Additional file 3. Recommendations through open-ended question

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| Type of recommendation made | N |
| Tailored advice/in line with someone's symptoms | 33 |
| Expand awareness | 30 |
| More empathy/support from an expert | 28 |
| Expanding treatment options | 14 |
| Attention to personal situation | 13 |
| More attention to pain complaints | 13 |
| Provide support in the self-management process | 12 |
| take seriously / treatment | 11 |
| Facilitate access to tools and information | 10 |
| Expert caregivers | 8 |
| Multidisciplinary care | 8 |
| Preference for surgery | 8 |
| Facilitate access to care | 7 |
| Shorten waiting times | 7 |
| Reimbursement in care package | 5 |
| Provide clear information | 4 |
| Expanding scientific research | 4 |
| Provide consistent information | 3 |
| More attention to fatigue complaints | 3 |
| Improve aftercare | 3 |
| Provide current information | 2 |
| More attention to weight loss | 2 |
| More attention for prevention | 2 |
| Information in understandable language | 1 |