

Implementation of an in situ developed Patient Reported Outcome Measure in rural Ecuador.

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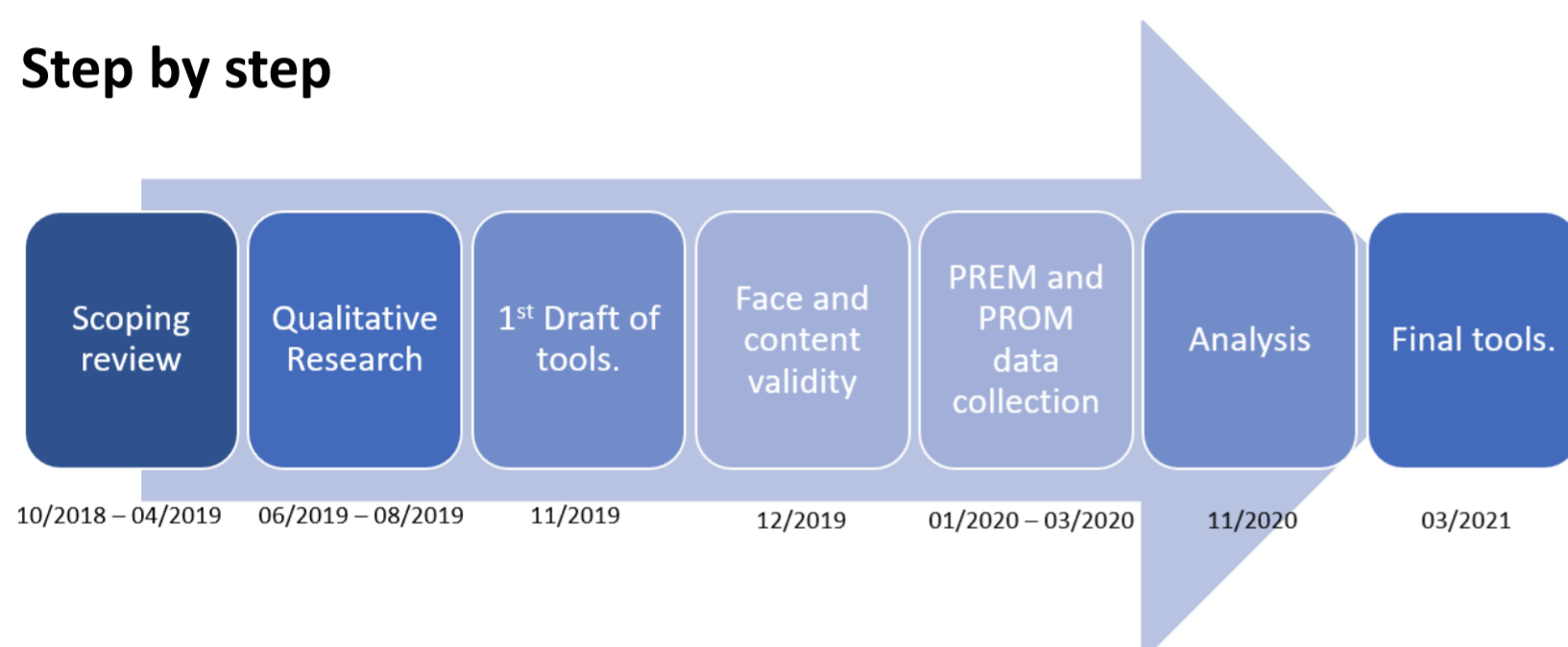
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Introduction

In Ecuador, diabetes is the second cause of death, only after ischemic heart disease of which is also a well established risk factor. A recent scoping review of patient reported measures could not retrieve any in-situ developed diabetes specific tool in low and middle-income countries. All of them were developed in high-income countries with strong economies and robust health care systems. Nowadays, the evaluation of healthcare services should not be done without patients' perspective, taking advantage of the information they provide to increase quality levels of healthcare services. The objective of this study was to develop in Ecuador for the first time a PROM instrument, the EPD Questionnaire (EPD, Experiencia de la Persona con Diabetes).

Methods

Step by step



1st phase: Qualitative Research

- 4 focus groups and 6 semi-structured interviews.

2nd phase: Validation Study

- To be eligible participants had to be 18 years or older, been diagnosed with type 2 diabetes, be able to understand the questions.

- Setting of the study was primary care health centers from rural and urban areas of Ecuador.

- Selection process of respondents was randomly executed by healthcare professionals working in each of the participating health centers.

Sample size was established using the formula for finite universes considering the last available prevalence data of diabetes in Ecuador.

The PROM instrument of the EPD Questionnaire has 12 items and three factors measuring symptoms and burnout (factor 1), worries and fears (factor 2) and social limitations (factor 3).

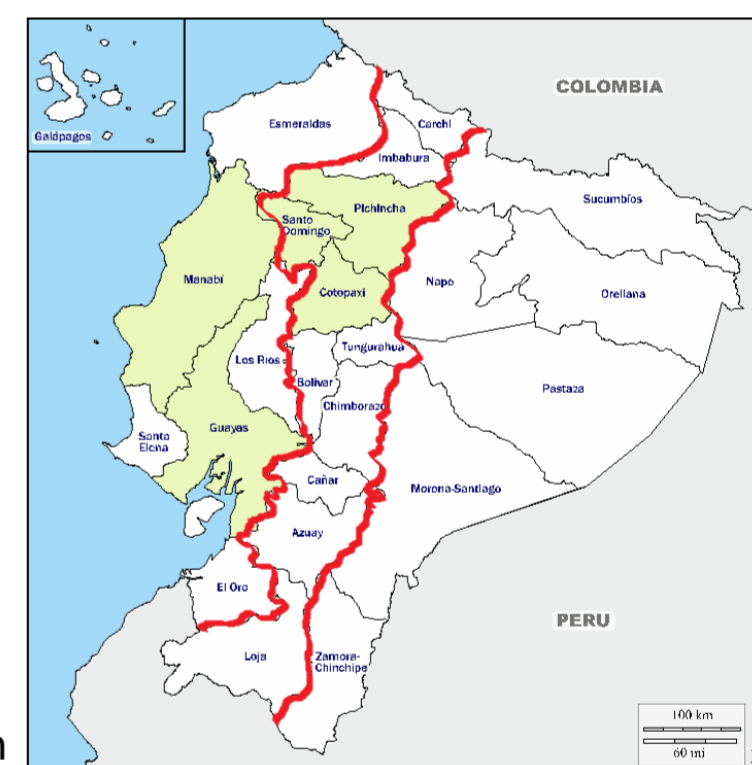
The recall period was last month, and responses are rated in a four-point Likert scale (4=hardly ever – 1=everyday).

Scores are calculated as the sum of the individual scores for each factor.

The hypothesis that scores on the scale would be higher in urban areas compared to rural areas was tested using the Mann-Whitney U test. This due that in urban areas exists a higher education level and improved access to health.

The study was approved by a Local Ethics Committee (HCK-CEISH-19-0041)

Image shows a map of geographic location of the intervention



Results

A total of 486 patients from urban (57%) and rural areas (43%) from coastal and highlands were included. 58% were women, mean age of participants was 59.2. Overall patients from rural areas reported worse outcomes in all three factors ($p < 0.05$), symptoms and burnout (15.9 vs 17.1) worries and fears (5 vs 5.7) and social limitations (16.9 vs 17.4).

	Rural (N=207)	Urban (N=281)	p-value
1. I am very thirsty even if I drink water.	3,0 ± 0,9	3,4 ± 0,7	<0.001
2. I have been feeling weak	3,2 ± 0,7	3,4 ± 0,7	0.001
3. I am afraid I'll go blind	2,3 ± 1,1	2,7 ± 1,0	<0.001
4. I am afraid to go to dialysis.	2,6 ± 1,1	3,0 ± 1,0	<0.001
5. I have stopped treatment for diabetes because I have difficulty paying for it.	3,4 ± 0,6	3,5 ± 0,6	0.04
6. I have trouble getting my work done.	3,4 ± 0,6	3,5 ± 0,6	0.04
7. I have been alone in the face of illness.	3,3 ± 0,7	3,4 ± 0,6	0.02
8. I have had problems with my family or friends because of diabetes (for example, an argument about what I can eat).	3,3 ± 0,6	3,4 ± 0,6	0.004
9. I have stopped going on vacations or weekends because of my diabetes treatment.	3,4 ± 0,7	3,5 ± 0,6	0.1
10. I use natural treatments instead of pills.	3,4 ± 0,6	3,5 ± 0,6	0.3
11. I have trouble knowing how much to eat.	3,2 ± 0,7	3,4 ± 0,7	<0.001
12. I have felt defeated by living with diabetes.	3,3 ± 0,7	3,4 ± 0,6	0.002
Factor 1: 1, 2, 8, 11, 12	15,9 ± 2,8	17,1 ± 2,7	<0.001
Factor 2: 3, 4	5,0 ± 2,0	5,7 ± 1,8	<0.001
Factor 3: 5, 6, 7, 9, 10	16,9 ± 2,4	17,4 ± 2,5	0.02
Total	37,8 ± 4,6	40,2 ± 4,9	<0.001

Conclusion

The EPD Questionnaire is probably the first instrument developed in a middle-income country, which included a mixed-methods study to capture all dimensions relevant for the intended population. In our study we have assessed results taken into consideration other variables more socially related, such as urban and rural areas. Each of them poses different characteristics for individuals, related with access to health, income, and education. In general, individuals located in urban areas show better results indicating a flaw of the national health system.

Martin-Delgado J, et al. Patient-Reported Experience and Outcome Measures in People Living with Diabetes: A Scoping Review of Instruments. The Patient-Patient-Centered Outcomes Research. 2021 May 27:1-5. <https://doi.org/10.1007/s40271-021-00526-y>

Martin-Delgado J, et al. Development and validation in Ecuador of the EPD Questionnaire, a diabetes-specific patient-reported experience and outcome measure: a mixed-methods study. Health Expect. 2021. <https://doi.org/10.1111/hex.13366>

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