CAPRICORD Survey Clinicians & Patients

Fields marked with * are mandatory.

Patients & Clinical Experts involvement in P&R processes Survey

About the CAPRICORD project

A project funded by the European Health and Digital Executive Agency (HaDEA), titled: Competent Authorities for Pricing and Reimbursement to coordinate Involvement of Clinical Experts and Patients, to manage uncertainty and the challenges associated with orphan medicinal products.

The overarching objective of the project is to strengthen cooperation among the various stakeholders responsible for medicine pricing and reimbursement, as well as healthcare payers, operating at different stages of the medicinal product life-cycle (Joint Action) across the European Union.

One of the project's activities is to strengthen the capacity of national competent authorities responsible for pricing and reimbursement to engage the public and increase transparency. This activity is implemented, inter alia, through surveys targeted at clinical experts and patients.

About the survey

This survey is part of a broader study seeking to map how clinical experts and patients are engaged in pricing and reimbursement processes. Your input as a clinical expert or patient is highly valuable and will complement a systematic literature review. By contributing your perspective, you will help us better understand the key barriers, enabling factors, and policy approaches influencing this area. Your input will be anonymised. The information provided in this survey will be used solely for the purposes of the CAPRICORD project. The information collected from this survey will be handled with the highest possible level of diligence. The report and any other project-related publications will not disclose who provided which information. Information will be presented per stakeholder group (e.g. patients, patient organizations, clinical experts) and country.

Completing the survey will take you approximately 15-20 minutes. You can stop completing the survey at any time and save your responses as a draft.

THE SURVEY IS OPEN UNTIL 15 AUGUST 2026

Thank you for your support,

CAPRICORD Consortium

1 Consent

* 1.1 Consent.

I was informed about the survey, and I understand its aims. I understand that there is no remuneration for my participation in the survey. I agree to participate in this survey by providing information and perspectives. By participating in the survey, I acknowledge that the results will be published and I hereby consent to this.

- Yes
- No

2 Administrative part

* 2.1 Please indicate the EU country you are representing. If you do not represent EU country please finish the survey.

- AT - Austria
- BE - Belgium
- BG - Bulgaria
- HR - Croatia
- CY - Cyprus
- CZ - Czechia
- DK - Denmark
- EE - Estonia
- FI - Finland
- FR - France
- DE - Germany
- EL - Greece
- HU - Hungary
- IE - Ireland
- IT - Italy
- LV - Latvia
- LT - Lithuania
- LU - Luxembourg
- MT - Malta
- NL - Netherlands
- PL - Poland
- PT - Portugal
- RO - Romania
- SK - Slovak Republic
- SI - Slovenia
- ES - Spain
- SE - Sweden

* 2.2 Are you involved in national processes related to access to medicines, such as health technology assessment (HTA), pricing, reimbursement, or decision-making?

- ○ Yes
- ○ No

* 2.3 According to your knowlegde is there possibility to involve clinicians, patients, or patient representatives in medicines reimbursment processes?

(Tick ✓ if you **know** this happens)

- ☐ No
- ☐ Yes, during health technology assessment
- ☐ Yes, in decision-making stage
- ☐ Yes, when the price of a medicine is set or negotiated
- ☐ Yes, when changes of reimbursement (ie. changes in therapeutic/financing protocols; or reimbursement conditions)
- ☐ I have no knowledge of involvement in the processes described above

* 2.4 Please specify whether you would like to be involved in the processes mentioned above and provide reasoning

* 2.5 Which perspective do you represent?

- ○ Patient/Representative of patient organisation
- ○ Clinician/Rrepresentative of the medical association

* 2.6 The answers to the survey represent:

- ○ The official position of institution with which you work or cooperate
- ○ Your personal opinion

2.7 Please indicate the full name of your institution

75 character(s) maximum

3 Clinical experts involvement

In this section, you will be asked about your experience and involvement in processes for medicines. The questions focus on whether, how, and at which stage(s) of the process you are engaged (e.g. HTA, pricing, reimbursement), as well as your views on current practices.

* 3.1 Please choose which field(s) of medicine you are representing

- [ ] Diabetology
- [ ] Oncology
- [ ] Rare diseases
- [ ] Cardiology
- [ ] Neurology
- [ ] Rheumatology & autoimmunology
- [ ] Psychiatry
- [ ] Pulmonology & allergology
- [ ] Other

* 3.2 Please specify

* 3.3 At which stage of the reimbursement process are you typically involved? Please select all that apply

- [ ] HTA assessment
- [ ] Price negotiations
- [ ] Reimbursement decision-making
- [ ] Other

3.4 Please specify

* 3.5 Please specify how you receive information about opportunities to participate in the process:

- [ ] I actively search for information myself
- [ ] I am invited by the competent authority in my country
- [ ] I am invited by a pharmaceutical company
- [ ] I am formally appointed as a member of the advisory body
- [ ] I am informed through patient organizations or professional associations
- [ ] I am informed through stakeholder network

* 3.6 Where do you find information about how to get involved and share your opinion?

- [ ] Internet site of the competent authority
- [ ] Internet site of the manufacturer of the medicinal product
- [ ] Internet site of patient organisation
- [ ] Social media
- [ ] Newsletter
- [ ] Other

3.7 Please specify

* 3.8 Which option best reflects how you are usually invited to participate?

- ○ I/my organisation is formally invited to participate in the process by the competent authority
- ○ The competent authority informs me about ongoing processes and opportunities to participate.
- ○ I am invited by the competent authority to serve as a member of an advisory body
- ○ Other

3.9 Please specify

3.10 How do you participate? Please choose the option that best describes your involvement in the process. If none of the processes listed below match your involvement, please choose "I do not participate" and proceed to question 3.13.

	I present my perspective on a competent authority, committee or working group meeting (in-person)	I complete a survey prepared by a competent authority	I complete a survey prepared by a pharmaceutical company	I write statement, opinion or applications	I review and provide comments on documents	I participate in workshops, focus groups, or advisory panels	Other	I do not participate
* Submitting proposals of medicinal products for reimbursement	☐	☐	☐	☐	☐	☐	☐	☐
* Health technology assessment (HTA)	☐	☐	☐	☐	☐	☐	☐	☐
* Pricing and negotiations	☐	☐	☐	☐	☐	☐	☐	☐
* Decision-making	☐	☐	☐	☐	☐	☐	☐	☐
* Procurement	☐	☐	☐	☐	☐	☐	☐	☐

* Reassessment and/or monitoring	☐	☐	☐	☐	☐	☐	☐	☐

3.11 If you have chosen 'Other', please specify what part of the process you are involved in and how you participate.

3.12 Please desribe the process(es) you are involved in and what types of information are you most commonly asked to provide, if none of the processes listed in the table 3.10 match your involvement.

3.13 What types of information are you most commonly asked to provide? Please choose the description that best fits your experience. If none of the description listed below match your involvement, please choose "Not applicable – I am not involved in this particular process" and proceed to question 3.15.

	Overall experience with treating this condition	Experience with and opinions on the medicinal product under assessment	Unmet medical needs related to a specific condition	Financial burden associated with a specific condition	Knowledge of the size and characteristics of the target population	Other	Preferences and values	Ethical aspects	Social impact	Not applicable – I am not involved in this particular process
* Submitting proposals of medicinal products for reimbursement	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
* Initial health technology assessment (HTA)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
* Pricing and negotiations	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
* Decision-making	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
* Procurement	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

* Reassessment and/or monitoring	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

3.14 If you have chosen 'Other', please specify the process you are involved in and what types of information are you most commonly asked to provide.

3.15 Please desribe the process(es) you are involved in and what types of information are you most commonly asked to provide, if none of the processes listed in the table 3.13 match your involvement.

* 3.16 Do you have voting rights in the decision-making processes you are involved in?

- ○ Yes
- ○ No
- ○ Depends on the scope of the collaboration
- ○ I don't want to answer/I can't answer

3.17 Please describe

3.18 Do you feel that your input influences the competent authority's decision?

- ○ Yes
- ○ No
- ○ Sometimes
- ○ I am not sure/unable to assess

3.19 What outcomes do you expect from your involvement in the processes?

150 character(s) maximum

* 3.20 Are you required to disclose conflicts of interest when providing your opinion?

- ☐ Yes, always
- ☐ Yes, under special circumstances
- ☐ No
- ☐ I don't know

3.21 Do you receive any incentives or support to encourage your participation?

- ☐ Financial support to cover participation-related costs (eg. travel expenses, accommodation, lost income or time off work)
- ☐ Non-financial incentives (e.g. training, capacity-building, certification)
- ☐ Depends on the scope of the collaboration
- ☐ Remuneration for participation

- [ ] No
- [ ] I don't want to answer/I can't answer

3.22 Which of the following statements best reflects your assessment of current engagement experience?

- ( ) Fully meet my needs
- ( ) Meet my needs, with only minor areas for improvement
- ( ) Partially meet my needs, with considerable room for improvement
- ( ) Do not meet my needs

3.23 Do you have any additional comments or suggestions?

300 character(s) maximum

4 Patients involvement

In this section, you will be asked about your experience and involvement in national medicines access decision-making processes (like pricing, reimbursement, HTA). The questions focus on whether, how, and at which stage(s) of the medicines access decision-making processes are you participating (e.g. public consultations, assessment of clinical effectiveness, price negotiations, inclusion on reimbursement list), as well as your views on current practices.

* 4.1 When giving your opinion on a medicine, are you acting on behalf of:

- [ ] Yourself
- [ ] A family member or the person you care for
- [ ] A patient organization you represent

* 4.2 Please choose which field(s) of medicine you are representing

- [ ] Diabetology
- [ ] Oncology
- [ ] Rare diseases
- [ ] Cardiology
- [ ] Neurology
- [ ] Rheumatology & autoimmunology
- [ ] Psychiatry
- [ ] Pulmonology & allergology
- [ ] Other

4.3 Please specify how do you usually learn about opportunities to participate in a medicines access decision-making processes?

- [ ] I find information by myself
- [ ] I am invited by a public institution in my country (e.g. ministry of health, HTA agency, public payer)

- [ ] I am invited by a pharmaceutical company
- [ ] I am formally appointed as the patient group representative
- [ ] I am formally appointed as a member of the advisory body
- [ ] Other

4.4 Please specify

* 4.5 Where do you find the information?

- [ ] Website of the public institution
- [ ] Website of the producent of the medicinal product
- [ ] Website of patient organisation
- [ ] Other

4.6 Please provide the link

* 4.7 Is it easy for you to find opportunities to participate in in the processes?

- ( ) Yes
- ( ) No

* 4.8 Could you briefly describe what makes it difficult?

4.9 How easy was it to understand information about:

at least 4 answered row(s)

	very easy	easy	difficult	very difficult	I have not seen any information on this topic / Not applicable
* The purpose, rules and overall framework of participation	( )	( )	( )	( )	( )
* Eligibility criteria and conditions that must be met to participate	( )	( )	( )	( )	( )
* Expected tasks and deadlines for providing input	( )	( )	( )	( )	( )
* Responsibilities and any legal implications of providing input	( )	( )	( )	( )	( )

4.10 How do you participate? Please choose the option that best describes your involvement in the process. If none of the processes listed below match your involvement, please mark 'I do not participate' and proceed to question 4.12.

	I present my perspective on a competent authority, committee or working group meeting (in-person)	I complete a survey prepared by a competent authority	I complete a survey prepared by a pharmaceutical company	I write statement, opinion or applications	I review and provide comments on documents	I take part in workshops, focus groups, or advisory panels	Other	I do not participate
* Submitting proposals of medicinal products for reimbursement	☐	☐	☐	☐	☐	☐	☐	☐
* Initial health technology assessment (HTA)	☐	☐	☐	☐	☐	☐	☐	☐
* Pricing and negotiations	☐	☐	☐	☐	☐	☐	☐	☐
* Decision-making	☐	☐	☐	☐	☐	☐	☐	☐
* Procurement	☐	☐	☐	☐	☐	☐	☐	☐

* Reassessment and/or monitoring	☐	☐	☐	☐	☐	☐	☐	☐

4.11 If you have chosen 'Other', please specify the process you are involved in and how you participate.

4.12 Please describe the process you are involved in and how you participate, if none of the processes listed in the table 4.10 match your involvement.

4.13 What types of information are you most commonly asked to provide? Please choose the description that best fits your experience. If none of the processes listed below match your involvement, please mark 'Not applicable – I am not involved in this particular process' and proceed to question 4.15.

	Unmet medical needs related to a specific condition	Experience with the medicinal product that is the subject of the works	Experience with condition in general	Access to treatment	Financial burden related to a specific condition	Ethical aspects	Social impact	Preferences and utility values	Other	Not applicable – I am not involved in this particular process
* Submitting proposals of medicinal products for reimbursement	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
* Initial health technology assessment (HTA)	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
* Pricing and negotiations	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
* Decision-making	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
* Procurement	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
* Reassessment and/or monitoring	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐

4.14 If you have chosen 'Other', please specify the process you are involved in and most common things you are being asked about.

4.15 Please desribe the process you are involved in and most common things you are being asked about, if none of the processes listed in the table 4.13 match your involvement.

* 4.16 Do you have voting rights in any committiees or bodies involved in reimbursement-related processes?

- ○ Yes
- ○ No
- ○ Depends on the scope of the collaboration
- ○ I don't want to answer/I can't answer

4.17 Please describe

* 4.18 Do you feel that your input influences public institution's decision?

- ○ Yes
- ○ No
- ○ Sometimes
- ○ I am not sure/unable to assess

4.19 Do you receive any incentives or support to encourage your participation?

- ☐ Financial support to cover participation-related costs (e.g. travel expenses, accommodation, lost income or time off work)
- ☐ Non-financial incentives (e.g. training, capacity-building, certification)
- ☐ Depends on the scope of the collaboration
- ☐ Remuneration for participation
- ☐ No
- ☐ I don't want to answer/I can't answer

4.20 What motivates you to participate in the process?

Use drag&drop or the up/down buttons to change the order or accept the initial order.

- ⠿ The opportunity to present my perspective (in-person or online)
- ⠿ Feeling I can influence national decisions
- ⠿ My own illness or the illness of a family member or a close person

- Lack of available treatment options for me/family member/close person
- Remuneration
- Non-financial incentives

4.21 How well does the current engagement process meet your expectations?

- ○ Fully meet my needs
- ○ Meet my needs, with only minor areas for improvement
- ○ Partially meet my needs, with considerable room for improvement
- ○ Do not meet my needs

4.22 Do you have any additional comments or suggestions?

300 character(s) maximum

5 Challenges and barriers

In this section you will be asked for your opinion on the challenges and barriers related to access to medicines.

5.1 How relevant are the following barriers to your participation? Please rate each issue on the dot scale from 1 (not at all) to 5 (very big problem).

Limited access to information about participation opportunities and procedures	○ ○ ○ ○ ○
Limited opportunities to participate	○ ○ ○ ○ ○
Administrative burden and complex requirements	○ ○ ○ ○ ○
Time constraints	○ ○ ○ ○ ○
Communication and accessibility barriers	○ ○ ○ ○ ○
Limited transparency and feedback	○ ○ ○ ○ ○
Lack of influence or trust in the process	○ ○ ○ ○ ○
Lack of resources and support	○ ○ ○ ○ ○

5.2 Please describe any additional obstacles that are not listed above.

150 character(s) maximum

5.3 Please provide any suggestions that could improve participation in the process or make it more accessible?

150 character(s) maximum

6 Thanks and next steps

Your survey has been completed. Thank you for participating.

* 6.1 I consent to being contacted using the contact details provided for the purpose of clarifying my responses.

- Yes
- No

* 6.2 Please give your email

6.3 Please provide your name and if relevant your afiliation (institution/organisation you represent)