

Questionnaire for ePatients.

A. In this section, we are interested in your usual follow-up in general, once your chronic hypoparathyroidism is at steady state, without any complications/symptoms:

1. How often your physician(s) check for your plasma calcium concentration? <1/year 1/year 2/year 3/year 4/year >4/year I have never been at steady state
2. Did your physician(s) check for kidney imagery? Yes No
 - a. If yes, how often? <1/year 1/year >1/year NA
 - b. If yes, what kind of imagery was the most often performed? Plain X-ray Ultrasonography Computerized tomography Other: NA
3. Did your physician(s) check for eye complications? Yes No
 - a. If yes, how often? <1/year 1/year >1/year NA
4. Did your physician(s) check for bone mineral density? Yes No
 - a. If yes, how often? only once <1/year 1/year >1/year NA
5. Did your physician(s) check for brain imagery? Yes No
 - a. If yes, how often? only once <1/year 1/year >1/year NA
6. Did your physician(s) check for another morphological examen (excluding any biology)? Yes : No
7. If your chronic hypoparathyroidism is not related to surgery, did your physician propose any genetic testing? Yes No The cause of my chronic hypoparathyroidism is surgery
8. If your chronic hypoparathyroidism is not related to surgery, did your physician ask for any family history? Yes No The cause of my chronic hypoparathyroidism is surgery

B. In this section, we will focus on the target(s) of your treatment:

9. Were you involved into defining the aims and targets of your treatment with your physician? Yes, totally Yes, partly Not at all
10. Were symptoms (their absence) a target? Yes No I don't know
11. Was the plasma calcium concentration a target? Yes No I don't know
 - a. If yes, what was the target value? <2.0 mmol/L (80 mg/L) 2.0-2.2 mmol/L (80-88 mg/L) 2.2-2.4 mmol/L (88-96 mg/L) >2.4 mmol/L (96 mg/L) I don't know
12. Was the plasma phosphate concentration a target? Yes No I don't know
13. Was the calcium-phosphate product in blood a target? Yes No I don't know
14. Was the urine calcium content a target? Yes No I don't know
 - a. If yes, how often did you collect your urine for checking calcium content? <1/year 1/year >1/year I don't remember having collected my urine for this purpose

C. The following questions are about you, personally:

15. How old are you? _ _
16. Are you A man? A woman?
17. Which year the diagnosis of your chronic hypoparathyroidism was confirmed (i.e. when a physician told you so)? _ _ _ _
18. Which year do you think your chronic hypoparathyroidism already started (i.e. the year of the surgery that causes it, if so, or the year you felt the first symptoms)? _ _ _ _
19. How many physicians (including the actual one) did you consult for finding one to take care of your hypoparathyroidism? 1 2 >3 4 >4
20. How far are you from the physician who follows your chronic hypoparathyroidism (answer only one way)? _ _ _ km
21. What is the actual main cause of your chronic hypoparathyroidism? Neck surgery Gene defect Radiotherapy Auto-immune/infiltrative Other:
22. Select the therapies you actually follow for treating your chronic hypoparathyroidism: calcium-rich diet Calcium supplements vitamin D native (« D3 » in pills, or Uvédose®, Dédrogyl®) Un-alfa® Rocaltrol® magnesium supplements Diuretics to limit the amount of calcium in urine phosphate binders (not including calcium-based ones) PTH injections Other:
23. What is the specialty of the physician who follows your chronic hypoparathyroidism?
24. What is their structure to follow your chronic hypoparathyroidism? For profit private Non-profit private Non-university public University public
25. What is the district code of the physician who follows your chronic hypoparathyroidism? _ _
26. Do you already participate in the Épi-Hypo study (www.epihypo.org)? Yes No I don't know