

Online survey on GH treatment discontinuation in adults with GH deficiency

About You		
<input type="checkbox"/> Consultant Endocrinologist	<input type="checkbox"/> Specialist Nurse	<input type="checkbox"/> Other (please specify)
Place of Work		
<input type="checkbox"/> England <input type="checkbox"/> Scotland <input type="checkbox"/> Wales <input type="checkbox"/> Northern Ireland Region (please specify): _____		

1. Do you look after adult patients (over 18 years of age) with growth hormone deficiency (GHD) on GH replacement therapy? (please tick the answer that applies to your practice)

	Yes
	No (<i>No further question needs answering, please tick DONE at the end of this page. Thank you for your time in taking part in this survey</i>)

2. In total, how many adult patients (over the age of 18 years) with GHD do you currently treat with growth hormone in your practice?

Estimate or approximate number

3. How many of your adult patients on growth hormone treatment are over the age of 25 years?

Estimate or approximate number

4. How many of your adult patients, over the age of 25 years who are currently on growth hormone treatment, have been on this therapy for more than 5 years?

Estimate or approximate number

5. Do you routinely offer a trial period of discontinuation of growth hormone therapy to adult patients who have been on treatment for a long time?

	Yes
	No (skip question 6)

6. Aside from the absolute contraindications of growth hormone treatment (e.g. active malignancy and allergy), what criteria do you use when offering a trial of growth hormone therapy discontinuation to your adult patients who have been on long-term treatment (please tick all that apply)?

a. Duration of treatment	
<input type="checkbox"/>	If patient has been on treatment for more than 3 years
<input type="checkbox"/>	If patient has been on treatment for more than 5 years
<input type="checkbox"/>	If patient has been on treatment for more than 7 years
<input type="checkbox"/>	If patient has been on treatment for more than 10 years
<input type="checkbox"/>	If patient has been on treatment for more than 15 years
b. Patient's age	
<input type="checkbox"/>	If patient is over the age of 60
<input type="checkbox"/>	If patient is over the age of 70
<input type="checkbox"/>	If patient is over the age of 80
<input type="checkbox"/>	If patient is over the age of 90
<input type="checkbox"/>	Not applicable (Regardless of age)
c. Patient's choice (due to:)	
<input type="checkbox"/>	Side effects of growth hormone treatment
<input type="checkbox"/>	Poor concordance/adherence with the daily injection
<input type="checkbox"/>	Patient finding the routine of daily injection cumbersome/laborious
<input type="checkbox"/>	Needle phobia
<input type="checkbox"/>	Patient no longer experiencing positive effects from growth hormone treatment
d. Clinical judgement (due to:)	
<input type="checkbox"/>	Side effects of growth hormone treatment
<input type="checkbox"/>	Poor concordance/adherence with the daily injection
<input type="checkbox"/>	Patient finding the routine of daily injection cumbersome/laborious
<input type="checkbox"/>	Needle phobia
<input type="checkbox"/>	Patient no longer experiencing positive effects from growth hormone treatment
e. Other (please specify)	
<input type="checkbox"/>	

7. Do you have a clinical guideline/protocol for discontinuing long-term growth hormone replacement therapy in adults in your department?

<input type="checkbox"/>	Yes
<input type="checkbox"/>	No

8. Should adult patients who have been taking growth hormone treatment for a long time, be offered routinely a trial period of discontinuation of treatment?

<input type="checkbox"/>	Yes
<input type="checkbox"/>	Maybe
<input type="checkbox"/>	No (skip question 9)

9. Aside from the absolute contraindications of growth hormone treatment (e.g. active malignancy and allergy), what criteria do you think should be used when considering a trial of growth hormone treatment discontinuation to adult patients who have been on long-term therapy (please tick all that apply)?

a. Duration of treatment	
<input type="checkbox"/>	If patient has been on treatment for more than 3 years
<input type="checkbox"/>	If patient has been on treatment for more than 5 years
<input type="checkbox"/>	If patient has been on treatment for more than 7 years
<input type="checkbox"/>	If patient has been on treatment for more than 10 years
<input type="checkbox"/>	If patient has been on treatment for more than 15 years
b. Patient age	
<input type="checkbox"/>	If patient is over the age of 60
<input type="checkbox"/>	If patient is over the age of 70
<input type="checkbox"/>	If patient is over the age of 80
<input type="checkbox"/>	If patient is over the age of 90
<input type="checkbox"/>	Not applicable (Regardless of age)
c. Patient choice (due to:)	
<input type="checkbox"/>	Side effects of growth hormone treatment
<input type="checkbox"/>	Poor concordance/adherence with the daily injection
<input type="checkbox"/>	Patient finding the routine of daily injection cumbersome/laborious
<input type="checkbox"/>	Needle phobia
<input type="checkbox"/>	Patient no longer experiencing positive effects from growth hormone treatment
d. Clinical judgement (due to:)	
<input type="checkbox"/>	Side effects of growth hormone treatment
<input type="checkbox"/>	Poor concordance/adherence with the daily injection
<input type="checkbox"/>	Patient finding the routine of daily injection cumbersome/laborious
<input type="checkbox"/>	Patient no longer experiencing positive effects from growth hormone treatment
<input type="checkbox"/>	Other (please specify):
e. Other (please specify)	
<input type="checkbox"/>	

10. If you are currently offering (or if you were to offer) a trial of growth hormone treatment discontinuation to adult patients, how soon after stopping their treatment would you monitor your patients?

<input type="checkbox"/>	Within 3 months
<input type="checkbox"/>	3-6 months
<input type="checkbox"/>	Within 12 months
<input type="checkbox"/>	Other (please specify):

11. If you are currently offering (or if you were to offer) a trial of growth hormone treatment discontinuation in adult patients, what monitoring do you complete during follow-up clinic visit? (please tick all that apply)

a. Observations	
<input type="checkbox"/>	Blood pressure
<input type="checkbox"/>	Heart rate
<input type="checkbox"/>	Weight
<input type="checkbox"/>	BMI
<input type="checkbox"/>	Waist-hip circumference

b. Biochemical parameters	
	IGF-1
	HbA1c
	Lipid profile
	Fasting glucose
c. Radiological assessment	
	Body composition measurement (muscle mass)
	Body composition measurement (fat mass)
	Bone mineral density (DXA scan)
d. Quality of life assessment	
	AGHDA
	SF-36
	TRIM-AGHD
e. Signs and symptoms assessment (please specify)	
f. Other (please specify)	

12. If you are currently offering (or if you were to offer) a trial of growth hormone treatment discontinuation to adult patients, how often should patient be reviewed in clinic if they decide to remain off treatment?

	3 monthly during the first year then back to standard care
	6 monthly during the first year then back to standard care
	Back to standard care
	Other (please specify):

Thank you for your time in completing this survey