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| Item | Response rate No. (%) | Item“Does not apply”No. (%) | Floor effectNo. (%) | “High burden” (score>7)No. (%) |
| 1A. The taste, shape or size of your tablets and/or the inconvenience caused by your injections (e.g., pain, bleeding, scars) | 496(98.8 %) | 91(18.3 %) | 180(44.4 %) | 44(10.9 %) |
| 1B. The number of times you have to take your medication every day | 498(99.2 %) | 61(12.2 %) | 166(38.0 %) | 36(8.2 %) |
| 1C. The things you do to remind yourself to take your daily medication and/or to manage your treatment when you are not at home. | 499(99.4 %) | 71 (14.2 %) | 149(34.8 %) | 60(14.0 %) |
| 1D. The specific conditions when taking your medication (e.g., taking it at a specific time of the day or meal, not being able to do certain things after taking them like driving or lying down) | 501(99.8 %) | 132(26.3 %) | 166(45.0 %) | 45(12.2 %) |
| 1E. The conditions for storing your medications (e.g., in your refrigerator) | 500(99.6 %) | 258(51.6 %) | 155 (64.0 %) | 29(12.0 %) |
| 2A. Lab tests and other exams (frequency, time spent and inconvenience of these exams) | 500(99.6 %) | 31(6.2 %) | 104 (22.2 %) | 85(18.1 %) |
| 2B. Self-monitoring (e.g., taking your blood pressure or measuring your blood sugar yourself: frequency, time spent and inconvenience of this surveillance) | 499(99.4 %) | 243(48.7 %) | 91(35.5 %) | 43(16.8 %) |
| 2C. Doctors visits (frequency and time spent for the visits) | 496(98.8 %) | 27(5.4 %) | 126(26.9 %) | 75(16.0 %) |
| 2D. Arrange appointments and schedule doctors visits and lab tests | 499(99.4 %) | 35(7.0 %) | 129(27.8 %) | 87(18.7 %) |
| 3. How would you rate the burden associated with taking care of paperwork from health insurance agencies, welfare organizations, hospitals and/or social care? | 499(99.4 %) | 56(11.2 %) | 146(33.0 %) | 84(19.0 %) |
| 4. How would you rate the constraints associated with your diet (e.g., not being allowed to eat certain food)? | 500(99.6 %) | 183(36.6 %) | 87(27.4 %) | 73(23.0 %) |
| 5. How would you rate the burden associated with the recommendations from your doctors to practice regular physical exercises? | 496(98.8 %) | 138(27.8 %) | 128(35.7 %) | 73(20.4 %) |
| 6. What is the impact of your healthcare on your social relationships (e.g., need for assistance, being ashamed to take your medication in front of people)? | 498(99.2 %) | 84(16.9 %) | 218(52.7 %) | 67(16.2 %) |
| 7. "Frequent healthcare reminds me of my health problems" | 495 (98.6 %) | - | 187(37.8 %) | 128(22.2 %) |

Appendix 2. Characteristics of the items presented to patients (n=502 patients). Floor-effect frequencies and “high burden patients” frequencies relate to patients concerned by the item and thus not checking “Does not apply”.