

CAPRICORD Survey Competent Authorities

Fields marked with * are mandatory.

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 to 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 improve the capacities 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

The survey is addressed to public institutions involved in the reimbursement and pricing of medicines. 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 representative of competent authority, 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 anonymized. The information provided in this survey will be used solely for the purposes of the CAPRICORD project. The information from this survey will be dealt with the highest possible level of diligence. No individual responses will be attributed to specific respondents in the report or any other project-related publication. Information will be presented per type of competent authority and country. Completing the survey will take you approximately 15-20 minutes. You can stop completing the survey at any time and save it as a draft.

About patient and expert engagement

For the purposes of this survey, patient and clinical expert engagement is defined as a structured and systematic activity that may take place at any stage of the medicinal product lifecycle. It involves two-way communication or active participation of patients and clinical experts, with the aim of gathering meaningful insights, enhancing the transparency of reimbursement processes, and strengthening trust in decisions made by health authorities. In this survey, engagement refers specifically to activities related to the post-authorisation phase of a medicinal product, including its submission for reimbursement, health technology assessment, pricing and negotiation, decision-making, procurement, monitoring and reassessment.

Survey open till 15 August 2026

Thank you for your support,

* 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

1 Administrative part

* 1.1 What country is your institution based in?

- ☐ 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

* 1.2 What institution do you represent?

100 character(s) maximum

* 1.3 Does your institution engage:

- ☐ Patients or their representatives (e.g. patient organisations, carers, or family members)
- ☐ Clinical experts
- ☐ Both patients or their representatives and clinical experts
- ☐ None of the above

2 Patient engagement

* 2.1 Does your institution engage patients or their representatives during any of the reimbursement related processes listed below? Select all that apply.

- ☐ Health technology assessment (HTA)
- ☐ Pricing and negotiations
- ☐ Reimbursement decision-making
- ☐ Procurement
- ☐ Monitoring and/or reassessment
- ☐ Other (please specify)

* 2.2 Please specify

* 2.3 How are patients or their representatives informed about opportunities to participate in reimbursement-related processes? Select all that apply.

- ☐ Via the institution's website
- ☐ Through direct communication with patients or patient representatives (e.g. email, letters, phone calls)
- ☐ Through stakeholder networks or patient organisations
- ☐ Through public announcements via other channel (e.g. newsletters, social media, press releases)
- ☐ Other

* 2.4 Please provide link(s) to the section(s) of your website where the participation opportunities are announced

* 2.5 Please specify

* 2.6 Which of the following methods or tools are used by your institution to engage patients or their representatives? Select all that apply.

- ☐ Surveys / questionnaires
- ☐ Review and commenting on documents
- ☐ Invitation to attend committee meetings, workshops, focus groups or advisory panels related to reimbursement decisions
- ☐ Oral presentation of patient perspectives to committees or working groups
- ☐ Other

* 2.7 Please specify

* 2.8 Is it possible for patients or their representatives to participate remotely?

- ☐ Yes
- ☐ No
- ☐ I don't know

* 2.9 When engaging with your institution, are patients or their representatives asked to disclose any conflicts of interest?

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

* 2.10 Please specify

* 2.11 Does your institution have formal policies, procedures, regulations, or guidance documents defining eligibility or selection criteria for patient and patient representative engagement?

- ☐ Yes
- ☐ No
- ☐ I don't know

* 2.12 Are these regulations or guidelines publicly available online?

- ☐ Yes
- ☐ No

* 2.13 Please provide a link

* 2.14 Please briefly describe the eligibility or selection criteria

* 2.15 What types of information does your institution typically seek from patients or their representatives through engagement activities?

Select all that apply.

- ☐ 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
- ☐ Financial burden related to a specific condition
- ☐ Preferences and utility values
- ☐ Ethical aspects
- ☐ Social impact
- ☐ Other

* 2.16 Please, specify

2.17 Is there any information your institution would like to collect from patients or their representatives that is not currently being gathered? If yes, please specify.

* 2.18 Prior to engagement, does your institution provide patients or patient representatives with any educational materials or activities? Select all that apply.

- ☐ Yes – training or briefing sessions facilitated by a moderator or trainer available for participation
- ☐ Yes – written or multimedia materials provided for self-study
- ☐ No – no educational or preparatory materials or activities are provided

* 2.19 Do patients or their representatives have voting rights in any committees or bodies involved in reimbursement-related processes?

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

* 2.20 What types of support or incentives are available to help patients in engagement activities? Select all that apply.

- ☐ Remuneration
- ☐ 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)

- ☐ No specific motivational or support provisions are applied
- ☐ Other

*2.21 Please specify

*2.22 Difficulties identifying and reaching relevant participants.

Select all that apply.

- ☐ Limited participation opportunities or willingness to participate
- ☐ Administrative, legal or procedural constraints
- ☐ Time constraints
- ☐ Lack of resources and organisational support
- ☐ Communication and accessibility challenges
- ☐ Limited transparency, feedback or evaluation of engagement
- ☐ Concerns about the value, impact or influence of engagement
- ☐ Other
- ☐ No significant difficulties

*2.23 Please specify

*2.24 Does your institution collect feedback on patients' satisfaction with their participation in the process?

- ☐ Yes
- ☐ No
- ☐ I don't know

*2.25 Are patients or their representatives informed about how their input has been considered in the final decision or assessment?

- ☐ Yes
- ☐ No
- ☐ I don't know

*2.26 Does your institution evaluate the impact or effectiveness of patient engagement activities?

- ☐ Yes, systematically
- ☐ Yes, occasionally
- ☐ No
- ☐ I don't know

2.27 Please share any additional information on the pricing and reimbursement process in your country that you consider relevant to patients and patient representative engagement

3 Clinical expert engagement

* 3.1 Does your institution engage clinical experts during any of the reimbursement-related processes listed below? Select all that apply.

- ☐ Health technology assessment (HTA)
- ☐ Pricing and negotiations
- ☐ Decision-making
- ☐ Procurement
- ☐ Reassessment/ post-launch/monitoring
- ☐ Other

* 3.2 Please, specify

* 3.3 How is information about participation opportunities communicated to clinical experts? Select all that apply.

- ☐ Via the institution's website
- ☐ Through direct communication with clinical experts (e.g. email, letters, phone calls)
- ☐ Through stakeholder networks or professional associations
- ☐ Through public announcements via other channel (e.g. newsletters, social media, press releases)
- ☐ Other

* 3.4 Please provide link(s), to the section(s) of your website where the participation opportunities are announced

* 3.5 Please specify

* 3.6 Which of the following tools or methods are used by your institution to engage clinical experts? Select all that apply.

- ☐ Surveys / questionnaires
- ☐ Review and commenting on documents
- ☐ Oral presentation of clinical expert's perspectives to committees or working groups
- ☐ Invitation to attend committee meetings, workshops, focus groups or advisory panels related to reimbursement decisions
- ☐ Other

* 3.7 Please specify

* 3.8 Is it possible for clinical experts to participate remotely?

- ☐ Yes
- ☐ No
- ☐ I don't know

* 3.9 When engaging with your institution, are clinical experts asked to disclose any conflicts of interest?

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

* 3.10 Please, specify

* 3.11 Does your institution have any formal regulations defining eligibility or selection criteria for engagement of clinical experts? (Select one)

- ☐ Yes
- ☐ No
- ☐ I don't know

* 3.12 Are these regulations or guidelines publicly available online?

- ☐ Yes
- ☐ No

* 3.13 Please provide a link

* 3.14 Please briefly describe the eligibility or selection criteria

* 3.15 What types of information does your institution typically seek from clinical experts through engagement activities? Select all that apply.

- ☐ Unmet medical needs related to a specific condition
- ☐ Experience with the medicinal product that is under assessment
- ☐ Experience with condition in general
- ☐ Financial burden related to a specific condition

- ☐ Preferences and values
- ☐ Ethical aspects
- ☐ Social impact
- ☐ Other

3.16 Please, specify

3.17 Is there any information your institution would like to collect from clinical experts that is not currently being gathered? If yes, please specify.

*3.18 Prior to engagement, does your institution provide clinical experts with any educational materials or activities? Select all that apply.

- ☐ Yes – training or briefing sessions facilitated by a moderator or trainer available for participation
- ☐ Yes – written or multimedia materials provided for self-study
- ☐ No – no educational or preparatory materials or activities are provided

*3.19 What barriers does your organisation face when involving clinical experts in engagement and decision-making activities? Select all that apply.

- ☐ Difficulty identifying, recruiting or retaining participants
- ☐ Limited availability, time or willingness to participate
- ☐ Lack of financial, logistical or staff resources
- ☐ Lack of procedures, guidance, training or organisational support
- ☐ Administrative, legal, regulatory or confidentiality constraints
- ☐ Perceived limited value or impact of engagement activities
- ☐ Other
- ☐ No significant barriers

3.20 Please, specify

*3.21 Are any support mechanisms or incentives available to facilitate the participation of clinical experts in engagement activities?

- ☐ Remuneration
- ☐ 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)
- ☐ No specific motivational or support provisions are applied
- ☐ Other

*3.22 Please, specify

*3.23 Does your institution evaluate the impact or effectiveness of clinical expert engagement activities?

- ☐ Yes, systematically
- ☐ Yes, occasionally
- ☐ No
- ☐ I don't know

3.24 Please share any additional information on the pricing and reimbursement process in your country that you consider relevant to clinical expert engagement.

4 General views & opinions

This section includes general questions about your views on public engagement and its usefulness for your institution. Please answer all questions regardless of whether your institution currently engages patients and/or clinical experts.

*4.1 Which of the following statements best reflects your assessment of current engagement activities within your institution?

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

4.2 What are the key advantages of involving patients or clinical experts in pricing and reimbursement decision-making?

*4.3 Is your institution currently undertaking any work to develop a new or improve an existing practice?

- ☐ Yes
- ☐ No
- ☐ I do not know

4.4 Please describe

5 Thank you and next steps

Thank you for your participation. The following questions are intended for representatives of European Union Member States. If this does not apply to you, you may now exit the survey.

Your survey has been completed. Thank you for your participation.

* 5.1 I consent to my contact details for follow-up contact for further clarification (single choice).

☐ Yes

☐ No

5.2 Please, enter your name

5.3 Please, enter your e-mail