

## 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](http://www.epihypo.org))?  Yes  No  I don't know