

Patient Involvement in Finland - Experiences of Patient Organisation Collaboration in Guideline Development and Implementation

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Background

It has been suggested that the stronger the patient involvement in guideline development, the more probable the implementation of the guideline. At the G-I-N Conference 2008, Current Care hosted a workshop, "Patients and guidelines - is there a living connection?" In this workshop each group was asked to imagine what kind of content a patient expects from a lay version of guidelines in the context of disease symptoms, diagnosis, treatment, prevention/rehabilitation and any other issues? After the workshop in the spring of 2009, we analysed the content of the lay version in more depth, alongside representatives of Finnish patient organisations.

Purpose

We wanted to analyse the following topics: 1. What key questions of patients would a lay version of a guideline need to answer? 2. How might patient organisations utilise the original guideline and its lay version in their own work? 3. How might patient organisations get involved in the development and implementation of the guideline?

Methods

In our study, patients were represented by patient organisations. A web-based questionnaire was sent to 45 representatives of patient organisations, in order to study the use and usability of a guideline and its lay version. Of these, 24 persons answered (53 %). The questionnaire included questions on the guidelines and the use and usability of their lay versions. In addition, the most important ten issues to the patient were asked. A half-day workshop with patient organisations was organised, at which the results of the questionnaire were presented and ideas generated for further collaboration between Current Care and patient organisations.

Results

The key issues in each part of the lay versions were defined by patient organisations (Table 1.) Over half of the organisations used guidelines and lay versions a lot or very much (Figure 1). Ways of utilising the guidelines are shown in Figure 2. Future plans for collaboration methods between Current Care and patient organisations were planned and agreed. These were as follows: in the guideline updating process, patient organisations introduce the 10 questions most frequently asked by patients to the guideline working group. Patient organisations are regularly asked to give a statement on updated guidelines in their own field. In the future, regular meetings will be organised with the patient organisations once a year.

Discussion

The guideline organisation's further development of the guidelines and lay versions requires the active involvement of the patient organisation and an understanding of the differences between, and needs of, both patient and professional guidelines. In the guideline implementation process, the role of both patients and patient organisations is evident.

Figure 1. How much are the original guidelines and lay versions utilised in the work of your own patient organisation? Scale 1-5, 1=not at all, 5=very much, n=24.

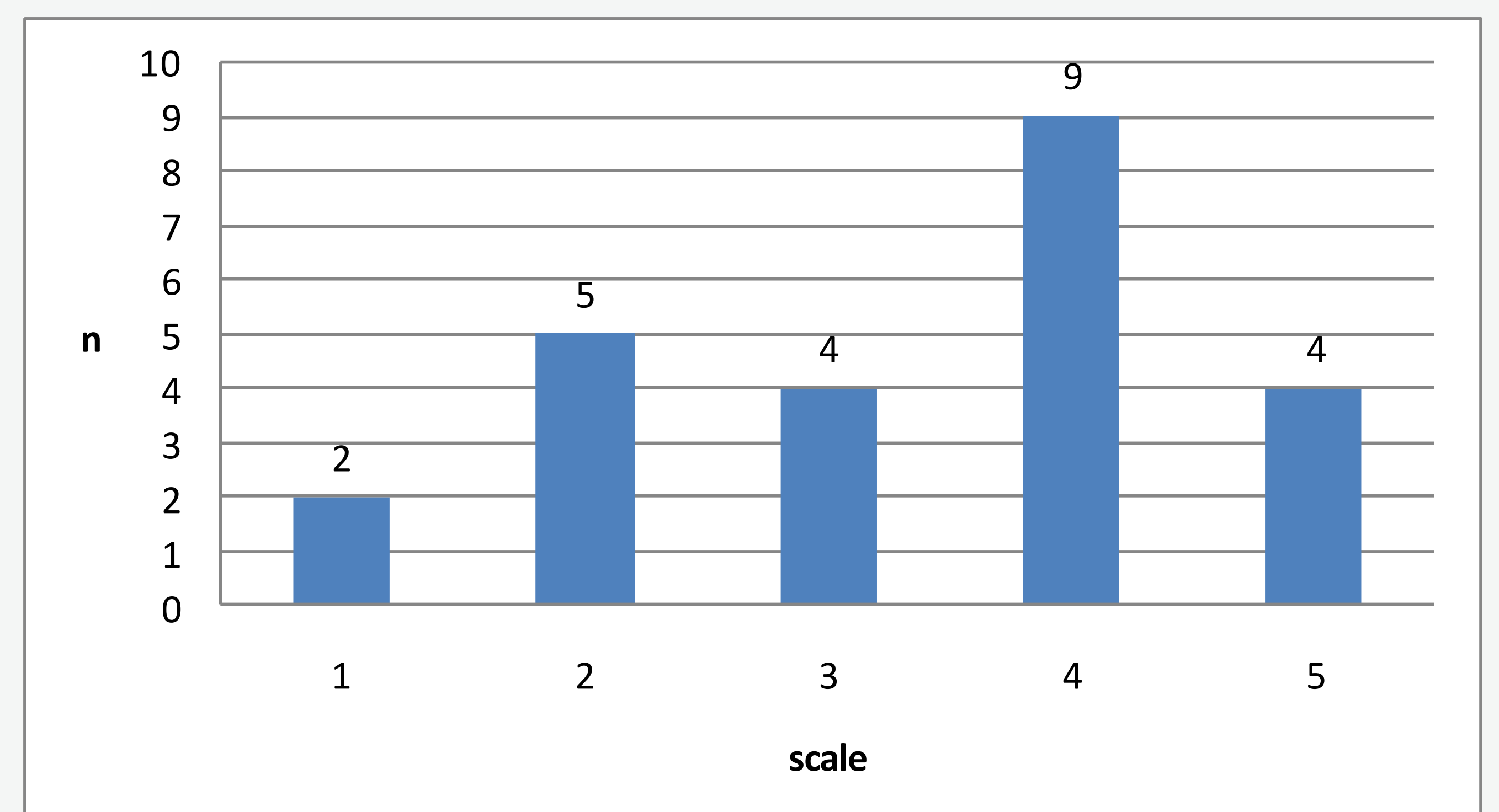


Figure 2. Ways of using lay versions of guidelines within patient organisations, n=24.

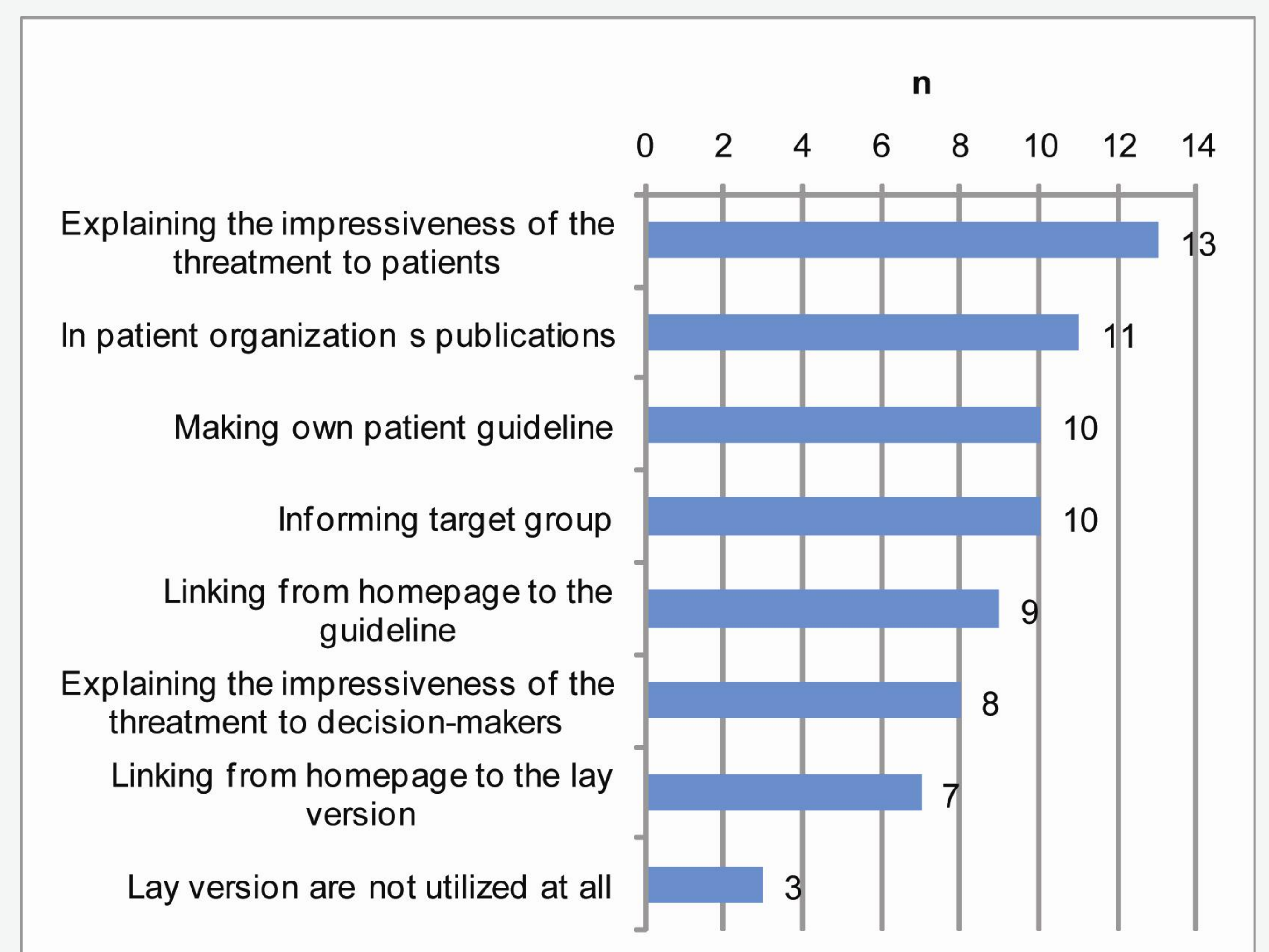


Table 1. The three key questions on diseases, to which patients require answers in the lay version of the related guideline.

| Section of guideline and its lay version | Key questions in lay version of guideline? |
|--|--|
| Disease | What is the prognosis of the disease? |
| | What is the disease in question? |
| | How does the disease advance? |
| Symptoms | What are the most typical symptoms? |
| | What symptoms should I be worried about? |
| | How can I treat the disease at home? |
| Diagnosis | Who can diagnose the disease reliably? |
| | How accurate are the diagnosis tests? |
| | Are there diagnosis criteria? |
| Treatment | How can I treat myself? |
| | What is the best treatment? |
| | Does the medication have side-effects? |
| Prevention / rehabilitation | Do I need rehabilitation? |
| | Do I need to change my lifestyle? |
| | Is the disease preventable? |