

# Correlation of Lymphoma Patient Information Level with Healthcare Experience

## 1) INTRODUCTION & OBJECTIVES

Across recent health reform research, there is growing advocacy and awareness surrounding the idea that patients should act as more effective managers of their health and healthcare. Knowledge dissemination is frequently named as a preliminary requirement for this shift in attitude and behaviours. In 2017, the Lymphoma Coalition (LC) conducted a mixed methods investigation to determine if evidence exists pointing to better outcomes for more 'informed' patients. A key theme was identified: when a patient has knowledge surrounding their condition, they are more inclined to be confident in sustaining an active patient role, they ask more questions and their patient experience is improved.

To continue this investigation, the LC utilised the 2018 Global Patient Survey (GPS) on Lymphomas and CLL to further explore patient awareness and understanding, sources and level of information, support from healthcare professionals, and the impact this has on the patient experience.

## 2) METHODS

### Study Design

- Online global survey (2018 LC GPS) of patients with lymphomas (including CLL).
- Hosted on a third-party portal from January 2018 to March 2018 in 19 languages.
- Question topics: patient information and support, fear of relapse, fatigue, living with side effects, and barriers to care.

### Participants

- The survey was advertised through the social media of 65+ lymphoma-related patient organisations, Lymphoma Hub, scientific partners, INTERLYMPH, and HCPs.
- **6631** participants took part from all over the world (70+ countries).

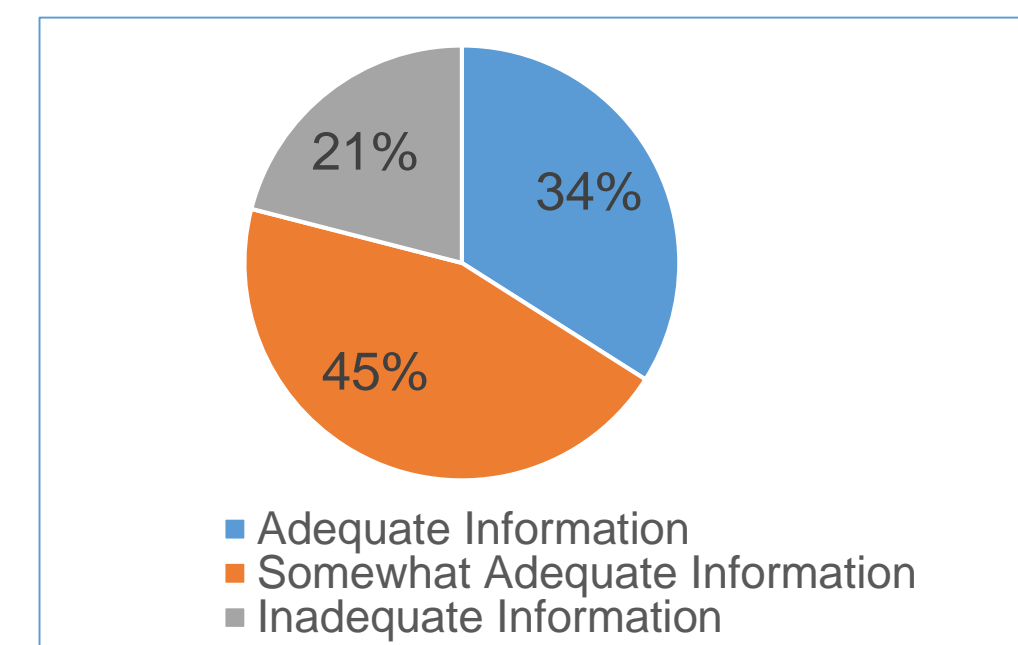
### Statistical Analysis

- A minimum completion threshold (Total\_M 0.70) was defined in order to eliminate partially completed surveys. Additional data sanitisation was completed.
- Descriptive statistics were performed for all questions of the survey. Associations between factors were examined through cross-tabulations and chi-square tests ( $p=0.05$ ).
- All statistical analyses were performed by a third-party scientific research institute with IBM SPSS v21.

## 3) RESULTS

### 3.1 Levels of Understanding

The impact of perceived information level (Figure 1) was reflected in respondent's understanding of the medical aspects of their lymphoma, diagnosis and care (Table 1, Figures 2(a) &(b)).

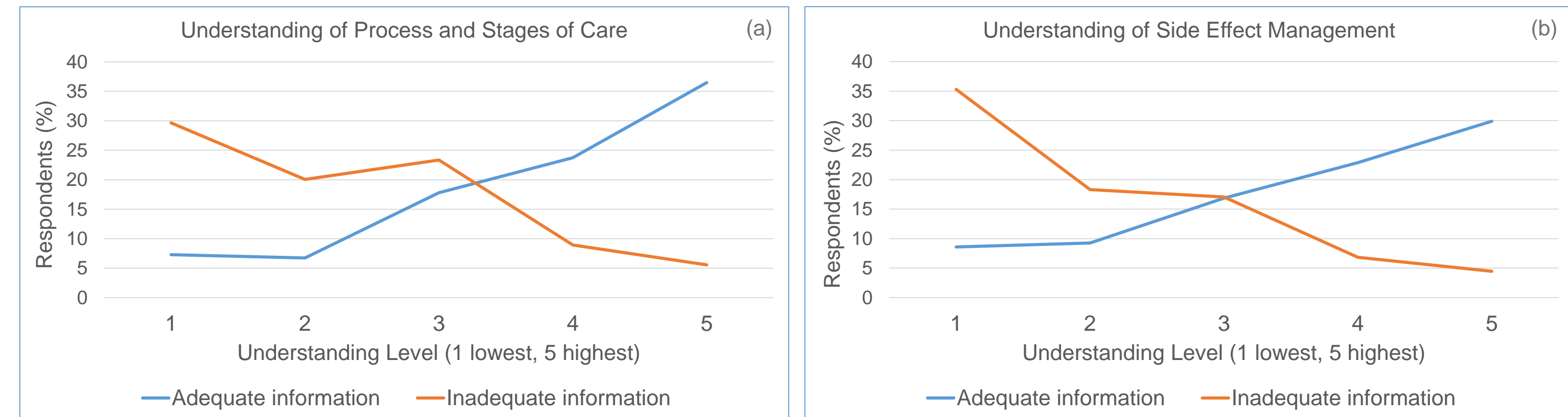


**Figure 1.** Level of information respondents perceived they had overall

**Table 1.** Respondents' understanding after their initial visit with the doctor based on their perceived information level

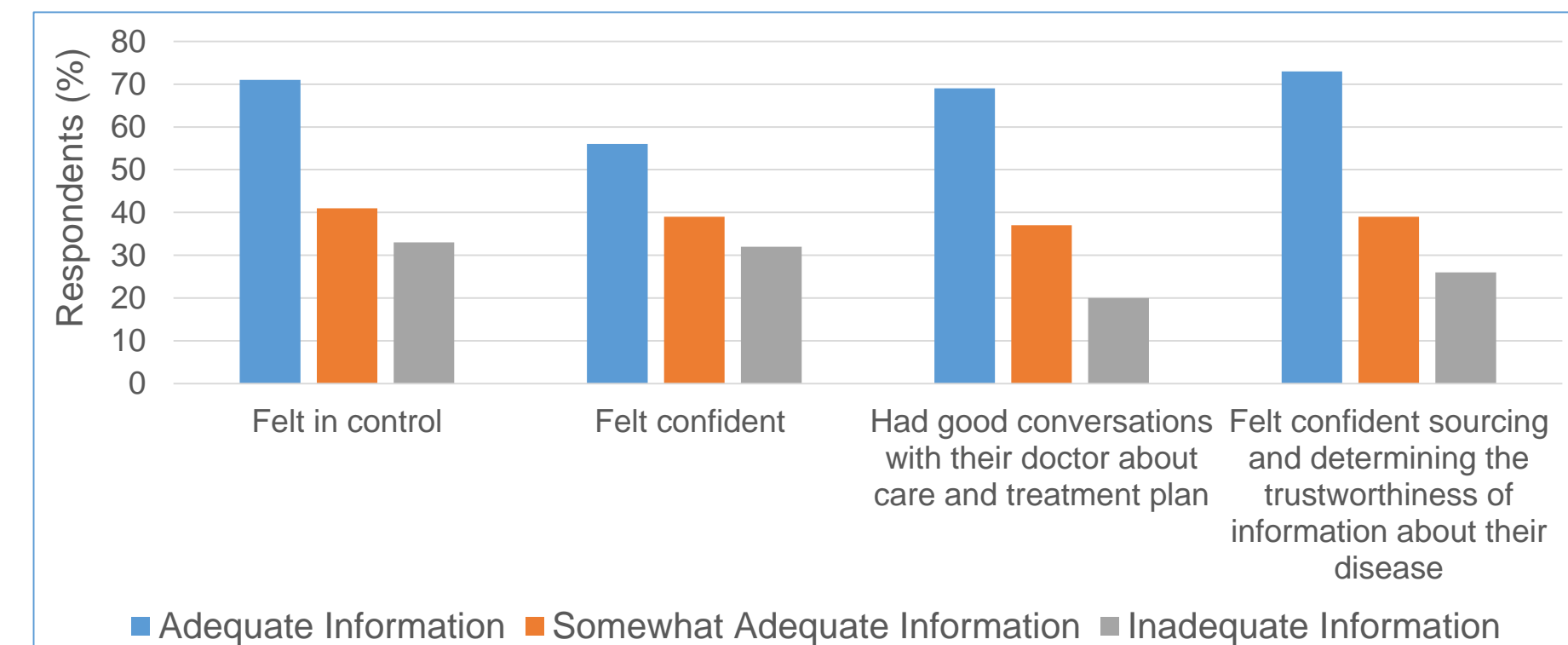
Topics Around Diagnosis and Care	Adequate Information (%)	Somewhat Adequate/Inadequate Information*
Diagnosis	69	36
Characteristics of the particular subtype	54	27
Different medical treatment options	64	28
Initial treatment if started right away	74	39
Potential side effects of treatment options	66	34
Side effect management	60	26
Process and stages of care	65	32
Active surveillance ('watch and wait'), if applicable	71	38

\*Somewhat/inadequate information levels grouped as a comparator



**Figure 2.(a)** Respondents' understanding of the process and stages of their care and **(b)** side effect management after their initial visit with their doctor based on perceived information level

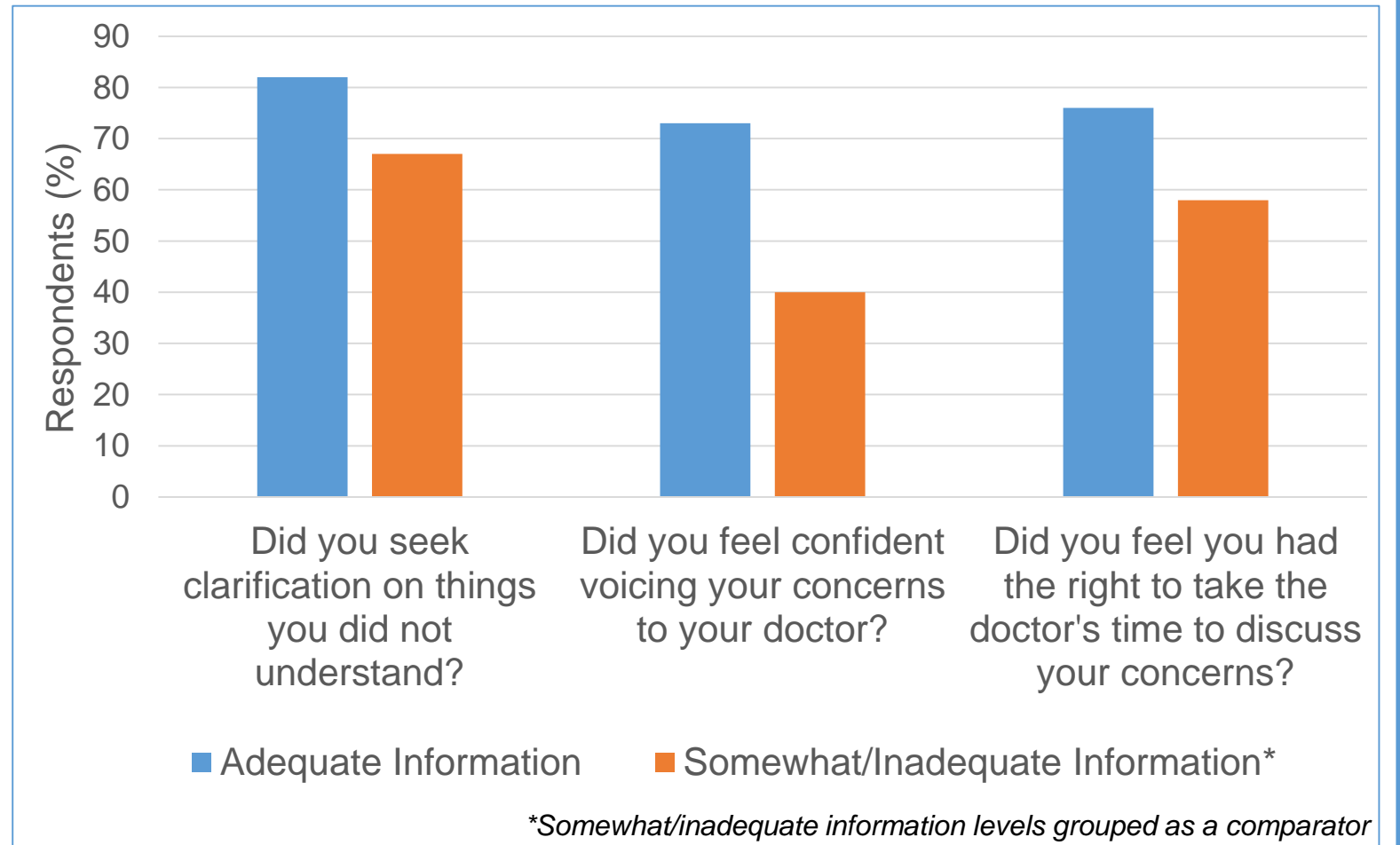
### 3.2 Respondent Feelings



**Figure 3.** Respondents' feelings 'most days' according to perceived information level

Adequately informed respondents felt more confident in determining the need for medical care vs. handing a health problem on their own (59%) compared to somewhat (35%) and inadequately (22%) informed respondents. Similar trends were observed across the majority of feeling categories (Figure 3). 'Most days', adequately informed respondents reported experiencing low levels of negative feelings (out of control, fearful) and inadequately informed respondents reported experiencing low levels of positive feelings (in control, mentally/physically strong).

## 3.3 Doctor-Patient Communication



**Figure 4.** Respondents' communication with the doctor based on perceived information level

Across all categories, improved communication was reported by those with adequate information (Figure 4). Additionally, the general reporting of physical, medical, and psychosocial side effects was statistically dependent on the information level variable.

## 4) CONCLUSION

Having a perceived adequate information level was correlated with more self-reported positive healthcare experiences. Patients with adequate information reported better management of their health and healthcare through improved understanding, confidence levels, and communication. Therefore, access to credible timely information is an important aspect to a successful patient experience. These results present implications for both patient outcomes (health behaviours, health status) and costs to the healthcare system.

## ACKNOWLEDGEMENTS

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