

# Development of explain.me.uk: Communication with Young People

J. Downing<sup>a</sup>, H. Gleeson<sup>b</sup>, P.E. Clayton<sup>c</sup>, J.R.E. Davis<sup>c</sup>, P. Dimitri<sup>d</sup>, J. Wales<sup>e</sup>, B. Young<sup>a</sup>, P. Callery<sup>c</sup>

<sup>a</sup>University of Liverpool. <sup>b</sup>Queen Elizabeth Hospital, Birmingham. <sup>c</sup>The University of Manchester. <sup>d</sup>Sheffield Children's NHS Foundation Trust. <sup>e</sup>Lady Cilento Children's Hospital, South Brisbane.

## Helping young people to talk with clinicians

As young people grow up they have to take more responsibility for engaging with their health care. The transition from child to adult changes the way that patients, parents or other carers and clinicians communicate with each other.

## Aims and objectives

- To study communication between young people, their parents/ carers and healthcare professionals in endocrine clinics
- To select and adapt Communication Interventions (CI) to meet the preferences and needs of young people, their parents/carers and health professionals for use in endocrine clinics
- To assess the feasibility and acceptability of use of the Communication Interventions to empower young people in endocrine clinics

## Design

The project had 3 stages:

- Communication Study
- Development of Interventions
- Feasibility Testing

## Communication study

### Methods

We recorded 40 consultations and interviews with young people aged 11-25 attending paediatric or adult endocrine clinics with conditions requiring long term adult endocrine care.

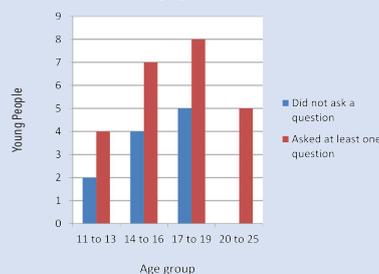
Quantitative analysis of consultations included:

- how long young people, parents and clinicians talked, questions asked by young people,
- rating by the Paediatric Consultation Assessment Tool (Howells et al. 2010),
- rating by the OPTION tool for shared decision making (Elwyn et al. 2005).

Qualitative analysis of consultations and interviews included: what was talked about in consultations, how young people, parents and clinicians communicated in consultations, communication problems

### Key results

Young people's engagement in consultations was limited. They spoke for a lower proportion of consultations (mean 17%) than parents or clinicians. The variation in the time talked increased in older age groups, at 20-25 years the range was 11%-43%. Question asking also varied widely. Eleven (31%) did not ask a single question of any type. The difference between the least and most questions asked widened in each age group and the range was 2-20 in the 20-25 age group.



### Young people who asked or did not ask any questions during their consultation

Young people had important questions that they did not ask during consultations

"...when he says about the diabetes insipidus, I still don't really know what diabetes insipidus is"

Interviews identified important gaps in some young people's knowledge and understanding of their conditions.

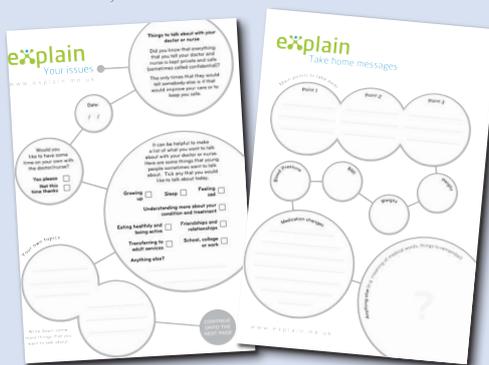
Young people and parents identified potential areas for interventions:

- Pre-consultation – support to prepare questions
- During consultations – diagrams to illustrate explanations of endocrine conditions
- Post-consultation – summaries of key information to take away.

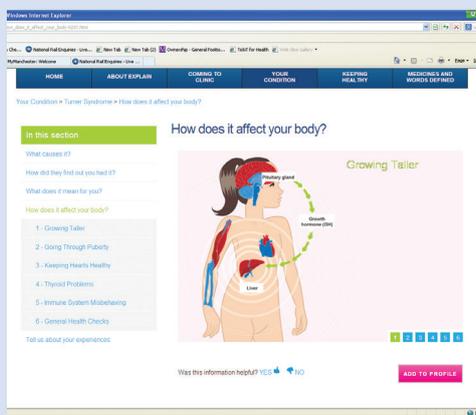
## Development of Explain toolkit

14 young people and parents met in groups with clinicians to develop:

- "Your Issues" - a prompt sheet for young people to influence consultation agendas and raise questions
- "Take Home Messages" on the reverse to summarise answers and other key information



Explain.me.uk a website with animations about Turner's Syndrome, Congenital Adrenal Hyperplasia and Hypopituitary conditions for use in clinics.



Explain.me.uk also has a section with supporting text for young people to review and to log information and generate an individual growth chart



Offering young people a recording of their consultation to take away.

## Feasibility study

### Methods

We recorded 24 routine endocrine consultations and interviews in which young people had the option to use a communication intervention. Scores for PCAT and OPTION were compared between consultations with and without intervention use via 95% confidence intervals for difference in means.

### Key results

15 young people used at least one of the interventions.

Consultations were not longer when interventions were used

The mean duration of consultations in which an intervention was used (20.7mins) was similar to consultations in which none were used (20.4 mins).

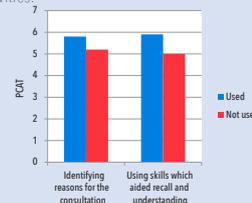
**Young people who used the intervention had less rapport with their doctor and comfort communicating (MISS-21)**

Questions asked

Fewer young people (3, 16%) asked no questions than in Stage 1 (11, 31%), suggesting that CIs could help some young people to ask questions during consultations.

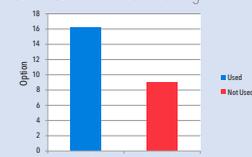
## Communication Quality

Consultations in which interventions were used had higher scores for "identifying reasons for the consultation" (95% CI for difference in means 0.0 to 1.1) and "using skills which aided recall and understanding" (95% CI 0.1 to 1.7). This suggests that intervention use may support these activities.



### Better performance when intervention used for two aspects of PCAT

The mean OPTION score was higher for parents when interventions were used (16.2 v 9.0, 95% CI for difference 1.2 to 13.2) but not for children (15.0 v 11.9, 95% CI -3.4 to 9.5). This suggests interventions may support parental involvement in decision making.



### Parents were more involved in decision making when interventions were used (OPTION)

## Conclusions

Young people can have limited involvement in consultations and this can persist into young adulthood. Interventions have the potential to improve communication particularly for young people who find communicating in a health care setting challenging.

The explain.me.uk website is designed to:

- help young people identify issues and formulate questions to raise in consultations
- support clinicians to answer questions
- provide young people with a record of personalised information to take from consultations

## References

- Elwyn, G., Edwards, A., Wensing, M. & Grol, R. (2005) Shared Decision Making: measurement using the OPTION instrument, Cardiff University, Cardiff.
- Howells, R.J., Davies, H.A., Silverman, J.D., Archer, J.C. & Mellon, A.F. (2010) Assessment of doctors' consultation skills in the paediatric setting: the Paediatric Consultation Assessment Tool. Archives of Disease in Childhood, 95(5), 323-329.

