

PATIENT NETWORKS AS A DATA-SOURCE FOR PRO RESEARCH. CARENITY EXPERIENCE

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OBJECTIVE

- To explore the potential of online patient networks (PN) as a viable source of PRO data for clinical research. Several PNs have emerged in the last few years in different European countries, and as a natural meeting point for chronic patients they represent a promising source of patient reported data. In this poster, the experience with the French PN “carenity.com” is described.
- carenity.com (Figure 1) helps patients from a wide variety of conditions monitor their health by gathering data about their treatments and symptoms.

METHODS

- Given the great heterogeneity of the users of “carenity.com”, and the fact that the test was computer-led by definition, a Computer Adaptive Test (CAT) was considered the best choice.
- The authors decided to use a culturally adapted version of CAT-Health system, which measures generic health-related quality of life (HRQoL).
- In absence of a calibration for the French population, a selection of the best items was used, using the Spanish calibration as a reference.
- All patients in the PN were invited to participate in the test. A score was estimated for the test using the Spanish parameters, as a rough approximation of the real score.
- Age, sex and the main pathology of the subjects were also collected.

RESULTS

- Preliminary results from the first week of data collection show 601 patients answered (Women: 404, Men: 140).
- The most frequent reported pathologies and their t-scores can be seen in Table 1.
- Significant differences ($p < 0.05$) were found in diabetes patients by sex, and between both types of diabetes and the other 3 most common pathologies (Figure 2).

Table 1. Most frequent conditions

Condition	N	Mean Score	SD
Multiple Sclerosis	92	37.91	5.86
Fibromyalgia	81	36.65	4.99
Ankylosing Spondylitis	60	37.74	5.32
Type I Diabetes	53	50.38	10.94
Type II Diabetes	41	48.12	10.04
Rheumatoid Arthritis	36	40.70	8.79
Lupus	30	41.41	4.74
Bipolar Disorders	24	42.64	7.29
Crohn and Ulcerative Colitis	20	42.97	4.01
COPD	14	47.41	12.73

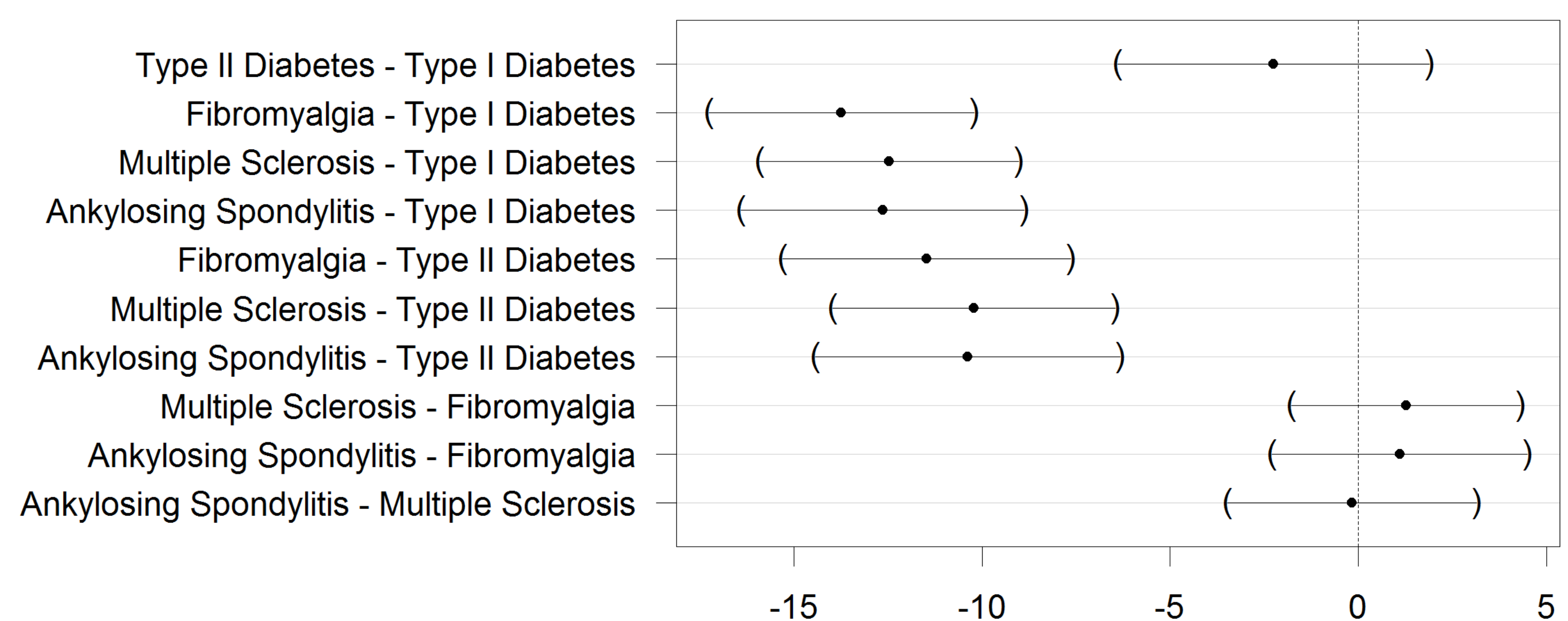
CONCLUSIONS

- Patient networks seem to be a fast way to obtain PRO scores directly from patients.
- Preliminary results show differences in the expected direction, backing the validity of the data collected from this source.

Figure 1. Screenshot of the carenity.com website



Figure 2. Tukey HSD confidence intervals for 5 most frequent conditions



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