

Supplementary Table: Questions included in the adult growth hormone deficiency (AGHD) survey (Form C)

1. How many pituitary patients did you follow on average annually, in your centre between 1/01/2017 and 31/12/18?
2. How many pituitary surgeries were performed on average annually, in your centre between 1/01/2017 and 31/12/18?
3. How many pituitary patients underwent radiotherapy on average annually, in your centre between 1/01/2017 and 31/12/18?
4. How many of your AGHD patients, fell into the following categories between 1/01/2017 and 31/12/18? Categories: Not treated with GH, GH therapy started, GH therapy started before 2017, GH therapy started after 01/01/2017, GH therapy interrupted before 31 Dec 2018
5. How many of your AGHD patients fell into the following gender categories? Categories: Male, female, unspecified, not answered
6. Of all your patients diagnosed with GHD, how many fell into the following categories? Categories <18 years, 18-25 years old, 26-45 years old, 46-65 years old, >65 years old
7. How many of your total AGHD patients fell into the following categories of age when treatment was initiated? Categories <18 years, 18-25 years old, 26-45 years old, 46-65 years old, >65 years old
8. How many of the listed adverse events leading to treatment interruption did you record in your patient cohort? Options: arthromyalgia, fluid retention/oedema, tumour recurrence, new cancer, headache, hyperglycaemia, other, none
9. In how many of your patients were the following a cause of GH treatment interruption? Categories: death, lack of perceived positive effect by patient, lack of compliance, administrative reasons, adverse event, other, none.
10. How many of the following GHD causes did you identify in your cohort of patients? Categories: non-functioning pituitary adenoma, Cushing's disease, prolactinoma, treated acromegaly, craniopharyngioma, other pituitary mass lesions (including cysts, inflammatory, etc.), vascular causes (Sheehan syndrome, apoplexy, etc.), idiopathic isolated GHD, genetic/congenital/mid-line malformations, traumatic brain Injury, cranial irradiation due to another malignant disease, other, not known, not answered.
11. How many other pituitary hormone deficiencies were identified in your patient cohort? Categories: TSH, ACTH, LH/FSH, ADH, Prolactin, none.
12. In how many of your patients, did you evaluate QoL with any of the following questionnaires? Categories: AGHDA, QLS-H, SF-36, EQ-5D, other, none.
13. If any of your AGHD patients were CO-AGHD, how many were referred to you as adults, for treatment with GH, for the reasons listed below? Categories: direct patient enquiry, referred from paediatrician/another practitioner, other, not known, not answered.
14. Of those CO-AGHD patients transferred from a paediatrician, how many interrupted GH treatment, for the following

time interval? Categories: <3 months, 3-6 months, 7-12 months, 13-24 months, >24 months, GH therapy was not interrupted, not known, not answered.

15. Of the CO-GHD patients who interrupted treatment during transition from paediatric to adult care, how many did so for the following reasons? Categories: poor patient compliance to GH therapy, GH therapy not reimbursed/other administrative issues, difficulty in referral to adult clinic, patient electing to stop treatment, discharge of patient by paediatric consultant, GH therapy was not interrupted, not known, not answered.
16. In your local setting, at what age are CO-GHD patients transitioned to adult care? Options: 14-18 years old, >18 years old.
17. In how many of your patients prior to first treatment did you perform any of the following GH stimulation tests? Categories: ITT, Glucagon, GHRH + arginine, GHRH alone, others, did not perform any stimulation test, not known, not answered.
18. How many patients underwent a pituitary MRI? Categories: Yes, No, not known, not answered.
19. Do you require IGF-I to be low to initiate GH therapy? Options: Yes, No, other (specify)
20. Do you still perform a GH stimulation test when the rest of endocrine axis is normal? Options: Yes, No, other (specify)
21. In the presence of 3 or more other pituitary deficiencies and low serum IGF-I, do you perform a GH stimulation test? Options: Yes, No, other (specify)
22. Which of the following alternative stimulation tests would you use for these patient groups (Older age, obesity, prior cranial irradiation, epilepsy, ischemic heart disease, lack of diagnostic product)? Options (click all that apply): Insulin tolerance test (ITT), Glucagon, Insulin tolerance test (ITT), GHRH + arginine, GHRH alone
23. In your local setting, which of the following cut off values do you use to indicate GH therapy after a GH stimulation test? Options: Please tick all that apply. <3 mcg/L for ITT + Glucagon, <5 mcg/L for ITT + Glucagon, when BMI <25 kg/m<sup>2</sup>, a peak GH <11 mcg/L for Arginine + GHRH, when BMI 25-30 kg/m<sup>2</sup>, a peak GH <8 mcg/L for Arginine + GHRH, when BMI >30 kg/m<sup>2</sup>, a peak GH <4 mcg/L for Arginine + GHRH, other (please specify)
24. What other criteria are required, in your local setting, before initiating GH therapy? Please tick all that apply. Options: impaired QoL, severe fatigability, central obesity, age <65 years, patient compliance, other (please specify)
25. In how many of your patients did the following additional criteria prevent you from initiating GH treatment? Categories: age over 65 years, compliance considerations, administrative reasons (i.e. lack of reimbursement), concomitant diabetes mellitus, persistent, stable pituitary tumour rests, other, none.
26. What initial dose regime did you select for the following patients (male, female, unspecified)? Options: 0.1mg/day, 0.2mg/day, 0.3mg/day, 0.4mg/day, 0.5-0.74mg/day, 0.75-1mg/day, >1mg/day, not known, not answered.
27. In how many of your patients did you recommend administering their GH at the following times of day? Categories:

Morning, lunchtime, evening/bedtime, anytime, not known, not answered.

28. In how many of your patients did you consider the following? Categories: A switch to transdermal or transvaginal route for a female on oral oestrogens, Increased monitoring for patients >65 years old, check free T4 when taking thyroxin replacement therapy, Increasing hydrocortisone replacement dose, other, none.
29. What initial dose regime do you usually select for the following patients (male/female in <18 years, 18-25 year, 26-45 years, 46-65 years, >65)? Indicate in mg/day. Options: 0.1mg/day, 0.2mg/day, 0.3mg/day, 0.4mg/day, 0.5-0.74mg/day, 0.75-1mg/day, >1mg/day, not known, not answered.
30. What IGF-I range levels do you aim to achieve with GH for your patients? Options: Within the normal range, A high-normal range, A mid-normal range, A low-normal range, not known, not answered.
31. Once a stable dose is reached, how many of your patients were followed, at the following times intervals? Categories: every 3 months, every 6 months, every 12 months, less frequently, not known, not answered
32. In how many of your AGHD patients did you evaluate the following measurements or investigations? Categories: weight, waist circumference, blood pressure, BMI, body fat, BMD, IGF-I, HDL, LDL, total cholesterol, HbA1c, other, none.
33. In how many of your patients did you monitor the following indicators? Categories: energy level, partner satisfaction, number of sick day leave, overall wellbeing, none.
34. Under the specific scenarios listed, how long after starting GH therapy would you perform a follow-up MRI (patients with residual tumours/patients without residual tumours)? Options: <6 months, 6-12 months, >12 months, other (specify)
35. How satisfied are you with the overall quality of AGHD patient treatment in your local setting? Options: very satisfied, satisfied, neither satisfied/dissatisfied, dissatisfied, very dissatisfied
36. How satisfied are you with the extent and quality of nurse training? Options: very satisfied, satisfied, neither satisfied/dissatisfied, dissatisfied, very dissatisfied
37. How satisfied are you with the AGHD awareness by non-endocrine health care professionals? Options: very satisfied, satisfied, neither satisfied/dissatisfied, dissatisfied, very dissatisfied
38. How satisfied are you with the extent and quality of patient information resources? Options: very satisfied, satisfied, neither satisfied/dissatisfied, dissatisfied, very dissatisfied
39. How satisfied are you with the extent and quality of post-graduate AGHD curriculum training? Options: very satisfied, satisfied, neither satisfied/Dissatisfied, dissatisfied, very dissatisfied
40. How satisfied are you that all patients in your country are undergoing optimal diagnosis and treatment according to the latest best practice guidelines? Options: very satisfied, satisfied, neither satisfied/dissatisfied, dissatisfied, very dissatisfied
41. Is the indication of GH treatment for AGHD approved in your country? Options: yes, no, other (specify)

42. Is GH therapy for adult GHD patients reimbursed by your health care system? Options: yes- in part; yes-in full; no-GH treatment is not reimbursed; other circumstances (please specify)
43. Can you/your institute gain access to global data sources on GH therapy within your country? Options: No, I do not have access to such data sources; Yes, I have access and can provide it to ESE; I don't know.
44. Where is GH dispensed, in your setting? Please tick all that apply. Options: at the hospital pharmacy of the patients' reference hospital, at the hospital pharmacy of the patients' regional or local hospital, at the patients local pharmacy, directly to the patient, via a registered online delivery service, other, please specify.

Abbreviations:

ACTH, Adrenocorticotrophic hormone; ADH, antidiuretic hormone; AGHD, adult growth hormone deficiency; AGHDA, Assessment of Growth Hormone Deficiency in Adults; BMD, body mass density; BMI, body mass index; CO-AGHD, childhood onset adult growth hormone deficiency; EQ-5D, EuroQol group 5 Dimensions; ESE, European Society of Endocrinology; FSH, follicle stimulating hormone; GH, growth hormone; GHD, growth hormone deficiency; GHRH, growth hormone-releasing hormone; HbA1c, haemoglobin A1c; HDL, high-density lipoproteins; IGF-I, Insulin-like growth factor-1; ITT, insulin tolerance test; LDL, low-density lipoproteins; LH, Luteinizing Hormone; MRI, magnetic resonance imaging; QLS-H, Questions on Life Satisfaction-Hypopituitarism; QoL, quality of life; SF-36, 36-item short form of the Medical Outcomes Study questionnaire; TSH, thyroid stimulating hormone; T4, thyroxin.