

Co-creation of patient materials for adrenal insufficiency to address patients' treatment concerns

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Introduction

Adrenal Insufficiency (AI) is a life-threatening rare disease¹.

Concerns about treatment are a barrier to adherence³; AI patients have reported concerns about side effects and the intrusiveness of therapy in their daily lives².

Patients with rare diseases can feel isolated and unheard⁴, due to this, **understanding patients' perceptions about AI and its treatment is especially important in this group.**

Adherence rates to cortisol replacement therapy can be as low as 15%²

Methods

The N4C (Need for Change) materials were co-created with endocrine experts and patients.

The **Perceptions and Practicalities Approach™ (PAPA)**³, a model for assessing behaviour of patients in relation to their disease and treatment, informed the design of a *brief patient questionnaire* and *patient information booklet*.

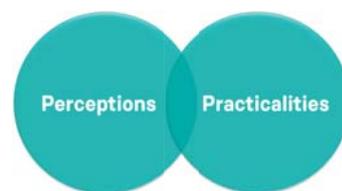
Patients recruited from UK support groups took an online survey using a 5-point Likert scale to test the effectiveness of the N4C questionnaire (n=87) and the booklet (n=85).

Quantitative and qualitative analysis of data was undertaken.

Objective

To co-create materials for AI patients that could be effectively used during consultations to optimise communication between patients and healthcare professionals (HCP).

Perceptions and Practicalities Approach (PAPA)™



Results

Questionnaire

Participants found negatively framed questions hard to answer

90% would recommend to other patients

Participants found it useful for identifying concerns they had about AI (83%) and treatment (82%)

Participants would have preferred a scale rather than a definitive yes/no answer

13% felt the questionnaire would not help them get more out of future appointments

74% felt more confident discussing their concerns about AI and its treatment with their doctor

93% said they would recommend the questionnaire to other patients

Booklet

Booklet could have had more detail

14% felt the booklet would not help them get more out of future appointments

Patients found the booklet useful for managing stress (80%), fatigue (67%) and preventing adrenal crisis (79%)

Patient characteristics

68% female	Age range 46-55 years	77% secondary AI
32% never had adrenal crisis	31% over 10 years since diagnosis	71% more than one medical condition

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References: 1. Bancos et al. *Lancet Diabetes Endocrinol.* 2015;3:216-26. 2. Chapman SCE, et al. *Clin Endocrinol.* 2016;84:664-671. 3. Horne R et al. *PLoS One.* 2013 Dec 2;8(12):e80633. 4. Limb et al. 2010. *Rare Disease UK.* Horne R. Compliance, adherence and concordance. In *Pharmacy Practice*; 2001. Ed. By KMG Taylor & G Harding. London: Taylor & Francis Programme.

Conclusion

The co-creation of patient materials with the patients themselves is imperative, so materials can be tailored specifically to the concerns of AI patients and used effectively in a real-world setting.