# Validation of a Quality-of-Life Questionnaire for Patients with Pituitary Adenoma

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ABSTRACT: *Background:* The purpose of this study was to develop and validate a self-administered questionnaire to measure the health-related quality of life of patients with pituitary adenoma. *Methods:* A patient-centred iterative process, involving a literature review and focus group interviews with 84 patients, was used to develop a preliminary 106-item questionnaire and to validate it. The final questionnaire comprised the 30 most important items chosen by 20 patients and 17 items considered important by health care professionals. For assessment of its validity and reliability, 55 patients were asked to complete the final questionnaire, RAND-36, FACT-G/FACT-Br, and Karnofsky Performance Scale (KPS). Concurrent validity of the results of our questionnaire with those of the other instruments was assessed with Pearson correlation coefficients. Known-group validity for the scores of extreme groups was assessed with a Student's t test. Test-retest reliability was determined with Pearson correlation coefficients and a Student's t test for two sets of scores obtained one month apart. *Results:* Forty-seven (85.5%) of the 55 questionnaires were completed. Our questionnaire was well correlated with the RAND-36, the FACT-Br, the FACT-G, and the KPS in the general health domain, but not with the KPS overall. Extreme groups (n=20) were significantly different. Test-retest reliability (n=24) was 0.88, and scores one month apart were not significantly different. *Conclusion:* Our patient-centred health-related quality of life questionnaire developed for patients with pituitary adenoma had good validity and reliability. This questionnaire could be used as a patient-centred outcome measure in clinical trials and for assessment of disease progression.

RÉSUMÉ: Validation d'un questionnaire sur la qualité de vie chez les patients porteurs d'un adénome pituitaire. Contexte: Le but de cette étude était de développer et de valider un questionnaire autoadministré pour mesurer la qualité de vie reliée à la santé chez les patients porteurs d'un adénome pituitaire. Méthodes: Un processus itératif centré sur le patient, comportant une revue de littérature et des entrevues de groupe échantillon de 84 patients a été utilisé pour développer un questionnaire préliminaire de 106 items et pour le valider. Le questionnaire final inclut les 30 items les plus importants choisis par 20 patients et 17 items considérés importants par des professionnels de la santé. Pour évaluer sa validité et sa fiabilité, on a demandé à 55 patients de compléter le questionnaire final, le RAND 36, le FACT-G/FACT-Br et l'échelle de Karnofsky (ÉK). La validité des résultats de notre questionnaire par rapport à celle des autres instruments a été évaluée au moyen du coefficient de corrélation de Pearson. La validité du groupe connu pour les scores de groupes extrêmes a été évaluée par un test t de Student. La fiabilité test-retest a été déterminée au moyen de coefficients de corrélation de Pearson et du test t de Student pour deux séries de scores obtenus à un mois d'intervalle. Résultats: Quarante-sept (85,5%) des 55 questionnaires ont été complétés. Il existait une bonne corrélation entre notre questionnaire et le RAND 36, le FACT-Br, le FACT-G et l'ÉK dans le domaine de la santé générale, mais pas pour l'ensemble de l'ÉK. Les groupes extrêmes (n = 20) étaient significativement différents. La fiabilité test-retest (n = 24) était de 0,88 et les scores à un mois d'intervalle n'étaient pas significativement différents. Conclusion: Le questionnaire sur la qualité de vie reliée à la santé, centré sur le patient, que nous avons élaboré pour les patients atteints d'adénome pituitaire, avait une bonne validité et une bonne fiabilité. Ce questionnaire pourrait être utilisé comme mesure des résultats centrée

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Pituitary adenomas, which represent ten percent of intracranial tumours¹ and affect people of all ages, may present with mass effect or endocrinopathies. Even with modern treatment, a significant number of patients have recurrences of the tumour or require long-term management and follow-up. Ahmed et al² reported the incidence of recurrence for pituitary-dependent Cushing's disease and acromegaly after five years to be approximately 19% and 33%, respectively. As with other chronic illnesses, the impact on a patient's life may be profound and long lasting. Ezzat³ reported that patients with acromegaly experience personality change, deterioration of self-confidence and initiative, mood changes, and increased absences from work.

In patients with non-secreting pituitary adenoma, Jonsson et al.<sup>4</sup> reported excess morbidity and a rate of retirement twice as high as that of the control group.

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RECEIVED JUNE 8, 2005. ACCEPTED IN FINAL FORM SEPTEMBER 17, 2005. Reprint requests to: Michael Cusimano, Division of Neurosurgery, St. Michael's Hospital, University of Toronto, 2004 - 38 Shuter Street, Toronto, Ontario, M5B 1A6, Canada. One method of assessing the impact of pituitary adenoma is to evaluate the patient's health-related quality of life (HRQOL). Despite consensus that HRQOL is a multidimensional construct, no definition has been universally accepted. Cella and Cherin<sup>5</sup> defined HRQOL as the "patients' appraisal of and satisfaction with their current level of functioning as compared to what they perceive to be possible or ideal." In contrast, Shumaker et al<sup>6</sup> defined HRQOL as "individuals' overall satisfaction with life and their general sense of personal well-being" while Schipper<sup>7</sup> described it as "a pragmatic, day-to-day, functional representation of a patient's physical, psychological, and social response to a disease and its treatment."

The definition of HRQOL is crucial to its measurement. The first two of these definitions require questioning patients about present and optimal levels of well-being in areas of functioning, with emphasis on their subjective evaluation. The third definition's use of the term "functional representation" suggests there is an objective aspect to the evaluation. Another possibility, perhaps a more valid definition, would be to define HRQOL according to both subjective perceptions and objective evaluations.

Self-administered questionnaires are frequently used to assess patients' HRQOL because they are patient-centred, simple to administer, and more resource-efficient than person-to-person or telephone interviews. Burman and Deijen<sup>8</sup> used the Nottingham Health Profile to assess the HRQOL of patients with pituitary deficiency; Page et al<sup>9</sup> used the Short-Form 36 and General Well Being Schedule to evaluate the HRQOL of patients after treatment of non-functioning pituitary tumours. Although these generic instruments are frequently used in quality-of-life (QOL) research in patients with pituitary tumours, they are designed neither to measure the range of health problems these patients experience nor to detect changes in these problems caused by effective interventions. For example, the Nottingham Health Profile<sup>10</sup> is a generic QOL instrument and is not sensitive to some of the factors specific to patients with pituitary adenoma, such as galactorrhea or headaches.

Because a questionnaire that is sensitive to the needs of patients with pituitary conditions and their physicians does not exist in the literature, we sought to develop and validate a simple questionnaire that would accurately measure the HRQOL of these patients. Such a questionnaire could be used as a patient-centred outcome measure in clinical trials and in the assessment of disease progression.

# **METHODS**

The development process for our questionnaire followed the guidelines of Cronin et al,<sup>11</sup> which have been successfully used to develop valid instruments for the HRQOL assessment of other chronic diseases. The process has five stages: identification of the patient population, item selection, item reduction, questionnaire design, and questionnaire validation.

# Identification of patient population

The 84 subjects recruited for the study were volunteers from across Canada who had some interaction with the Pituitary Tumour Support Network of Canada (PTSN), a patient self-help organization, during 1998-1999. They were responders to a

recruitment advertisement placed in the quarterly newsletter published by the PTSN. All patients included were diagnosed with pituitary adenoma. Patients who agreed to participate were enrolled in the study unless they had physical, linguistic, or cognitive difficulties serious enough to prevent them from attending focus group interviews or completing the questionnaire. None of the recruited patients were excluded based on these criteria. Written informed consent was obtained from each participant.

For all participants, we recorded their age, sex, race, level of education, employment, marital status, diagnosis, and duration of diagnosis. Descriptive statistics (mean, range, and standard deviation) were used to summarize the data.

#### Item selection

Item selection was patient-centred and iterative. Issues relevant to the QOL of patients with pituitary adenoma were collected through focus group interviews with nine patients recruited from the local branch as described above and two family caregivers, two registered nurses, and a neurosurgeon, all of whom were experienced in the management of patients with pituitary adenomas.

A small number of items were added after a search of the literature. We conducted a Medline search from 1966 to 1999 using the text words "pituitary adenoma," "pituitary insufficiency," "Cushing's disease," acromegaly," "prolactinoma," "quality of life," "health-related quality of life," and "quality-of-life questionnaire." We reviewed all potentially relevant articles, but found no disease-specific tool to assess the HRQOL of patients with pituitary adenoma. The issues identified from the literature search and interviews were combined to form the initial list of items. After the redundancies had been eliminated, we categorized the revised pool of issues into six domains: general health, emotional health, social and family well-being, health problems related to pituitary adenoma, treatment of pituitary adenoma, and relationship with physicians.

# Item reduction

A list of 106 items was generated from the initial item selection. These were given to 20 additional patients (the nine in focus group interviews were excluded) chosen at random from the study group for review and further suggestions. When no new items were generated, the iterative process was terminated, and item reduction began. Each of the 20 patients examined the final list individually to identify the issues most relevant to his or her OOL.

For each issue identified, the patient rated its importance on a scale ranging from 1 (not important) to 5 (extremely important). Every issue on the list was then assigned an impact score, defined as the product of the number of patients choosing it as relevant and the average score assigned to it.

To keep the final questionnaire short, we included only the top 30 issues as ranked by their impact scores, along with the 17 additional issues from the list that physicians and nurses considered important. The final questionnaire (Appendix 1) consisted of 54 questions rated on a 7-point scale (1 representing an excellent QOL and 7 a poor QOL), covering 47 issues.

#### Validation

Two copies of the final questionnaire were administered to the remaining 55 patients of the study sample from across Canada who represented the spectrum of all subtypes of pituitary adenoma; their responses were used to test the validity and reliability of the questionnaire. These patients returned the first questionnaire immediately in person at a national conference held by PTSN and were asked to complete and return the second questionnaire by mail one month later. After completing the initial questionnaire, each patient was asked to record the time taken for its completion and to state any difficulty in either understanding or completing it.

Concurrent validity, an independent corroboration that an instrument measures what it is intended to measure, <sup>12</sup> was assessed by calculating the Pearson correlation coefficients between the total and subscale scores on our final questionnaire and the scores obtained by our subjects on the following instruments: the RAND-36, <sup>13</sup> the Functional Assessment of Cancer Therapy (FACT-G) and its subscale for adult patients with brain tumours (FACT-Br), <sup>14</sup> and the Karnofsky Performance Scale (KPS). <sup>15</sup>

Known-group validity, which is based on the hypothesis that certain groups of respondents will score higher on a scale than others, <sup>16</sup> was determined by comparing the mean total scores on the final questionnaire of two extreme groups identified by their RAND-36 scores (ten patients with the highest and ten with the lowest RAND-36 scores) with a two-sided Student's t test.

Scores for the questionnaire administered twice, one month apart, to the same patients were also compared with a two-sided Student's t test, and the Pearson correlation coefficient for the two sets of scores was calculated. The results of both calculations were used to evaluate the test-retest reliability of the questionnaire. The Pearson correlation coefficient for the two corresponding sets of RAND-36 scores was used to estimate the change in QOL for these patients during the one-month period. P values of 0.05 or less were considered significant.

#### RESULTS

# Study population

The 84 study subjects were predominantly white (90%) and female (86%), and ranged in age from 20 to 71 years (mean 43).

Table 1: Correlations between scores on our questionnaire and corresponding scores on the RAND-36

RAND-36	Developed questionnaire	Pearson correlation coefficient
General health	General health	0.62
Social function	Social/family well-being	0.52
Emotional well-being	Emotional health	0.62
Total score	Total score	0.72

Table 2: Correlations between scores on our questionnaire and corresponding scores on the FACT-G/FACT-Br

FACT	Developed questionnaire	Pearson correlation coefficient
Physical health of FACT-G	General health	0.77
Social/family well- being of FACT-G	Social/family well-being	0.36
Emotional well-being of FACT-G	Emotional health	0.54
Total score (FACT-G)	Total score	0.68
Total score (FACT-Br)		0.49

FACT-G= Functional Assessment of Cancer Therapy - General; FACT-Br=FACT-G subscale for adults with brain tumours.

The prevalence of prolactinoma, Cushing's disease, acromegaly, and non-secreting adenoma among the study group was 38%, 9%, 13%, and 40%, respectively. The mean duration of diagnosis was seven years. Our study population consisted of a broad social background with a wide variety in employment, level of education, and marital status.

# Concurrent validity

The validity data were based on the responses of 47 subjects (85.5% response rate). The total and subscale scores of our questionnaire correlated well with corresponding scores on the RAND-36 and the FACT-G/FACT-Br (Tables 1 and 2). The same was true for the scores on the KPS and our general health domain: the Pearson correlation coefficient was 0.75. However, KPS scores correlated poorly with the total score of our questionnaire, with a Pearson correlation coefficient of only 0.27.

# Extreme-group validity

A better QOL was indicated by a lower score on our questionnaire and a higher score on the RAND-36. The ten patients with the highest RAND-36 scores had lower scores on our questionnaire than those with the lowest RAND-36 scores. The group with the highest RAND-36 scores had a mean score of 15.66 on our questionnaire, significantly lower than the mean score of 23.12 of the group with the lowest RAND-36 scores (P=0.011).

#### Test-retest reliability

The data for test-retest reliability were based on the responses of 24 patients who had completed the questionnaire twice (43.6% of the 55 asked to complete it twice). The scores for the respondents (n=24) tested twice, one month apart, were not significantly different (1st vs. 2nd score 21.42 vs. 20.68,

P=0.73), with a Pearson correlation coefficient of 0.88. The Pearson correlation coefficient for the two corresponding sets of RAND-36 scores was 0.75.

# Feasibility of questionnaire administration

The questionnaire took an average of 11 minutes to complete (median 10 min). All respondents completed the questionnaires independently and did not report any difficulty in understanding or completing it. The response rate on the first validation of the questionnaire was high (47/55, 85.5%), but much lower (24/55, 43.6%) on the second questionnaire returned by mail one month later.

#### DISCUSSION

The patient-centred, self-administered questionnaire developed in our study had good reliability and validity. The reproducible results for participants responding to the questionnaire twice after a one-month interval indicated its testretest reliability. Thus, the questionnaire results should be stable over time if the patient's health status remains unchanged. Our patients' health status was stable, as evident from the high correlation coefficient between the corresponding sets of RAND-36 scores one month apart.

The patient-centred, iterative design process, with input from the literature and from health professionals experienced in the management of patients with pituitary adenoma, ensured the content validity of the questionnaire. The significant difference between the scores of the two extreme groups on our questionnaire suggests that it was sensitive to the differences in HRQOL between different patient groups.

The independent correlation between total scores on our questionnaire and those obtained on other instruments (0.72 with RAND-36 and 0.68 with FACT-G) confirmed the concurrent validity of our questionnaire. It had a higher overall correlation with the FACT-G than the FACT-Br,<sup>14</sup> its brain subscale, likely because FACT-Br was a QOL instrument developed for patients with glioma, a much more fatal neoplasm than pituitary adenoma, and they defined issues important to QOL differently than the patients with pituitary adenoma did.

Although the overall correlation of our questionnaire is high with both RAND-36 and FACT-G, the correlation between the individual corresponding subscales is lower (e.g., 0.52 with RAND-36 social function and 0.36 with FACT-G family/social well-being). This supports our theory that, although wellvalidated generic instruments are available for QOL research in patients with pituitary tumors, they are not developed to measure the specific health and health-related problems these patients experience. In other words, although FACT-G, a QOL questionnaire developed by breast, lung, and colorectal cancer patients for evaluating patients receiving cancer treatment, and RAND-36, a general instrument for measuring health status in any generic population, can provide a crude estimate of the overall QOL of patients with pituitary tumours (illustrated by the high overall correlation of the three questionnaires), they are not sensitive to many of the factors specific to patients with pituitary adenoma, such as endocrinopathies, visual disturbances, and impact of surgery (as evident from the lower correlation of the RAND-36 and FACT-G subscale scores to our questionnaire).

Correlations between scores on our questionnaire and the KPS also provided evidence for the validity of our questionnaire as a disease-specific instrument. Quality of life (QOL) is a multidimensional construct that encompasses many more domains than just physical well-being. The KPS, a unidimensional measure of physical functional status, cannot measure them all, 10 as was evident from the high correlation (r=0.75) between the scores on the KPS and the general health subscale of our questionnaire, and the low correlation (r=0.27) between the KPS scores and the total scores on our questionnaire. Further, with one exception, our subjects' KPS scores ranged from 70 to 90 and had significantly less variability than their scores on our questionnaire and the RAND-36. These findings suggest that the KPS is not sensitive enough to distinguish the differences in the OOL of our patient population and a QOL questionnaire sensitive to the needs of patients with pituitary conditions is needed.

The questionnaire appears to have good acceptability. Patients who are not neurologically impaired completed our questionnaire in 11 minutes, on average, with no assistance. Furthermore, the questionnaire seems user-friendly and easy to complete and does not place an increased burden on patients, as evident from the high response rate (85.5%) to its initial administration. The fall in the response rate (to 43.6%) in the subsequent administration through the mail strongly suggests that the questionnaire is better administered directly in person.

The frequency of different types of adenoma in our study sample approximates closely that reported by Horvath and Kovacs<sup>17</sup> in unselected surgical biopsies, supporting the resemblance of our study population to the general patient population with pituitary adenomas. In addition, although our patient sample was predominantly white female, they were representative of the general population with a broad social and demographic background (a wide variety in age, employment, level of education, and marital status).

The findings of our study, nevertheless, may be limited because of our study population. Our selection of subjects from a patient support group may have biased the results: Patients with other chronic illnesses, such as diabetes, who attend support groups tend to know more about their illness and may enjoy a QOL different from that of the general population of patients with the disease under study. 18 Likewise, our patients' views of the important issues in QOL assessment may differ from those held by the general population of patients with pituitary adenoma. However, our questionnaire design process, which included input from health professionals and the literature, likely compensated for this potential source of selection bias. Future studies comparing the scores of members of the study population who regularly attend support groups with those of inactive members more characteristic of the general patient population would allow us to examine differences between these groups.

Successful treatment of pituitary adenoma that reduces the burden of symptoms and associated psychosocial stress should improve a patient's QOL. Therefore, QOL assessment could contribute vital information to an evaluation of the effectiveness of treatment. In this study, we developed and validated a HRQOL questionnaire specific to patients with pituitary adenoma. It fits well with the current concept of a modular approach<sup>9</sup> to QOL instruments, in which a disease-specific

instrument is used to complement a general measure. In the future, subscales of our questionnaire will be further developed for different subtypes of pituitary adenoma.

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# APPENDIX 1. QUALITY OF LIFE QUESTIONNAIRE FOR PATIENTS WITH PITUITARY TUMOUR

Listed below are a number of questions concerning issues of importance to patients with pituitary tumour. Please indicate the extent to which you experienced each item by circling the appropriate numeral for each item.

#### General Health

#### In the last 7 days, describe your:

- 1. Health in general (excellent) 1 2 3 4 5 6 7 (extremely poor)
- 2. Energy level (excellent) 1 2 3 4 5 6 7 (extremely poor)
- 3. Level of physical pain (none) 1 2 3 4 5 6 7 (intolerable)
- 4. Independence of others in every day living (totally independent) 1 2 3 4 5 6 7 (totally dependent)
- 5. Ability to perform work (extremely high) 1 2 3 4 5 6 7 (severely impaired)
- Sexual function (excellent) 1 2 3 4 5 6 7 (extremely poor)
  (e.g. Male = erection/orgasm/ejaculation. Female = pain/discomfort/bleeding during intercourse/ability to achieve orgasm)
- 7. Sex drive (excellent) 1 2 3 4 5 6 7 (extremely poor)

#### In the last 7 days,

- 8. Rate the quality of your sex life (excellent) 1 2 3 4 5 6 7 (poor)
- Looking at the above 8 questions, how much would you say your General Health affects your quality of life? (not at all) 1 2 3 4 5 6 7 (very much so)

#### Emotional Health

#### In the last 7 days, describe your:

- 10. Level of anxiety (none) 1 2 3 4 5 6 7 (extremely high)
- 11. Sense of peacefulness (extremely high) 1 2 3 4 5 6 7 (none)
- 12. Level of happiness (extremely high) 1 2 3 4 5 6 7 (none)
- 13. Outlook on future (extremely optimistic) 1 2 3 4 5 6 7 (extremely pessimistic)
- 14. Level of stress (none) 1 2 3 4 5 6 7 (extremely high)
- 15. Sense of control over life (extremely high) 1 2 3 4 5 6 7 (none)
- 16. Sense of accomplishments (extremely high) 1 2 3 4 5 6 7 (none)

# In the last 7 days,

- 17. Did you worry that your condition would get worse? (never) 1 2 3 4 5 6 7 (always)
- 18. Looking at the above 8 questions, how much would you say your **Emotional Health** affects your quality of life? (not at all) 1 2 3 4 5 6 7 (very much so)

# Social/Family Well-Being

#### In the last 7 days,

- 19. Rate your relationship with family (excellent) 1 2 3 4 5 6 7 (poor)
- 20. How did your tumour and its treatment(s) affect your relationship with family? (currently free of treatment) 0, (drastically improved) 1 2 3 4 5 6 7 (drastically disrupted)
- 21. Rate your relationship with friends (excellent) 1 2 3 4 5 6 7 (poor)
- 22. How did your tumour and its treatment(s) affect your relationship with friends? (currently free of treatment) 0, (drastically improved) 1 2 3 4 5 6 7 (totally disruptive)
- 23. Rate the amount of support you received from your family (plenty) 1 2 3 4 5 6 7 (none)
- Rate the amount of support you received from your friends (plenty) 1 2 3 4 5 6 7 (none)
- 25. Rate the amount of support you received from support groups (plenty) 1 2 3 4 5 6 7 (none)
- 26. Looking at the above 7 questions, how much would you say your **Social/Family Well-Being** affects your quality of life? (not at all) 1 2 3 4 5 6 7 (very much so)

#### Health Problems Related to Pituitary Tumour

# In the LAST 4 WEEKS, describe your:

 Menstrual period (not applicable) 0, (no effect) 1 2 3 4 5 6 7 (totally disruptive)

- 28. Ability to conceive (not applicable) 0, (no effect) 1 2 3 4 5 6 7 (totally disabled)
- 29. Personality change (none) 1 2 3 4 5 6 7 (extremely severe)

#### In the LAST 7 DAYS, describe your:

- Frequency of headaches (not applicable) 0, (no effect) 1 2 3 4 5 6 7 (severely increased)
- 31. Intensity of headaches (not applicable) 0, (no effect) 1 2 3 4 5 6 7 (severely increased)
- 32. Experience with nausea/vomiting (extremely frequent) 1 2 3 4 5 6 7 (none)
- 33. Ability to concentrate (excellent) 1 2 3 4 5 6 7 (extremely poor)
- 34. Vision (excellent) 1 2 3 4 5 6 7 (extremely poor)

#### In the LAST 7 days:

- 35. To what extent did you notice bruising on your body? (unnoticeable) 1 2 3 4 5 6 7 (very extensive)
- 36. To what extent did you notice stretch marks on your skin? (unnoticeable) 1 2 3 4 5 6 7 (very extensive)
- 37. To what extent did you notice an excessive amount of hair growth on your face/body? (unnoticeable) 1 2 3 4 5 6 7 (very excessive)
- 38. To what extent did you notice an excessive roundness of your face? (unnoticeable) 1 2 3 4 5 6 7 (very excessive)
- 39. To what extent did you notice a "hump" on your back? (unnoticeable) 1 2 3 4 5 6 7 (very extensive)
- 40. To what extent did you notice an unexplained gain in weight? (unnoticeable) 1 2 3 4 5 6 7 (very extensive)
- 41. To what extent did you notice the darkening of your skin compared to its usual colour? (unnoticeable) 1 2 3 4 5 6 7 (very extensive)
- 42. To what extent did you notice a decrease in muscle bulk? (unnoticeable) 1 2 3 4 5 6 7 (very extensive)
- 43. How frequently did you experience unexplained fractures (especially fractures of the spine)? (never) 1 2 3 4 5 6 7 (frequently)
- 44. To what extent did you notice an excessive size of your tongue, lips, hands, or feet? (unnoticeable) 1 2 3 4 5 6 7 (very excessive)
- 45. To what extent did you notice milky discharge from your nipples? (unnoticeable) 1 2 3 4 5 6 7 (very excessive)
- 46. Looking at the above 19 questions, how much would you say your **Health Problems Related to Pituitary Tumour** affects your quality of life? (not at all) 1 2 3 4 5 6 7 (very much so)

#### Treatment of Pituitary Tumour

- 47. Rate your satisfaction with the treatment(s) for pituitary tumour in controlling/curing your pituitary tumour and improving your quality of life (currently free of treatment) 0, (excellent) 1 2 3 4 5 6 7 (poor)
- 48. To what extent have the side effects of treatment(s) affected your life? (currently free of treatment) 0, (no side effects) 1 2 3 4 5 6 7 (extremely disruptive)
  - Please specify the treatment and the side effects of the **specific** treatment:
- Looking at the above 2 questions, how much would you say your Treatment and its Side Effects affects your quality of life (not at all) 1 2 3 4 5 6 7 (very much so)

#### Relationship with Physician

#### In general

- 50. Rate the overall satisfaction of your family physician in managing your pituitary tumour. (not applicable) 0, (very satisfied) 1 2 3 4 5 6 7 (very dissatisfied)
- Rate the overall satisfaction of your endocrinologist in managing your pituitary tumour. (not applicable) 0, (very satisfied) 1 2 3 4 5 6 7 (very dissatisfied)
- Rate the overall satisfaction of your neurosurgeon in managing your pituitary tumour. (not applicable) 0, (very satisfied) 1 2 3 4 5 6 7 (very dissatisfied)
- 53. Looking at the above 3 questions, how much would you say your Relationship with Physician affects your quality of life? (not at all) 1 2 3 4 5 6 7 (very much so)
- 54. If you have any other medical conditions, rate the degree to which these other conditions affect your quality of life (other medical conditions have the main/major influence on my quality of life) 1
  - (pituitary tumour and the other conditions have an equal influence on my quality of life) 2
  - (pituitary tumour has the main/major influence on my quality of life) 3

please specify the other medical conditions