

Binder for Lymphoma Patients

made
with
patients

Description: In partnership with a national Lymphoma advocacy group, Janssen developed a binder for patients to keep all their disease-related information together and easily accessible



1

Starting with a common purpose based on patient needs and shared objectives.

2

Discussing validating patients' needs. The project built in time for patients to discuss with their peers. Patients' equal contribution determined the agenda.

3

Established an editorial board, consulted patient members, got input from the patient information phone and consulted a reader panel in order to establish representativeness of the target audience.

4

Roles and responsibilities discussed and detailed before the project start, contracts were created with the aim for equality between partners.

5

Made sure that all partners were equipped to participate on an equal basis. Acknowledged that a small patient organisation is different from a big company and each have different assets to contribute. Janssen provided knowledge from the medical team.

6

Communication and transparency were key in project and potential impact of collaboration was discussed upfront.

7

Continuity and a potential longer term partnership was discussed upfront.

Impact: 1) Awareness of possible hurdles we might not foresee, 2) Checklist to see if we were doing the right thing (gap analysis)

Lessons learned: 1) True co-creation can result in making changes and sometimes doing things differently than we are used to, 2) The legal process is not always up to speed without collaborative ambition, 3) There is huge (potential) gap between capacity of a patient organization (driven by volunteers) and a big company → Janssen to increase internal awareness about working with patients, 4) Being alert on not to fall back on usual roles pharma-patient roles.