papilloedema
Q1	H 204b). What is the diagnostic test accuracy of retinal imaging with standard tests compared with standard tests alone for IIH
Q1	H 211b). What are the best evidence based diagnostic tests for differentially diagnosing papilloedema and anomalous disc for those presenting with mild disc
Q1	H 219). What is the diagnostic test accuracy of the battery of tests for IIH in people with unilateral papilloedema
Q1	H 222f). What is the diagnostic test accuracy of presence of spontaneous venous pulsations to rule out raised CSF pressure
Q1	H 247b). What is the diagnostic test accuracy of Optical coherence tomography for pseudo and true papilloedema
Q1	O 190g). What is the best evidence based visual fields test for people with IIH
Q3	P 132). What is the tolerability of visual field tests involving light spots for those with headache/migraine and photosensitivity
Q3	H 250). Are there techniques that could be developed for visual field assessments that could be carried out by an unskilled person
Q3	H 73). What is the best evidence based methods for follow up of visual deterioration
Q3	O 202a). What is the normal fluctuation pattern of visual field in people with IIH and when should treatment be offered
Q3	H 227). What are the best evidence based criteria for prioritise people with IIH who are at most risk of vision problems
Q3	H 234b). What are the criteria which indicate whether or not a person with IIH needs repeated lumbar puncture treatment
Q3	Sa). Which type of visual field test is best and how often should visual field tests be conducted
Q3	H 253). What is the role of retinal imaging in IIH

K3. In IIH, can self-monitoring be an effective screening test?

Q3	P 16b). What type of events/changes in vision should be reported to health care professionals by person with IIH
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Known unknown

	Q3	P 35c). What are the best strategies for enabling effective self monitoring of visual health and ensuring people with IIH know which symptoms to report to a healthcare	
	Q3	P 65a). What are the best strategies for enabling effective self monitoring of visual health and ensuring people with IIH know which symptoms to report to a healthcare	
	Q3	P 83). What are the best strategies for enabling effective self monitoring of visual health and ensuring people with IIH know which symptoms to report to a healthcare	
	Q3	P 128). What are the best strategies for enabling effective self monitoring of visual health and ensuring people with IIH know which symptoms to report to a healthcare	
	Q3	P 160b). What are the best strategies for enabling effective self monitoring of visual health and ensuring people with IIH know which symptoms to report to a healthcare	
	Q3	H 181). What is the effectiveness of self-monitoring and electronic reporting of vision outcomes by person with IIH to manage vision loss and instigate intervention	
	Q3	O 202b). What is the safety and accuracy of patient self assessment and reporting of blind spots	
	Q6	F 86). Can people with IIH accurately predict if their own ICP is high	

K4. How can disease state be judged in an optic nerve with atrophy (non-functioning nerve fibres)?	Q3	P 19). How does an ophthalmologist measure (CSF?) pressure in individuals with severe scarring caused by papilloedema	Known unknown
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N6. Would psychological support be beneficial in IIH	Q5	P 21). What are the real physiological barriers to weight loss when you have IIH	Known unknown
	Q7	O 190a). What are the psychological factors impacting body image and weight loss in individuals with IIH	
	Q6	P 107). Would psychological support benefit people with IIH	
	Q6	H 171c). Would psychological support benefit people with IIH	
	Q6	P 268). Would people with IIH benefit from psychological support	
	Q6	P 291). Do people with IIH need more support than they currently receive	
	Q6	H 304). Would people with IIH benefit from better psychological support	
	Q7	P 45). What are the best strategies for parents/carers to help people with IIH to manage their symptoms	
	Q7	P 51). Do people with IIH require a more holistic approach to their care given the high incidence of co-morbidities	

N7. What determines remission in IIH	Q4	P 29). What are the criteria for concluding IIH is in remission, are these evidence based and adequate	Not research question
	Q4	O 202b). What are the criteria for stopping treatment in IIH	
	Q4	H 221). What are the criteria for withdrawal of oral medications for treatment of headache in people with IIH	
	Q4	H 222b). What parameters should we be using to define improvement/remission	
	Q4	H 228b). Patients can be well treated from an eyesight point of view and still have headache: How can the patient feel safe?	
	Q2	H 57). What causes resolution of disease in those people who do not lose weight	
	Q4	H 195b). Should a diagnostic lumbar puncture be performed to check pressure before medications are reduced or stopped	
	Q7	H 256). What parameters best demonstrate that a patient is in remission	

Do support groups exist for people with IIH	Q6	H 351). Do support groups exist for people with IIH	Known known	https://en-gb.facebook.com/Idiop
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What are the best strategies for management of severe metabolic acidosis caused by diamox	Q7	P 28b). What are the best strategies for management of severe metabolic acidosis caused by Diamox	Known known	severe metabolic acidosis
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N10 (combined with Q2) Which is the best type of surgery to treat IIH and when should surgery be performed?	Q4	130d). What are the symptoms/characteristics of people with IIH who should be offered shunts for treatment of headache pain	Known unknown
	Q4	P 154). What are the best strategies for managing headache pain in people with IIH when oral treatments are failing to relieve symptoms	
	Q4	H 183). What are the symptoms/characteristics of people with IIH headache pain which indicate use of therapeutic lumbar puncture, shunts or venous stenting	
	Q4	H 234b). What are the symptoms/criteria which indicate that a person with IIH needs repeated lumbar puncture treatment	
	Q4	H 222e). What are the symptoms criteria that indicate invasive treatment is justified for headache in people with IIH	
	Q7	P 101). What symptoms/criteria indicate a person with IIH should be offered a shunt	
	Q3	H 183). What characteristics/symptoms/risk factors indicate for the use of serial lumbar puncture/shunts or venous stenting in people with IIH	
	Q3	H 186b). What are the criteria which indicate the need for invasive management of vision problems using CSF diversion	
	Q3	H 187). What are the criteria which indicate the need for invasive management of vision problems using CSF diversion versus continuation of medical treatment of	
	Q1	H 70). Is there a set of Neuro-imaging criteria to suggest certain patients will benefit from venous sinus stenting in addition to or instead of conventional means of	
	Q7	P 176). What are the symptoms/criteria which indicate that a person with IIH would benefit from having a shunt fitted	
	Q3	H 124a). What are visual criteria for CSF diversion surgery	
	Q3	H 140). What are visual criteria for CSF diversion surgery	
	Q4	130f). What is the safety and efficacy of ventriculoperitoneal shunts compared with lumbar peritoneal shunts for headache pain in people with IIH	
	Q4	P 165). What is the safety and efficacy of shunts for treatment of headache pain in people with IIH	
	Q4	H 174). What is the safety and efficacy of shunt insertion for treatment of headache only in people with IIH	
	Q4	H 182c). What is the safety and efficacy of CSF shunts for treatment of headache pain in people with IIH	
	Q4	H 234a). Does optic nerve sheath fenestration have any role in 2017	

Q4	H 264b). What is the comparable long term safety and efficacy of lumbar peritoneal shunts, ventriculoperitoneal shunts and optic nerve fenestration for treatment of
Q4	P 296). What is the safety and efficacy of shunts compared with other therapies for treating IIH headache without causing rebound headache
Q4	H 306a). What is the safety and efficacy of surgical intervention for treatment of headache in people with IIH and no vision problems
Q4	H 306b). What proportion of people with IIH who undergo surgical intervention continue to experience headache not related to raised ICP
Q4	P 311). What is the safety, reliability, efficacy and cost effectiveness of programmable shunts compared with standard shunts for people with IIH
Q4	H 349a). What is the safety and efficacy of CSF diversion therapies for headache in people with IIH
Q7	H 75). What is the safety and efficacy of shunt for people with IIH headache and vision stable
Q3	P 282). Are shunts indicated for use in improving non-vision outcomes of IIH
Q1	O 190d). Are cranial pressure measurements affected by the presence of shunt
Q4	H 53). What is the effectiveness of CSF diversion surgery on managing headache
Q3	F 102). What is the safety and efficacy of surgery for non-vision symptom of high CSF pressure
Q3	H 118b). What is the safety and efficacy of optic nerve sheath fenestration compared with lumbar peritoneal shunt for severe IIH
Q3	P 135). What is the safety and efficacy of shunts compared with standard treatment for non-vision outcomes in people with IIH
Q3	H 136). When should serial lumbar punctures, lumbar drains and other surgical techniques be used in the treatment pathway of a person with IIH
Q7	175b). What is the safety and efficacy of ventriculoperitoneal shunt compared with ventriculopleural shunt for treatment of IIH
Q7	P 302). What is the safety, tolerability and efficacy of lumbar peritoneal shunt valves for treatment of IIH
Q7	H 171a). What is the safety and efficacy of Lumbar peritoneal shunts compared with ventriculoperitoneal shunts for treatment of IIH
Q7	H 171b). What is the role of valves (particularly anti-gravity mechanisms) in the management of symptoms and ICP control
Q7	H 171c). What is the safety and efficacy of siphoning with LP shunts for treatment of IIH
Q7	H 171d). What is the role of cranial expansion procedures
Q7	H 172a). What is the role of shunts
Q7	H 175a). What is the safety and efficacy of Optic nerve fenestration with intensive weight loss management compared with shunts for treatment of IIH
Q7	H 349b). What is the safety and efficacy of stenting for people with IIH
Q7	H 351). What are the safety and efficacs of lumbar peritoneal shunts and ventriculoperitoneal shunts compared with each other and with no surgery for

N11. (J3?) What is the best IIH treatment in the atypical IIH patients (e.g. male, low BMI)?	P 33b). What are the best evidence based treatments/strategies for managing symptoms in people with IIH who are underweight	Known unknown
Q2	P 314). What are the best evidence based treatments for IIH in people who are not and have not formerly been overweight	
Q5	P 315). What is the safety and efficacy of successful weight loss for people with IIH who are not overweight	
Q5	P 155a). Can heavy lifting cause vision loss	
Q3	P 27). What is the efficacy of possible lifestyle changes for treatment of vision problems in IIH	
Q3	P 65b). What are the safety and efficacy of various vitamin supplements compared with each other and with no supplements for maintaining eye health in people with	
Q3	P 90). What is the effectiveness, safety and tolerability of natural, non-pharmaceutical and non-invasive interventions to reduce ICP compared with	
Q3	H 211c). What is the long term safety and efficacy of optic nerve sheath fenestration compared to standard treatment for vision outcomes in IIH	
Q3	H 263a). What are the relative efficacies of the available treatments for visual symptoms in IIH	
Q3	P 333). What are the best evidence based interventions for light sensitivity in vision for people with IIH	
Q3	O 13). Are long term treatments required for vision problems in IIH or are treatments usually short term	
Q3	P 60b). What actions can be taken to halt vision loss	
Q3	P 111). What improvements could be made to the general management of vision outcomes in IIH after diagnosis	
Q3	H 226). What are the best strategies for treatment of vision problems in IIH	
Q3	H 239). What are the best evidence based strategies for deciding treatment pathways for urgent/acute versus non-urgent cases of IIH	
Q3	H 243). What are the criteria/symptoms that indicate surgical intervention is required	
Q3	H 245). What are the criteria to indicate that optic nerve fenestration or ventriculoperitoneal shunt	
Q3	H 246b). What are the criteria to indicate that surgical approaches should be used	
Q3	H 298). What are the risk factors/symptoms that indicate optic nerve fenestration is necessary	
Q3	H 306a). When should surgery be considered	
Q3	H 332). What are the symptoms that indicate surgical intervention is required to treat vision problems in IIH	
Q3	H 344). What are the best evidence based strategies for improving vision outcomes in people with IIH	
Q3	H 196). What is the role of optic nerve sheath fenestration in management of vision in IIH	
Q3	H 330). What are the best strategies for treatment (in addition to weight loss) and monitoring of vision problems in IIH	
Q3	H 185). Should a lumbar drain be inserted whilst waiting for surgery	
Q3	P 18). What treatments are available for visual field defects and blurred vision and what are the safeties and efficacs of these treatments for IIH	
Q3	P 42). What are the best evidence based treatments for severe vision loss in IIH	
Q3		

Q3	P 43c). What are the best evidence based treatments for person with IIH related vision problems with no optic nerve swelling	
Q3	P 43d). What are the best evidence based treatments for vision loss in people with IIH who have been shunted	
Q3	P 46). What are the best evidenced based treatments for vision loss in IIH	
Q3	P 91). What is the long term effectiveness of interventions for vision loss in IIH	
Q3	H 180a). What are the best evidence based treatments for vision problems in IIH	
Q3	H 204b). What is the safety and efficacy of optic nerve fenestration compared with standard treatment for vision problems in IIH	
Q3	H 205). What are the relative efficacies of the available vision sparing treatments in IIH	
Q3	H 206). What are the safety and efficacies of alternative treatment options to optic nerve fenestration for vision problems in IIH	
Q3	H 217). What is the the best evidenced based intervention for treating vision problems in IIH	
Q3	H 223a). What is the best evidence based treatment for vision problems in IIH	
Q3	H 223b). What are the best treatment options if Diamox and weight loss fail in the treatment of vision problems in IIH	
Q3	H 351). What are the relative safety and efficacies of medications, shunts, optic nerve sheath fenestration and venous sinus stenting for managing vision in people	
Q3	H 353b). What are the safety and efficacies of successful weight loss strategies inc. bariatric surgery, shunting, therapeutic lumbar puncture and medical therapy for	
Q3	H 71a). Under what circumstances should people with IIH be considered for shunts	
Q3	H 72). What is the effectiveness of nerve sheath fenestration for vision loss in people with IIH	
Q3	H 124b). What is the safety and efficacy of optic nerve sheath fenestration compared with lumbar peritoneal or ventriculoperitoneal shunt for vision problems	
Q3	H 130d). What is the short and long term efficacy and safety of optic nerve sheath fenestration for people with IIH	
Q3	H 142). What is the effectiveness of shunts compared with optic nerve sheath fenestration for treatment of vision problems in IIH	
Q3	H 171c). What is the efficacy of fenestration when used at earlier and later stages of the treatment pathway	
Q3	H 172). What is the efficacy of optic nerve fenestration/decompression compared with alternative treatment options for treating worsening vision in IIH	
Q3	H 174). What are the comparable efficacies of ventriculoperitoneal and lumbar peritoneal shunts and optic nerve sheath fenestration for visual outcomes in IIH	
Q3	H 182b). What is the comparable effectiveness of available surgical techniques for treatment of vision outcomes in fulminant IIH	
Q3	O 190b). What is the effectiveness and safety of bariatric surgery compared with lumbar puncture or venous stenosis procedures for treatment of vision problems in	
Q3	O 190e). What is the safety and efficacy of venous sinus stenosis and when should they be used	
Q3	H 215). What is the safety and efficacy of optic nerve sheath fenestration for vision outcomes in people with IIH	
Q3	H 220). What is the safety and efficacy of venous stenting for treatment of vision problems in IIH	
Q3	H 221c). What are the relative safeties and efficacies of the available surgical interventions for treatment of progressive vision loss in IIH	
Q3	H 229). What are the best evidence based criteria for determining when surgical intervention is necessary to preserve/restore vision	
Q3	H 234a). What is the safety and efficacy of optic nerve sheath fenestration for vision problems in IIH	
Q3	H 248a). What is the safety and efficacy of shunting for treatment of vision problems in people with IIH	
Q3	H 255). What are the characteristics/symptoms/risk factors of the people with IIH for whom venous sinus stenting is indicated	
Q3	H 264b). What are the relative efficacies and safeties of lumbar peritoneal shunt and ventriculoperitoneal shunt and optic nerve fenestration for vision problems in IIH	
Q3	H 306b). What are the relative efficacies of optic nerve sheath fenestration, ventriculoperitoneal shunt and lumbar peritoneal shunt for vision problems in IIH	
Q3	P 345). What is the safety and efficacy of delayed shunting with period for weightloss before surgery compared with shunting as soon as vision is deemed to be	
Q3	H 354). What is the effectiveness of venous stenting for vision problems in IIH	
Q7	P 55). What is the safety and efficacy of spinal shunts for protection of vision in people with IIH, do the risks outweigh the benefits	
Q3	H 353a). What is the safety and efficacy of optic nerve fenestration for treatment of vision problems in IIH	
Q3	H 70). What is the effectiveness of using imaging criteria to determine treatment with venous sinus stenting in addition to conventional therapy compared or	
Q3	P 30b). What is the efficacy of spectacles for correction of vision problems in IIH	
Q3	P 138). What is the efficacy of spectacles for treatment of vision problems in IIH	

N12. (combined with L3 in part) Do the benefits of the drug treatments for IIH outweigh the side effects?		
Q5	P 72). Should all individuals be counselled regarding weight loss despite their starting BMI	Known unknown
Q4	H 204a). What is the safety (in terms of medication overuse outcomes), efficacy and optimum dose of acetazolamide for chronic treatment of raised intracranial pressure	
Q4	H 264a). Do any of the diurectic treatments have a proven protective effect for people with IIH	
Q4	H 347b). Do any of the available treatments target the specific cause behind IIH headache	
Q5	P 30a). Does Diamox cause weight gain	
Q5	P 269b). Does Diamox cause weight gain	
Q5	H 261b). What other interventions, alongside weight loss, are efficacious in relieving symptoms and/or improving prognosis	
Q6	p 68). What are the alternative disease modifying treatments apart from weight loss	
Q2	P 269). What is the safety and efficacy of Octreotide for treatment of IIH	
Q3	P 272). Is blurry vision a known side effect of acetazolamide and can this be managed	
Q7	P 163). What are the best treatments/strategies to reduce the frequency of surgeries required manage symptoms of IIH	

	H 184d). does medication overuse exacerbate IIH?		
Q4	H 184e). Does medication overuse reduce the effectiveness of drugs used to treat headache in people with IIH		
Q4	P 60b). Are standard medications for IIH effective at managing raised CSF pressure		
Q2	P103a). What are the long term safety profiles, particularly in terms higher risk of miscarriage, of the current standard medications and are they tolerable for this		
Q1	P 3). What are the relative safety and efficacies of available treatments for cranial nerve palsy caused by IIH		
Q3	5b). Which current drugs are best to treat IIH		
Q3	P 21). What is the safety, efficacy and tolerability of delayed treatment with Diamox compared with early treatment with Diamox		
Q3	P 23). What is the safety and efficacy of treatments targeting reduction in production of CSF for vision outcomes compared with migraine/seizure medications		
Q3	H 133). What is the safety and efficacy of steroids for treatment of vision problems in IIH		
Q3	H 141). What is the efficacy of current medications for treating vision problems in IIH, are they more effective for some people than others		
Q3	H 184). What is the effectiveness of standard medications for treatment of vision loss and for preventing need for shunting in people with IIH		
Q3	P 194). What are the safety, efficacy and tolerability of treatment alternatives to lumbar puncture for treatment of vision in IIH		
Q3	H 218b). What is the maximum therapeutic dose of acetazolamide that should be given to treat vision problems in people with IIH		
Q3	H 218c). What are the safety and efficacies of medications other than diamox for treating vision problems in IIH		
Q3	H 222c). What are the guideline doses of acetazolamide/topiramate for treatment of vision problems in IIH		
Q3	H 225). What is the safety and efficacy of steroids for treatment of vision problems in IIH		
Q3	H 234c). What is the safety and efficacy of corticosteroid treatment for vision problems in IIH		
Q3	P 237). What are the relative safety and efficacies of the available medications for treatment of vision problems in IIH		
Q3	H 248b). What is the safety and efficacy of acetazolamide for treatment of vision problems in people with IIH		
Q3	H 264a). What is the safety and efficacy of diuretics for protection of vision in people of IIH		
Q3	P 288). What are the relative efficacies of all available treatments for vision problems in IIH		
Q3	H 304). What are the relative efficacies of the available treatments for preservation of vision in people with IIH		
Q3	H 316). What are the best evidence based treatments for management of vision problems in IIH		
Q3	P 319). What are the efficacies of the standard treatments for vision problems in IIH, are they inadequate		
Q3	O 320a). What are the relative efficacies of the available treatments for vision problems in IIH		
Q3	H 191). What are the comparable safeties and efficacies of standard medications for treatment of vision problems, shunts and venous stenting for people with IIH		
Q4	P 311). Is there any medication that effectively reduces intracranial pressure		
Q4	H 344). How effective are current treatment strategies for people with IIH		
Q7	P 79). What is the most effective treatment for tinnitus caused by IIH		
Q4	P 85). Which medications are safe and effective to use for people with IIH		
Q5	P 37b). Do the medications prescribed for symptom control in IIH contribute to weight gain		
Q5	P 163). What is the safety, tolerability and efficacy, particularly in terms of quality of life (side effects) of medical management of IIH and do the medications make		
Q5	P 309a). Do the medications used to treat pain and other IIH symptoms cause weight gain		
Q7	P 33a). What is the safety and tolerability issues with long term treatment of IIH with Diamox		
Q7	P 93). What is the tolerability of side effects of medications for IIH compared with the symptoms of the disease itself		
Q7	P 97b). What are the long term effects of daily acetazolamide		
Q7	H 121d). What are the best evidence based treatments for IIH		
Q7	H 188). What is the safety and efficacy of using hormonal contraceptives or hormone replacement therapy for people with well managed IIH		
Q7	H 249). What are the best evidence based treatments for IIH		
Q7	H 257a). What are the best evidence based treatment options for raised CSF pressure in IIH		
Q7	H 285). What are the current best treatment options and do they need to be improved upon		

N13. What is the economic impact of IIH and its treatment in the UK?		H 184a). What is the cost of treating people with IIH in the UK	Known unknown
	Q7	H 205). What is the economic impact of IIH and its treatment in the UK	
	Q6		

N14. Is adequate social care provided for people with IIH?		F 82). Is adequate social care provided for people with IIH	Known unknown
	Q7		

N15. How can employers support individuals with IIH?		P 319). How can employers support individuals with IIH?	Known unknown
	Q6		

Formed question	Contributing uncertainties	Certainty	Reference
Q1. (combined with Q3, Q5) Can novel therapies for IIH be developed which are effective, safe, and tolerable and potentially help with weight loss as well as reducing brain pressure?	Q3	P 44c). Are further drugs in development for treatment of papilloedema	Known unknown
	Q3	P 42b). Can further treatments be developed to restore or slow severe cases of vision loss in IIH	
	Q6	P 48b). What are the alternatives to diamox to treat IIH	
	Q6	P 176a). What are the alternatives to diamox to treat IIH	
	Q2	P 60c). What are the safety and efficacy ratings of available preventative treatments	
	Q1	P 103b). Are there new therapeutic drugs with more favourable safety profiles in development	
	Q3	P 108). What research is ongoing into developing medications to treat IIH which have fewer/more tolerable side effects	
	Q5	P 309b). Are alternatives treatments for IIH in development which have more tolerable side effect profiles and do not cause weight gain	
	Q7	P 28a). Are new drugs in development that target IIH symptoms/cure and have fewer side effects	
	Q7	P 122). Are there any alternative treatment options to acetazolamide in development which will have more tolerable side effects	
	Q7	P 326b). Are there more tolerable alternative medications to acetazolamide	
	Q3	P 96b). What research is ongoing into developing medications to treat intracranial hypertension in people with IIH	
	Q6	H 263b). What new treatments are in development	
	Q7	H 187). Are there any experimental treatments currently being trialled for use in IIH	
	Q7	P 291). What new research is occurring into IIH and its treatment	
	Q7	P 328). Are studies needed to investigate interventions for people with IIH without papilloedema	
	Q7	P 274). Is there as need for further clinical trials to assess the treatment options for people with IIH	
	Q6	O 320). What are the best evidence based non-medical interventions for treatment of IIH	
	Q7	P 40). What is the safety and efficacy of holistic/complimentary therapies for treatment of IIH	

Q1. Would a national venous stent registry be useful to monitor outcomes and improve patient care?	Q5	H 178b). Should we have a national registry of stenting with outcomes.	Known unknown
	Q1	H 129). What is the safety and efficacy of venous stenting compared with other treatments for IIH	
	Q7	P 323a). How often do stents fail	
	Q7	H 349a). What is the safety and efficacy of lumbar peritoneal shunts compared with ventriculoperitoneal shunts for treatment of people with IIH	
	Q7		

Out of scope submissions					
12	12a). Are there any painful procedures involved?	Q1	H 12a).	Health or Social Care Professional	Out of scope
	P 43b). What are the best available evidence based diagnostic criteria for IIH	Q1	International out of scope	Person with IIH	
	44c). Why was my diagnosing lumbar (2 years later with papilloedema) undertaken by a junior doctor who had never	Q1	??	Person with IIH	
53	How do we decide if headaches are due to recurrence of IIH in someone previously treated with old optic nerve changes	Q1	H 53). What is the best evidence based test/set of criteria to determine whether headache is due to IIH recurrence in	Health or Social Care Professional	
82	Is adult IIH the same as paediatric IIH?	Q1	F	Friend/family member of someone with IIH	paediatric IIH
	163b). Also, why do people like myself, get funneled into certain areas that except and acknowledge our disease. Why are	Q1	P 163b). (Outside of UK) issue specific to country outside of UK	Person with IIH	
	163c). Why can't insurance companies cover our medical care more for people with IIH, and all the many tests and medications needed.	Q1	P 163c). (Outside of UK) issue specific to country outside of UK	Person with IIH	
181	181) What proportion of diagnostic lumbar punctures are carried out in A&E setting	Q1	Not research question	Health or Social Care Professional	Out of scope
209	In children - Diagnosing papilloedema/Drusen is now fraught. People seem to have lost the skill to measure opening pressure - sedation,	Q1	H	Health or Social Care Professional	paediatric IIH
	211d). Is IIH more of a syndrome than specific diagnosis? There seem to be different clinical groups, whose papilloedema and	Q1	H 211d). Suggestion: Should IIH be classified as a syndrome	Health or Social Care Professional	Aetiology
	why do you need a lumbar puncture	Q1	including lumbar puncture compared with standard testing without lumbar puncture/does patient require understanding	Person with IIH	Diagnostic test accuracy
237	How frequently does someone have to have high levels of csf for IIH for the condition to be named chronic	Q1	P	Person with IIH	
268	Can it be a rule that all patients with scoliosis have the spinal tap done under fluoroscopy? I had four failed attempts the first time	Q1	P 284). Scoliosis issue not IIH issue	Person with IIH	OUT OF SCOPE
284	Does normal high blood pressure cause iih diagnose or only lumbar puncture	Q1		Person with IIH	
287	302a). I am no the normal case. I was diagnosed as a child and not overweight. Is there a way to get get the the diagnosis to include the	Q1	P 302a). Do diagnostic criteria extend to those who are not overweight but have IIH (paediatric IIH out of scope)	Person with IIH	paediatric IIH?
302	1b). Is there a difference between adult and paediatric IIH?	Q2		Carer/former carer of someone with IIH	paediatric IIH
33	33a). I've been told overweight menopausal women get it but I got it when I was 13, I'm now 31, still have it and have a bmi of 17! I	Q2	P 33). What causes IIH in the underweight population (paediatric IIH at onset)	Person with IIH	
40	I understand that there is no definitive cause but strongly feel that some indepth research needs to be done into patients full medical	Q2	P 40). What causes IIH???	Person with IIH	Aetiology
64	None, youre going to tell us soon that its DHT, and I believe it!	Q2		Health or Social Care Professional	
66	Why are we single out by our weight as slim gym or fat club get it then others don't?	Q2	P questions unclear	Person with IIH	
105	Chemicals in the food and water some of his hereditary some of his the medicines that the government gives you so government-related	Q2		Person with IIH	
109	How relevant is weight in cases of sudden onset iih due to taking deoxycyclin after its expiration date	Q2	P 109). What is the safety and efficacy of weight loss for treatment of sudden onset IIH caused by	Person with IIH	
	114b). Why is it not a disability ?	Q2	P 114b). Should IIH be classed as a disability	Person with IIH	management of diseases and conditions
	146e). Would greater investigation into the cause of an individuals IIH improve disease outcomes	Q2	P 146e). Not a research question	Person with IIH	
	285c). other med hx links?	Q2	H 285c).	Health or Social Care Professional	OUT OF SCOPE
295	It's idiopathic so I understanding there's no cause	Q2		Person with IIH	
	317a). After what period do people with IIH become symptomatic	Q3	P Unanswerable	Person with IIH	
	349b). why do some children who are not obese get it?	Q2	H 349b).	Person with IIH	
41	Can optic discs be damaged to a point they wont swell anymore and even ophthamologists won't be able to tell?	Q3	Person with IIH	Person with IIH	
56	With not having pap I feel my 3 month check ups are sufficient.	Q3	Person with IIH	Person with IIH	
64	Lots.... Encourage baseline estimations, inform about USS, recommend CSF	Q3	H 64). UNCLEAR	Health or Social Care Professional	
	67b). My opticans offer me eye check ups for free, so long as I've paid for one a year. I suspect they only do tho because they are	Q3	P 67b). What is the effectiveness of a scheme to subsidise visits to opticians for people with IIH on improving vision outcomes	Person with IIH	
94	I've lost some of my peripheral vision in my left eye that I know of I'm not sure Bout my right eye though. Nobody actually tells me	Q3	P 94).	Person with IIH	
	P 101b). can we get money off eyes tests and glasses.	Q3	P 101b).	Person with IIH	
105	Not all of them have problems with their Vision I am one that don't have problems with my vision so you can't category IH around vision	Q3	Person with IIH	Person with IIH	
116	Never seen anybody about my sight only optician	Q3	Person with IIH	Person with IIH	
	118a). What is the best visual outcome measure to use in clinical trials of IIH?	Q3	H 118a). Do guideline exist for the visual outcome measures that should be included in clincial trials		
122	None, both the Hospital and my optician do regular checks for any deterioration.	Q3	Person with IIH	Person with IIH	
153	My vision management has been good as this is my only 'big' symptom as I do not get headaches.	Q3	Person with IIH	Person with IIH	
	190c). clincila experinece is that once they lose weight - they never lose vision - but if weight creeps back up then vision is affected	Q3	successful and maintained weight loss in treatment of vision outcomes for IIH	Other	
	190a). Outcome of IIH- DT	Q3	Q 190). What is the outcome of the IIH:DT (drug trial)		

192	I would defer to an ophthalmologist	Q3	Health or Social Care Professional	Health or Social Care Professional	
	216c). Shouldn't neurology specialist nurses be trained to perform Goldman's field?	Q3	H 216c). Should neurology nurse specialists be trained to perform goldmans field test		
224	The organisation of a careful diagnostic and follow up with an experienced neuroophthalmologist	Q3	Health or Social Care Professional	Health or Social Care Professional	
271	How far does it have to go before something else happens	Q3	P 271). Unclear	Person with IiH	
278	Why isn't visionary tests managed more ? Seems along wait between?	Q3	P	Person with IiH	
291	Can someone with IiH have more than 1eye check up a year on NHS?	Q3	P 291). How frequently will NHS fund eye check ups for people with IiH	Person with IiH	
292	I don't have a question. I'm completely blind from IiH because no one diagnosed me for 20 years. I suffered for 20 years and now I'm	Q3	P 292).	Person with IiH	
296	I have no questions regarding this... the Southern General and now Queen Elizabeth in Glasgow were very helpful and explained their	Q3	Person with IiH	Person with IiH	
302	My family and I have been very careful to protect my vision but that has meant lots of medication and many surgeries with my LP Shunt.	Q3	Person with IiH	Person with IiH	
305	No - I've had amazing support from Basingstoke and North Hants hospital.	Q3	Person with IiH	Person with IiH	
307	None, we have great management in this area with regular checks and visual field tests	Q3	Carer/former carer of someone with IiH	Carer/former carer of someone with IiH	
323	Will it be likely that IiH patients can get financial help towards glasses due to the changes in vision. At present it is not exempt	Q3	P 323). What financial support is available for corrective eyewear required due to changes in vision caused by IiH	Person with IiH	
340	I'd like to see free eye checks with opticians as happens for those with glaucoma	Q3	P 340). Should people with IiH receive free appointments with opticians to monitor vision	Person with IiH	
37	How to access pain medication for headache?	Q4	P 37). How can pain medications be accessed by people with IiH	Person with IiH	
41	41a). Does smoking help	Q4	P 41a). Out of scope due to safety issue with recommending smoking	Person with IiH	
72	I have mainly found my own way to deal with headaches.I have IiH and Chiari.I have had IiH for 18 years diagnosed (22 years since first	Q4	P 72	Person with IiH	
81	Why are god trained in how to treat until a neurologist can be seen?	Q4	Person with IiH	Person with IiH	
83	Never get headaches! More research in to us atypical types please.	Q4	Person with IiH	Person with IiH	
95	How do you cope when you have a migraine as the medication don't always seem to work?? What other methods are there?	Q4	O Migraine	Other	
98	how is this maintain do we get help and support from nurses surgeons doctors etc	Q4	P Unclear	Person with IiH	
105	don't ever tell your patience they have to deal with the headache cuz I'll never get rid of it	Q4	P Unclear	Person with IiH	
121	What is the biological explanation for the effective reduction of CSF pressure with therapeutic lumbar puncture and the ensuing	Q4		Health or Social Care Professional	
150	My wife has never suffered with headaches only papilledema	Q4	Friend/family member of someone with IiH	Friend/family member of someone with IiH	
151	Can other things be offered other than tablets, injections etc?	Q4	P 151). Unclear	Person with IiH	
153	I do not get headaches	Q4	Person with IiH	Person with IiH	
176	I have serious headaches all the time and am extremely noise sensitive, which in turn causes anxiety. I wake up with a headache	Q4	P unclear	Person with IiH	
209	209b). In children especially - is the IiH headache really different and what about the ones who have NO headache - is this still IiH?	Q4	H 209b).	Health or Social Care Professional	Paediatric IiH out of scope
	211a). What is the biological explanation for the prolonged symptom relief resulting from a single lumbar puncture in some	Q4		Health or Social Care Professional	
	220b). What is the biological explanation for the extended (days or weeks long) period of symptom relief from single lumbar puncture	Q4		Health or Social Care Professional	
	222f). Is venous sinus stenosis really a thing?	Q4	H 222f). Is venous sinus stenosis really a thing?	Health or Social Care Professional	
242	Trials in Headache management in IiH need to be established.	Q4	H 242).	Health or Social Care Professional	of Treatments and
244	None, my consultant made me keep a headache diary for six months which detailed everything I eat, drank, how long I slept, what meds I	Q4	Person with IiH	Person with IiH	
250	None (don't think headache is that interesting- the harm comes from the visual problems)	Q4	Health or Social Care Professional	Health or Social Care Professional	
	257b). Comparative trials	Q4	H 257b).	Health or Social Care Professional	
281	In my case I'm just thrown a new load of meds each time	Q4	Person with IiH	Person with IiH	
17	Awaiting results of the weightloss trial.	Q5	Person with IiH	Person with IiH	
	18b). Also i think vouchers for free support for weightloss clubs.	Q5	P 18b). Should people with IiH receive help with the cost of weight loss support groups	Person with IiH	
26	Very little - I have access to a dietitian if I want to	Q5	Person with IiH	Person with IiH	
31	Refer to a dietician or nutritionist would of been helpful to design something that could of worked instead of saying you will do it all	Q5	P NOT Idiopathic?	Person with IiH	
33	None, in my opinion people use iih as a reason for their increased weight when realistically it's the other way around	Q5	Person with IiH	Person with IiH	
47	If it about weight why is children who is normal weight diagnosed	Q5	Paediatric	Person with IiH	
60	What are the issues with weight management?	Q5	P 60). What are the issues with weight management? Unclear	Person with IiH	

72	I wasn't overweight when diagnosed.	Q5	Person with IIH	Person with IIH	
78	Why does this not really seem to effect anything iih related?	Q5	P 78). Unclear meaning	Person with IIH	
79	I wasn't aware of any weight issues with IIH	Q5	Person with IIH	Person with IIH	
83	Weight loss support is fantastic. Seems to be the sickest that moan that weight isn't an issue and don't do anything to try	Q5	P 83).	Person with IIH	
105	It has nothing to do with weight	Q5	Person with IIH	Person with IIH	
112	Current theory	Q5	Person with IIH	Person with IIH	
116	Am not obese	Q5	Person with IIH	Person with IIH	
145b)	And if you say it's my weight, how does a little girl of 3, petite build get IIH then? And how will she get into remission?	Q5	145b). Paediatric IIH	Person with IIH	
153	I am not overweight	Q5	Person with IIH	Person with IIH	
159	Is it normal to gain and lose up to 15lbs easily over and over again? I will gain and then lose the same weight over and over again with	Q5	Person with IIH	Person with IIH	
181	None, I hope this will be answered by ongoing research	Q5	Health or Social Care Professional	Health or Social Care Professional	
306b).	Should all patients be offered a place on a weight loss programme subsidised by NHS?	Q5	H 306b). Should people with IIH receive help with the cost of weight loss support groups	Health or Social Care Professional	
13	Easy way to monitor and diagnose these changes	Q6	Q ??	Other	
60	No questions, I have received excellent care from neurologist and eye hospital.	Q6	Person with IIH	Person with IIH	
86	Consultants, Drs and staff on wards don't always believe it's IIH wen admitted and say migraines why? Why aren't all drs, consultants etc	Q6	P 86). How can clinical commissioning groups prioritise funding for treatment for IIH	Person with IIH	
153	As the condition as far as we know does not reduce life expectancy or cause serious health problems (providing you keep on top of the patient's should have a "care booklet" stating their operations, pressures, last visual assessment (inc charts) and meds which they	Q6	Person with IIH	Person with IIH	
169	199b). are there quality outcome measures?	Q6	H 169). Can patient management of medical records improve care	Health or Social Care Professional	
209	IIH children are largely forgotten - cover is patchy and there is lack of pathways	Q6	H 199b). Is there a set of validated outcome measures for use in clinical trials involving people with IIH	Health or Social Care Professional	
243	are there specialist centres in Scotland	Q6	Paediatric IIH	Health or Social Care Professional	
269	Where's the support? I live in a rural area alone. I'd bet my last quid if I blacked out nobody would notice.	Q6	Health or Social Care Professional	Health or Social Care Professional	
272	I would like to know why I seem to get lost in the system? I seem to be ok with the optomologist, but never seem to get follow up	Q6	P 269). Do people with IIH living in rural areas need more support than they currently receive	Person with IIH	
284	Could you do world wide teaching of neurologists to keep them up to date on the research? I have learned more about IIH from the UK	Q6	P 272).	Person with IIH	
287	Go no knowledge even consultant at hospital directed me to website!	Q6	Person with IIH	Person with IIH	
295	Can't comment. My go perscribes drugs that's it.	Q6	Person with IIH	Person with IIH	
319	How can my employer support me?	Q6	Person with IIH	Person with IIH	
11	1b). More needs to be done for social care for IIH patients. IIH is often a debilitating illness which means many women with young Chronic IIH?	Q7	C 1b). What role is there for social services in the care of individuals with IIH and their dependents?	Carer/former carer of someone with IIH	
13	Can one have IIH with raised intracranial pressure	Q7	?	Health or Social Care Professional	
18	I would like more resurch into side effects and information on them like dysphasia and smelling unusual things tittness etc	Q7	Drug side effects or IIH symptoms?	Other	
27	Can you claim pip and esa	Q7	To do with disease classification?	Person with IIH	
35	31b). I think they should investigate how it is all connected. The BP being high for example could just be because of anxiety or pain. It is IIH classed as a disability and should it be?	Q7	P 31b).	Person with IIH	
43a).	Do IIH patients require a medic alert bracelet?	Q7	To do with disease classification?	Person with IIH	
48	Does iih fall into dla or pip assessment criteria	Q7	P 43a). What is the safety, efficacy and cost effectiveness of medic alert bracelets for people with IIH	Person with IIH	
49	Will I have this pain till I die?	Q7	To do with disease classification?	Person with IIH	
117	Why cant we have the equivalent to a my plan. Where all concerned puts in reports that we can keep to show benefits or	Q7	P 49).	Person with IIH	
126	Can I be sent your research results and any info you uncover? Please. (email address provided)	Q7	Person with IIH	Person with IIH	
130	Can we get any assurance for the consistent availability of slow release Acetazolamide?	Q7	Person with IIH	Person with IIH	
132	Why us it so u recognised	Q7	H 130).	Health or Social Care Professional	
169	I have been trying to start a project on cognitive function in IIH for some time and the effect of shunting. I have a study design but	Q7	Person with IIH	Person with IIH	
190	190a). young women who are obese have a significant body image issue and are very emotive about it -	Q7	Health or Social Care Professional	Health or Social Care Professional	
		Q7	Q 190a). What	Other	

209	This is a good initiative to bring professionals together to comment and think about research questions and pathways of care.	Q7	H 209).	Health or Social Care Professional	
211	Think that covers it for now.....longer than 5 minutes.	Q7	Health or Social Care Professional	Health or Social Care Professional	
216	I believe that as Neurologist we don't get prompt and adequate support from ophthalmology.	Q7	H 216).	Health or Social Care Professional	
220	Does IIH vary in prevalence across the world? Does it have an ethnic variation?	Q7	~UK focus only	Health or Social Care Professional	
224	Better organisations of IIH research and treatment are needed so few national highly specialized centers can be recommended	Q7	H 224).	Health or Social Care Professional	
227	Ophthalmologists are in general not very good at it, why is that??	Q7	Health or Social Care Professional	Health or Social Care Professional	
232	What is the reason for sustained improvements in symptoms following therapeutic lumbar puncture	Q7		Health or Social Care Professional	
233	It might be sensible to discuss about terms and abbreviations, as intracranial hypertension and hypotension might get confused...	Q7	Health or Social Care Professional	Health or Social Care Professional	
281	It's a real health issue that shouldn't be taken for granted	Q7	Person with IIH	Person with IIH	
286	What research can be done for patients who respond positively to lumbar punctures and other tests/procedures e.g. ct venogram, so	Q7	P 286).	Person with IIH	
299	What do you do when your doctor tells you they can't lower your pressure where it needs to be? Have a LP Shunt with a button	Q7	and a lumbar peritoneal shunt that is failing to manage CSF pressure	Person with IIH	
319	Can I claim working disability as this does affect my working day?	Q7	Person with IIH	Person with IIH	
340	Yes the issues with diamox not always being available in SR due to manufacturing issues - like now we are struggling with the generic	Q7	Meds unavailable	Person with IIH	
348	Several studies have shown that intra abdominal pressure causes slower plural filling pressure and therefore cause raised intracranial	Q7	P 345). Could intra abdominal pressure be used as a therapeutic target or diagnostic indicator	Person with IIH	
348	Why is not enough allowance made by other medical bodies. No allowance is made for your condition, if you miss an	Q7	P 348). How should lack of attendance at hospital appointments due to illness be managed for IIH patients	Person with IIH	