

# Observations of patient preference in the creation of treatment support materials

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## INTRODUCTION



- Research into patient education and activation suggests that patients who feel well informed and empowered to participate in conversations with their healthcare team have improved health outcomes.
- Traditionally, formal patient education has been limited to materials available to the healthcare professional attending to the patient and the Patient Information Leaflet accompanying a prescribed treatment.
- Patient, caregiver and advocacy involvement in the co-creation of treatment-related and disease education support materials is considered the gold-standard for creating any disease-related treatment support and is now an industry-wide practice.

## OBJECTIVES

- The aim of this research was to determine the patient-reported preferences of disease-related patient support materials, highlighting the proportion of material requested in the areas of medical information, treatment-related information, additional or peripheral support and psychological support.

## METHODS

- The authors selected nine projects conducted by their project teams in collaboration with industry partners, according to the following criteria:



**Inclusion criteria**

Projects that were conducted in collaboration with industry partners which involved activities gathering direct preference feedback by patients or caregivers.

Projects conducted over the past two years.

Projects in which direct feedback was collected on the optimal patient support material.



**Exclusion criteria**

Projects without direct patient involvement were excluded.

- The authors held a series of meetings to identify projects and discuss experiences jointly, and key reflections were summarised.

## RESULTS

### Patients require information beyond the sponsor treatment

- When given an opportunity to feedback on disease awareness or treatment-related support materials, patients and caregivers report a need for a vastly wider range of content provision than the outlines initially presented (Table 1), particularly in the case of paediatric patients and caregivers of adult patients.
- Key unmet needs included: Disease education specifically tailored to a newly diagnosed population, including information such as general disease education and disease and treatment information tailored to a novice audience, as well as information on initial treatment options and information on all treatment side effects; details of what to expect as their disease progresses and how to find appropriate clinical trials; and practical guidance on self-management and accessing support beyond their immediate healthcare team.
- General inclusivity is requested by all audiences, emphasizing a need for simpler content and language adhering to the key principles of health literacy and delivered in accessible design formats with a choice of access points.
- All audiences express the desire for creative, engaging content solutions, similar to what they would experience in a commercial or social media environment.

### Patients also require support outside the clinical pathway

- In all cases, requests for information spanned beyond the sponsor treatment.
- Additional requests for content included information on additional treatment options (outside the sponsor treatment), information on clinical trials, and non-medical interventions.
- Providing content focused on life was a priority identified across all feedback analyzed; participants requested support and information on topics such as work, study, family life, caring for children, managing finances, travel, personal relationships and mental health.

## CONCLUSIONS

- In our experience, the Industry-sponsor teams engaged the patient preference across all requests wherever possible, extending the content outline discussed to include additional topics. In addition, all participants, both industry and patient/caregiver/advocacy, expressed a desire to continue the feedback process.
- These observations demonstrate a truly patient-centric approach to all patient and caregiver facing content generation that can significantly improve the material provided to patients and caregivers across therapy areas.
- Ensuring that patient and caregiver input in the form of co-creation and validation is built into the planning phase of all patient support materials can help to improve education, comprehension and adherence to the support provided and ultimately improve the patient and caregiver experience.

Table 1. Description of patient material requested in co-creation projects					
	Therapy area	Group demographic	Sample (n)	Nature of group involvement	Additional educational material requested
1	Gynaecological cancer	Patient advocates, women with gynaecological cancer, caregivers and HCPs	9	Editorial panel	A ‘starter’ guide; a choice of health literacy levels for educational material; interactive, engaging content; detailed treatment information; additional information on non-sponsor treatment options and clinical trials; peer-to-peer support; women’s health content; shared decision-making materials
2	Immunological disease	Adults with immunological disease	6	Online workshop	Additional information on non-sponsor treatment options and clinical trials; general disease education; side effects management information; tailored information on non-medical interventions; peer-to-peer support; engaging, interactive content
3	Neurological disease	Adults with neurological disease	7	Online advisory board	A ‘starter’ guide; interactive content; peer-to-peer support; a choice of health literacy levels for educational material; content specifically for the children; content specifically for parents and caregivers; women’s health content; appointment planners; shared decision-making materials
4	Genitourinary cancer	Adults with genitourinary cancer, caregivers and HCPs	7	Online workshop	A ‘starter’ guide; interactive content; a choice of health literacy levels for educational material; detailed treatment information; side effects management information; shared decision-making materials
5	Rare genitourinary cancer	Adults with rare genitourinary cancer and HCPs	5	Editorial panel	Interactive, engaging content; peer-to-peer support; general disease education; detailed treatment information; side effects management information; non-treatment related information; shared decision-making materials
6	Rare disease	Adults and children with rare disease, caregivers of children with rare disease and HCPs	7	Online advisory board	Detailed treatment information; additional information on non-sponsor treatment options and clinical trials; peer-to-peer support; shared decision-making materials
7	Rare disease	Adults and children with rare disease, caregivers of children with rare disease	6	Editorial panel	A ‘starter’ guide; interactive, engaging content; peer-to-peer support; a choice of health literacy levels for educational material; content specifically for the children; content specifically for parents and caregivers
8	Rare lung cancer	Adults with lung cancer	4	Online workshop	Interactive, engaging content; peer-to-peer support; general disease education; detailed treatment information; additional information on non-sponsor treatment options and clinical trials; shared decision-making materials
9	Blood cancer	Adult with blood cancer	1	Online interview	A choice of health literacy levels for educational material; interactive, engaging content; non-treatment related information