



Case study

Rare diseases



**Spoonful
of Sugar**

Making the most of medicines

Rare diseases

Behavioural Insights Research™, literature review, adherence tool and accompanying guidebook for clinicians

Overview

Facilitating open and honest communication between patient and clinician to promote active self-management of this rare disease.

Problem

In the context of this specific disease, there was a need for a more effective means of facilitating open and honest communication between patients and clinicians.

Patients were not always satisfied with the quality of the information they received, hindering their motivation to continue with treatment.

Situation

Rates of diagnosis with this particular disease are increasing (although it is still exceptionally rare), and the prevalence of multidisciplinary support needs (including polypharmacy) has left an unaddressed need to readdress and personalise support provided.

Value

We undertook in-depth insights research to uncover the behaviours and salient factors influencing uptake and adherence to therapy for this rare disease.

These findings, and a Pan-European 'steering committee' of expert clinicians and patients, have guided a holistic and co-creative approach to radically transforming perceptions of the current market and consequently disrupting the treatment 'status quo'.

The materials created have therefore been guided and informed by first-hand insights, best clinical practice, and latest thinkings in the disease area and behavioural medicine.

Our approach has ensured the most effective means possible of identifying patient and clinicians' concerns about treatment, of optimising the three-way interaction between patient, clinician, and medicine, and of directly addressing the barriers we have identified to adherence.

The resulting intervention facilitates open communication between doctor and patient, empowers and educates all in personalising the medicine to best fit patient need, and ultimately, promotes optimum patient self-management in their disease.

Implications

Disrupting the existing market for treatment encourages all stakeholders to refresh their perspective on currently-available therapies.

A sense of 'ownership' over intervention materials empowers stakeholders, which leaves them better positioned to fully engage with the intervention.

Our work augments intrinsic motivation to engage with and adhere to treatment, providing a more powerful, longer-lasting impact on adherence and clinical outcomes.