A national cross-sectional survey on real-world experiences of calcitonin gene-related peptide (CGRP) monoclonal antibody use in adults with migraine in Finland

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Supplementary methods

Final survey questionnaire

[The original survey was conducted in Finnish; an English translation has been provided here for publication. Brand names of drugs have also been removed or revised to generic names in this version for publication]

National migraine study – Patient survey for biological preventative migraine medication users in Finland

Welcome to participate the national migraine survey!

The study is targeted at migraine patients over 18 years old who **currently use or have previously used any of the following biological preventative migraine medication: erenumab, fremanezumab or galcanezumab** to treat their condition. In this survey we would like to collect answers about your experiences of everyday life with migraine and its medication. Data from this study will be used for scientific purposes.

The survey includes 46 questions and it will take approximately 10–15 minutes to answer.

The survey is completely anonymous and does not collect any such information that could be used to identify you afterwards. Participation in the survey is completely voluntary and you may skip questions or stop answering at any point of the survey if you so wish to do.

More information about data protection and privacy:
https://www.oriola.com/fi/palvelut/apteekit/tutkimusapteekit/tutkimusten-tietosuojaselosteet/

We ask you to carefully read each question and the answer options, and then answer each question as truthfully as possible. You may have received an invitation to participate in this survey through your pharmacy or Migraine Finland, but regardless, we ask you to participate in the survey only once.

☐ I have carefully read the instructions for this study and I want to participate in the national migraine study

A. I am <u>over 18 years old</u>, and I use or have used biological preventative migraine medication (fremanezumab, erenumab or galcanezumab) as follows:

- **I currently use this medication → Continues**
- **I have used this medication but discontinued or I am having a break- → Continues (Q3 and section 2 not shown)**
- **I have not used this medication → The survey ends**

Thank you for your interest in this study!

SECTION 1/5 First, we would like to ask few questions about your migraine and migraine medication.

1. Which one of the following biological preventative migraine medications and doses do you **<u>currently</u>** use to treat your migraine?
    - Fremanezumab 225 mg
    - Fremanezumab 675 mg (225 mg × 3 injections)
    - Erenumab 70 mg
    - Erenumab 70 mg (×2 injections)
    - Erenumab 140 mg
    - Galcanezumab 240 mg as a loading dose followed by 120 mg
    - Galcanezumab 120 mg
    - None of the above mentioned →2 (skip Q3 and section 2, not shown, if Q4 is no→ the survey ends)

1B. How often do you administer [**medication name**] to treat your migraine?

- Once every week
- Once every 2 weeks
- Once every 3 weeks
- Once every 4 weeks/Once every month
- Once every 2 months
- Once every 3 months

- Once every 4 months

2. Approximately how old were you when you were first diagnosed with migraine?
    - Under 18
    - 18–24
    - 25–34
    - 35–44
    - 45–59
    - 60–80
    - Over 80

3. How long have you been using the **current** biological preventative migraine medication?
    - I am just about to start → (skip section 2)
    - 0–4 weeks
    - 1–3 months
    - 3–6 months
    - 6–12 months
    - 1–2 years
    - 2 years or longer
    - I do not remember

4. Have you previously been treated with any biological preventative migraine medication (erenumab, fremanezumab, galcanezumab)?
    - Yes → 4B
    - No → 5 (if Q1 is 'none of the above mentioned' – survey ends)
    - I do not remember → 5

4B. With which of the biological preventative migraine medications mentioned below have you previously been treated with? (Please select all that apply)

- ☐ Fremanezumab 225 mg → C
- ☐ Fremanezumab 675 mg (3 × 225 mg injections) → C
- ☐ Erenumab 70 mg → C
- ☐ Erenumab 140 mg → C
- ☐ Galcanezumab 120 mg → C
- ☐ I do not remember → 5.

4C. How long did you use [**brand name**]?

Goes back to 4B and repeats each of the selected options

- Less than 3 months
- 3 months or longer
- I do not remember

4D. [**brand name**] was discontinued for the following reasons (you may select more than one option):

- ☐ It was not suitable for me
- ☐ Administration device was too difficult to use
- ☐ It did not help at all
- ☐ It first helped but then the effect ceased
- ☐ I personally wanted to try another product
- ☐ Someone else recommended that I switch products
- ☐ I became pregnant or started breastfeeding
- ☐ My treatment was switched to another clinic/doctor and as a result my medication was changed
- ☐ Another similar medication came on the market
- ☐ The medication was too expensive
- ☐ I do not need the medication anymore
- ☐ Other
- ☐ I do not remember

5. How many oral **preventative medicines** have you tried before switching to injectable biological preventative migraine medication?

   (Such as betablockers [e.g. propranolol, metoprolol, bisoprolol, atenolol], antihypertensive medicines [e.g. candesartan, lisinopril, verapamil], anti-depressants [e.g., amitriptyline, nortriptyline, amitriptyline+benzodiazepine, venlafaxine], anti-epileptics [e.g. topiramate, sodium valproate, lamotrigine]).

   - 0
   - 1
   - 2

- 3
- 4
- 5
- 6
- 7
- 8
- 9
- 10
- more than 10

6. Do you use or have you previously used botulinum toxin as migraine treatment?
    - No
    - Yes, I have, but the treatment ended when I started to use the biological preventative migraine medication
    - Yes, I have, but the treatment ended for other reasons
    - Yes, I am currently using botulinum toxin
    - I do not remember

SECTION 2/5 Next, we would like to hear about your everyday life with migraine with the <u>current</u> biological preventative migraine medication you are using [insert brand name]

7. Are you satisfied/happy with the biological preventative migraine medication you are currently using?
    - Very satisfied → B.
    - Satisfied → B
    - Somewhat satisfied → B.
    - Neither satisfied nor dissatisfied → 8
    - Somewhat dissatisfied → C.
    - Dissatisfied →C
    - Very dissatisfied → C.

B. I am satisfied/happy with my current biological preventative migraine medication because:

- It has reduced the number of migraine days
- It has reduced the intensity of pain
- It has improved my quality of life
- It is easier to administer compared with the previous biological preventative medication I used
- I have fewer side effects than with my previous medication
- I don't have to take medicine every day
- I have become accustomed to the treatment
- Other

C. I am not satisfied/happy with my current biological preventative migraine medication because:

- I believe this is not the right medication for me
- I have the same amount of migraine days as before
- I have more migraine days than before
- I don't want to inject the medication
- The product is difficult to use
- The product availability is poor
- Storing the medicine is difficult

- Life with the current medication has not improved my quality of life
- The product is too expensive
- Other

8. How many **migraine days** on average do you typically have **per month with your current** biological preventative migraine medication? (A migraine headache is defined as a headache, **with or without** aura, lasting **at least 30 minutes**, **A) at least 2 of the following exist**: unilateral location; pulsatile quality; moderate or severe pain intensity; and aggravation caused by physical activity or avoidance of physical activity; and **B) at least 1 of the following exists**: nausea and/or vomiting and/or photophobia and phonophobia).
    - 0–3
    - 4–7
    - 8–11
    - 12–15
    - 16+

9. On how many migraine days **per month** do you also take acute migraine medication **with your current** biological preventative migraine medication?
    - 0–3
    - 4–7
    - 8–11
    - 12–15
    - 16+

10. Currently **migraine** affects my ability to work/study so that (select the option that best corresponds to your current situation; **after you have started to use the current** biological preventative migraine medication)
    - I am not able to work/study → B
    - I work/study less than 40% of full time → B
    - I work/study 40% of full-time → B
    - I work/study 60% of full-time → B
    - I work/study 80% of full-time → B
    - I am able to study/work full-time despite the migraine (with preventative migraine medication)

- I am able to study/work full-time despite the migraine (with preventative and acute migraine medication, such as pain killers)
- I do not know
- None of the above mentioned

B. Select the options that are relevant for you

- I receive disability benefits
- I receive partial disability pension/disability pension
- I receive partial rehabilitation allowance/rehabilitation allowance
- I receive unemployment allowance/labour market support
- I receive partial sickness allowance/sickness allowance
- I receive income support
- None of the above

11. How many absence days do you typically have **per month** (**with current biological preventative migraine** medication)?
    - 0–3
    - 4–7
    - 8–11
    - 12–15
    - 16+
    - I am not working or studying

12. How would you describe the average extent of typical migraine pain with **your current biological preventative migraine medication** when you **do not take** acute medication, on a scale from 0 to 10 (where 0 is no pain and 10 is the worst pain you have ever experienced)?
    - 0
    - 1
    - 2
    - 3
    - 4
    - 5
    - 6
    - 7
    - 8

- 9
- 10

13. Which of the following healthcare units is currently **mainly** responsible for your migraine treatment?
    - Occupational healthcare
    - Secondary healthcare
    - Primary healthcare
    - Private healthcare
    - Student healthcare (e.g. Finnish Student Healthcare Service)
    - I do not remember

SECTION 3/5 Answer the following questions based on your experience with the previous preventative migraine medication before you started your current preventative migraine medication.

14. From the following treatment options, choose the one you were using before you switched to the current preventative migraine medication.
    - Subcutaneous biological preventative migraine medication
    - Other preventative medication (e.g. beta blockers, antihypertensive medicines, anti-depressants, anti-epilepsy medicines)
    - Combination of subcutaneous biological preventative migraine medication + other preventative medication
    - Other

15. How many migraine days on average did you previously have **per month** (**before starting** the preventative medication you currently use)?

(A migraine headache is defined as a headache, **with or without aura**, lasting **at least 30 minutes**, **A) at least 2 of the following** exist: unilateral location; pulsatile quality; moderate or severe pain intensity; and aggravation caused by physical activity or avoidance of physical activity; and **B) at least 1 of the following exists**: nausea and/or vomiting and/or photophobia and phonophobia).

- 0–3
- 4–7
- 8–11
- 12–15
- 16+

16. When using your **previous** preventative medication, on how many migraine days **per month** did you also take acute migraine medication?

- 0–3
- 4–7
- 8–11
- 12–15
- 16+

17. **Migraine previously** influenced my ability to work/study so that (select the option that best corresponds to your situation **before** you started to use the current preventative migraine medication)
    - I was not able to work/study → B
    - I worked/studied less than 40% of full time → B
    - I worked/studied 40% of full-time → B
    - I worked/studied 60% of the full-time study/work → B
    - I worked/studied 80% of the full-time study/work → B
    - I was able to study/work full-time despite the migraine (with preventative migraine medication)
    - I was able to study/work full-time despite the migraine (with acute migraine medication, such as pain killers)
    - I do not know
    - None of the above mentioned

B. Select the options that were previously relevant for you

- ☐ I received disability benefits
- ☐ I received partial disability pension/disability pension
- ☐ I received partial rehabilitation allowance/rehabilitation allowance
- ☐ I received unemployment allowance/labour market support
- ☐ I received partial sickness allowance/sickness allowance
- ☐ I received income support
- ☐ None of the above

18. How many absence days from did you previously have **per month** (**before starting** the preventative medication you currently use)?
    - 0–3
    - 4–7
    - 8–11
    - 12–15
    - 16+
    - I did not work or study

19. How would you describe the average extent of typical migraine pain **before starting** the preventative medication you currently use when you **did not take** acute medication on a scale from 0 to 10 (where 0 is no pain and 10 is the worst pain you have ever experienced)?
    - 0
    - 1
    - 2
    - 3
    - 4
    - 5
    - 6
    - 7
    - 8
    - 9
    - 10

SECTION 4/5 The next questions are background information.

20. Sex
    - Female
    - Male
    - Other

21. Age
    - 18–24
    - 25–34
    - 35–44
    - 45–54
    - 55–64
    - Over 65

22. Education level (please, select your highest education level):
    - Comprehensive school / elementary school (compulsory education only)
    - Secondary education (upper secondary school / high school / vocational education)
    - Bachelor’s degree or similar qualification
    - Master’s degree
    - Doctoral degree
    - Another qualification
    - I do not remember

23. Current employment status
    - Full-time employee / full-time entrepreneur
    - Part-time employment / part-time entrepreneur
    - Subsidized employee / rehabilitative employment activity / Work trial
    - Unemployed / suspended without pay
    - Parental leave
    - Student
    - Pension (full old age pension or disability pension)
    - Part time pension
    - Other

24. Have you been diagnosed by a medical doctor with the following conditions **after being diagnosed with migraine**?

- ☐ Anxiety
- ☐ Major depressive disorder (MDD), single episode
- ☐ MDD, recurrent
- ☐ Gastroenteritis
- ☐ Crohn's disease
- ☐ Ulcerative colitis
- ☐ Irritable bowel syndrome (IBS)
- ☐ None of the above

25. Do you think that COVID-19 has affected your treatment intervals or somehow delayed the diagnosis or initiation of the treatment in general?

- o Yes, I think it delayed the initiation of the treatment
- o Yes, I think it has been more difficult to get a doctor appointment during the pandemic
- o No
- o I do not remember

26. Where did you get the information to participate this survey? (If you received the invitation from various sources, please select the option from which you received the information first)
    - o From a pharmacy → drop-down menu containing all pharmacy names
    - o Migraine Finland

SECTION 5/5 Migraine-specific quality of life questionnaire

Thank you for your time!

Your experience matter*s!*

Patient recruitment and data collection

Patients were recruited across the whole of Finland via Migraine Finland and at community pharmacies between June and September 2023.

Migraine Finland advertised the survey via electronic channels reaching over 16,000 members. In community pharmacies, calcitonin gene-related peptide (CGRP) monoclonal antibody (mAb) users were identified by pharmacists at the point of prescription collection; potential respondents were given a patient information letter with a link and quick-response (QR) code to participate. Altogether, 450 pharmacies were invited for data collection, of which 139 participated in the enrolment.

The survey collected patient-reported experiences prior to and/or after using CGRP mAb therapy; for example, number of monthly migraine headache days and sick leave days, ability to work or study, and intensity of migraine pain. Clinical characteristics, treatment patterns, and current quality of life (QoL; using the Migraine-Specific Quality of Life [MSQoL]) were also reported.

The MSQoL measures a patient's current QoL, while the survey asked patients to report other outcomes as a monthly average before and after CGRP mAb therapy initiation. The MSQoL consists of 20 items, each of which has four possible response categories scored from 1 to 4; higher scores indicate a better QoL [~~18~~17,~~19~~18]. The total score is calculated as a sum of the item scores, and ranges from 20 to 80.