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Development of an intervention to support communication in young people's consultations

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Background and objectives



- Young people can lose contact with endocrine care following transition (Downing et al, 2013)
- Children have limited involvement in consultations (Tates & Meeuwesen, 2001)
- Young people need support to become effective users of adult health consultations
- Aim: to develop feasible interventions to support young people's communication

Settings and participants



- Endocrine clinics at two paediatric and two adult regional centres
- Young people 11-25 with a range of long-term endocrine conditions.
- Development phase: 38 consultations recorded
- Feasibility phase: 24 consultations recorded (15 used at least one intervention)

Analysis of consultations



- Young people's contribution to talk: % of consultation
- Number of questions asked
- Direction of questions to clinicians
- Clinician communication behaviour (PCAT)
- Shared decision making (OPTION)

Young person talk (Pre-intervention)

Age group	Mean	Range	YP > parent
11-13	8%	2%-16%	1 (13%)
14-16	13%	5%-23%	4 (33%)
17-19	21%	13%-41%	9 (75%)
20-25	28%	11%-43%	6 (100%)

Young person questions

(Pre-intervention)

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Age Group	Did not ask a question	Asked 1+ questions	Range
11-13	3	4	1-5
14-16	4	7	1-5
17-19	3	8	1-16
20-25	0	5	2-20

Intervention development



- “Your Issues” - prompt sheet for young people to influence consultation agendas and raise questions
- www.explain.me.uk - animations to support explanations in clinics and at home
- “Take Home Messages” – summary sheet
www.explain.me.uk personalised space to log information
copy of the consultation recording

Things to talk about with your doctor or nurse

Did you know that everything that you tell your doctor and nurse is kept private and safe (sometimes called confidential)?

The only times that they would tell somebody else is if that would improve your care or to keep you safe.

Date:

/ /

Would you like to have some time on your own with the doctor/nurse?

Yes please
Not this time thanks

It can be helpful to make a list of what you want to talk about with your doctor or nurse. Here are some things that young people sometimes want to talk about. Tick any that you would like to talk about today.

Growing up Sleep Feeling sad

Understanding more about your condition and treatment

Eating healthily and being active Friendships and relationships

Transferring to adult services School, college or work

Anything else?

.....

.....

Your own topics:

.....
.....
.....

Write down some more things that you want to talk about.

.....
.....
.....

CONTINUE
ONTO THE
NEXT PAGE

HOME

COMING TO
CLINIC

YOUR
CONDITION

KEEPING
HEALTHY

GETTING ON
WITH LIFE

FEELING GOOD
ABOUT YOURSELF

[Your Condition](#) > [Turner Syndrome](#) > [How does it affect your body?](#)

In this section

[What causes it?](#)

[How did they find out you had it?](#)

[What does it mean for you?](#)

[How does it affect your body?](#)

[1 - Growing Taller](#)

[2 - Going Through Puberty](#)

[3 - Keeping Hearts Healthy](#)

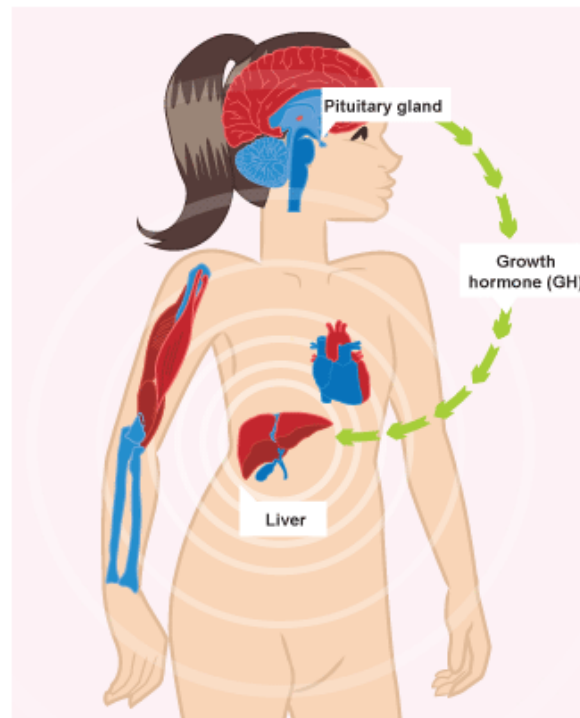
[4 - Thyroid Problems](#)

[5 - Immune System Misbehaving](#)

[6 - General Health Checks](#)

[Tell us about your experiences](#)

How does it affect your body?



1 - Growing Taller

Growth Hormone, GH for short, and insulin like growth factor 1, IGF-1 for short, are important hormones as they help you grow and keep your muscles and bones strong. GH is produced by the pituitary gland and sent in the blood. GH makes another hormone called IGF-1 (insulin like growth factor-1). This is made all over the body but mostly in the liver. GH and IGF-1 travel in the blood to different parts of the body making you grow and building up your muscles and bones. GH is produced throughout your life but is higher when you are a teenager and a young adult and then starts to fall as you get older.

1 2 3 4 5 6

Was this information helpful? [YES](#) [NO](#)

ADD TO PROFILE

Main points to take away

Point 1
.....
.....
.....

Point 2
.....
.....
.....

Point 3
.....
.....
.....

Blood Pressure

BMI

Weight

Height

Medication changes
.....
.....
.....
.....
.....
.....

Anything else (e.g. meaning of medical words, things to remember)
?

In this section

[Dashboard](#)

[Personal Journal](#)

[Medication](#)

[My Data](#)

Date	W(kg)	H(m)	BMI	
20-06-2013	87	1.79	28	<input type="checkbox"/>
19-06-2013	89	1.79	28	<input type="checkbox"/>
14-04-2013	91	1.79	29	<input type="checkbox"/>
24-12-1981	68	1.7	24	<input type="checkbox"/>
24-12-1979	58	1.5	26	<input type="checkbox"/>
24-12-1976	30	1.3	18	<input type="checkbox"/>

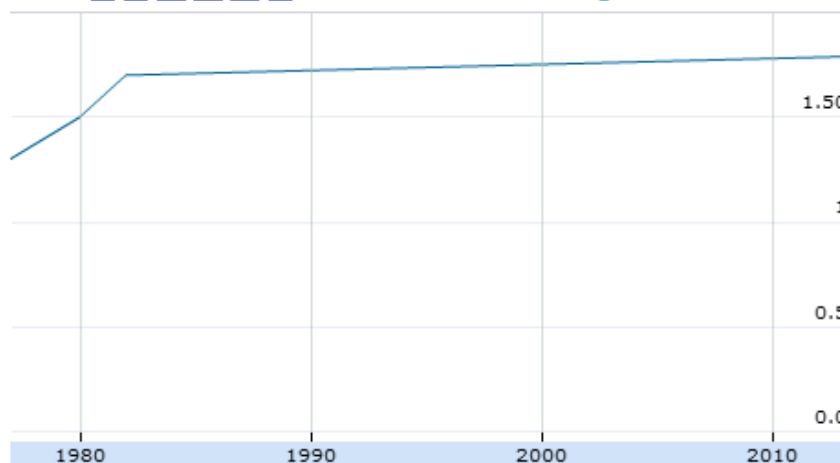
My Data

Add take home messages

[Height](#) | [Weight](#) | [BMI](#)

Zoom: [1d](#) [5d](#) [1m](#) [3m](#) [6m](#) [1y](#) Max

• Height 2 m | June 20, 2013



Enter your Take Home Messages to keep your personal record of consultations. You can add your previous height and weight measurements to make your personal growth chart.

Feasibility study



- 24 young people offered interventions
- 15 used at least one

Feasibility study

Young person questions

	No question asked		Range of questions	
Age	User	Non-user	User	Non-user
11-13	0	0	1	1
14-16	2	0	3-6	2-17
17-19	0	0	4-10	2-4
20-25	1	n/a	0-6	n/a

Questions to clinicians

	Pre-intervention (n=34)	Did not use intervention offered (n=8)	Used any of interventions (n=11)
Young People	62% asked 1-20 questions	63% asked 2-18 questions	73% asked 1- 6 questions
Parents/ others	83% asked 1-11 questions	75% asked 1-18 questions	89% asked 1-22 questions

PCAT and OPTION measures



- **PCAT** – no overall difference. Users higher:
“identifying reasons for the consultation”
(5.8 vs 5.2, 95% CI 0.0 to 1.1)
“using skills which aided recall and
understanding”
(5.9 vs 5.0, 95% CI 0.1 to 1.7)
- **OPTION** – higher mean score for parents
when interventions used
(16.2 v 9.0, 95% CI 1.2 to 13.2) - not young people

Implications



- Wide variations suggest some young people need support to talk and question
- More intervention users directed questions to clinicians
- Differences in PCAT and OPTION consistent with improved communication
- Suggests feasibility but further studies required to test effects

Acknowledgements



- Co-investigators: Peter Clayton, Julian Davis, Paul Dimitri, Jenny Downing, Helena Gleeson, Jerry Wales

This is a report of independent research funded by the National Institute for Health Research (NIHR) under its Research for Patient Benefit (RfPB) Programme (Grant Reference Number PB-PG-1208-16102. The views expressed are those of the author and not necessarily those of the NHS, the NIHR or the Department of Health.