Project name:

ERN eUROGEN

European Reference Network for rare urogenital diseases and complex conditions

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Authors:	**Darren Shilhan, ERN eUROGEN Performance Manager**
Date:	**December 2025**

ERN eUROGEN is a European Reference Network (ERN) approved by the ERN Board of Member States (BoMS). The ERNs are funded by the European Commission. For more information about the ERNs and the EU health strategy, please click here.

Funded by the European Union

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BACKGROUND

1. In terms of the ongoing evaluation of network activities, ERN eUROGEN carries out an annual network survey that is issued to the representatives of all HCP full members, Affiliated Partner members, ePAG representatives and supporting partner independent experts. This is T3.2 in the current grant.
2. For the current grant, ERN eUROGEN also agreed to undertake a detailed evaluation of a number of its activities.
    - The ERN eUROGEN website (as per T3.10)
    - The ERN eUROGEN Webinar series (as per T3.11)
3. The results of these are detailed below.
4. The ERN eUROGEN Quality Improvement Group (QIG) maintains an overview of all evaluation requirements for the network and will consider which other network activities should be assessed going forward.

QUALITY IMPROVEMENT GROUP (QIG)

5. ERN eUROGEN's Quality Improvement Group (QIG) was instituted in July 2023.
6. The group provides a focus for the ongoing evaluation of network activities, including changes to existing evaluation methodologies, e.g. updates to survey themes and structures, as well as the expansion of evaluation processes to additional areas as deemed necessary.
7. This ensures that we are able, as a network, to both assess the usefulness and value of our major network activities and be assured that those activities are implemented in a way that suits our members who are supporting those activities, as well as for those they are designed to benefit.
8. The ERN eUROGEN Quality Improvement Group currently comprises the following members:

- Wout Feitz (ERN eUROGEN Coordinator)
- Michelle Battye (ERN eUROGEN Programme Manager)
- Jen Tidman (ERN eUROGEN Business Manager)
- Darren Shilhan (ERN eUROGEN Performance & Data Manager)
- Parmida Anvary (ERN eUROGEN Clinical Data Specialist)
- Dalia Aminoff (ERN EUROGEN ePAG Representative)
- Kate Tyler (ERN EUROGEN ePAG Representative)

9. The network is still working to secure HCP representation on the group going forward but due to the high demands on time already made by ERN eUROGEN activities for our HCPs, there remains a lack of volunteers to join the group.
10. The group has met annually during the grant period to date.
    - 14 October 2024
    - 8 September 2025
11. From 2026 onwards, meetings will take place in May and November. This will enable the November session to consider the results of the Annual Network Survey and plan ahead for the annual Strategic Board Meeting in late February of the following year. The May session will consider the outcomes of the discussions from the SBM.

ANNUAL NETWORK SURVEY

12. This survey includes questions that cover all major network activities, as well as a SWOT analysis.
13. The survey has been carried out in both August 2024 and 2025 (D1.4). The survey was revised and expanded for 2025. The full results and comments for both years are provided in in **Annex A** and **Annex B** respectively.

EVALUATION OF ERN EUROGEN WEBSITE

14. Included as T3.10 in the current grant, analysis was undertaken at M23 based on data to June 2025 (M21), rather than on an annual basis.
15. Overall, it appears that the ERN eUROGEN website is moving in a positive direction, with increases in usage suggest that we are now reaching a wider audience.
16. Further evaluation of the ERN eUROGEN website will take place at around M48.
17. We shall also continue to identify improvements for the website via the QIG.
18. The full report (T3.10) is included in **Annex C**.

EVALUATION OF ERN EUROGEN WEBINAR PROGRAMME

19. Monitoring the quality of our webinar programme is done in three ways.
20. The first utilises the registration information for each webinar.
21. The second is via a regular questionnaire at the end of every session that is sent to all live attendees.
22. Finally, we also undertake an annual survey for our webinars , which is sent to all of our previous registrants. The most recent iteration of this was in September 2025.
23. These sources all show that the ERN eUROGEN webinar programme remains a popular and well thought of activity, with growing registrations and improved feedback from attendees.
24. The full report (T3.11) from December 2025 is included in **Annex D**.

NEXT STEPS

25. The QIG will:

- Monitor progress against the deliverables for WP3 for the remainder of the grant period.
- Consider the outputs of the ERN eUROGEN Strategic Board Meeting in February 2026 to identify how to assess and implement improvements in response to issues that are raised by members.

ANNEX A: ERN EUROGEN NETWORK SURVEY RESULTS 2024 (D1.4)

1. BACKGROUND

26. ERN eUROGEN first issued a network survey during the 2022-23 Bridging Grant. This is now undertaken as an annual process, in line with the requirements of the EC call for proposals.
27. The anonymous survey, slightly adjusted for 2024, asks respondents to score the progress and development of the network across a range of areas of its work:
    - The first question of the survey asks respondents to identify their type of role within the network (e.g. full-member representative, ePAG etc.).
    - Questions 2 to 12 ask for their opinion of the network's achievement in terms of the activities and results delivered by ERN eUROGEN since 2017 for a number of different topics. Free-text fields also allow respondents to give more precise feedback to support their score.
    - Questions 13 to 16 ask the respondents to state what they consider to be the strengths and weaknesses of the network, as well as what opportunities and threats they see on the horizon (SWOT analysis).
    - Finally, questions 17 and 18 ask for their overall rating of the network and provides the opportunity to add any additional thoughts or comments.
28. This report sets out the feedback that we have gathered via a network-wide survey that was issued in September 2024. We received 24 responses in total.
29. The full results and comments are provided in **Annex A**, alongside the results from the 2023 survey.

2. SUMMARY OF RESULTS FROM NETWORK SURVEY

30. The response to Q.2 regarding the mission of ERN eUROGEN, shows a high level of agreement and is slightly improved from the previous year.
31. For Questions 3 -12, the following areas saw a decline (in excess of 0.4 or more) in their mean scores between 2023 and 2024:

<u>Building a European-wide infrastructure for rare urogenital diseases and complex conditions</u>

- The reasons provided by a few respondents cite low levels of participation by and exchange between HCPs, as well as the need to widen the geographical coverage of the network. Another respondent feels that the network is not strong enough with HCPs who, in their opinion, do not have the necessary expertise, and these centres do not send patients to real expert hospitals, but rather continue to treat those patients themselves.
- Consideration by QIG: How to improve communication between member HCPs, as well as encouraging greater participation more generally in the network. See also paragraph 10 below.

<u>Usage of the Clinical Patient Management System</u>

- Commenters giving the lowest scores cite the difficulty in using the current system, plus the lack of time that clinicians have to get involved. However, these are hopefully issues that will be improved with CPMS v2.0, and therefore we will wait to see how this rating changes in 2025.

<u>Dissemination and communication from ERN eUROGEN (e.g. website, newsletter, etc.)</u>

- Previous issues around communication with the network have usually focused on members saying they receive too many eUROGEN emails. However, this is it brought up this time by those who left comments. The member scoring this the lowest explained that they have so much other stuff to read that they do not get around to the eUROGEN material. Given that this is out of our control, no further action to be taken. Elsewhere, the comment regarding the user friendly nature of the website is not detailed enough to take further action.

32. For Questions 3 -12, the following areas saw a similar mean score (less than or equal to a 0.3 change) between 2023 and 2024:

Working in partnership with patient representatives

- This are saw a small but noteworthy decline in its score. Most of the comments relate to the need to expand patient representatives across more Expertise Areas (sub-thematic areas). This has been included as a standing item on the agenda for the network ePAG meetings which happen every 3 months. However, this has previously been Identified as a challenge relatively unique to ERN eUROGEN. Patients and parents/care of children with uro-recto-genital diseases feel far less comfortable discussing symptoms such as incontinence in public. As a result, there are far less patient organisations in our medical area. We aim to tackle this through effective communication and dissemination activities, In collaboration with the scientific societies, wherever possible. There is also a call for patient representatives to be given more power in the network and this feedback will be explored and discussed in the regular ePAG meetings.

Development of patient pathways

- A small fall in scoring in 2024, but no serious problems identified via the comments, other than we still have work to do, and pathways are being worked on.

Educational and training activities (webinars, ERN Exchange Programme, etc.)

- There was no change in the mean score for this area. However, the comments highlight concerns around the webinar programme such as dissemination of knowledge to those unqualified and, conversely, the level of qualifications of those giving the presentations. Whilst these are always issues of which we are mindful, there is an obvious tension with the need both to spread knowledge and expertise, and trusting our expert centres to deliver appropriate and evidence-based information. A couple of comments also refer to the loss of the ERN Exchange Programme, which had proved very popular in ERN eUROGEN. This view was fed back to the DG SANTE and the ERN Knowledge Generation Working Group, which selected other priorities for collective action. ERN eUROGEN will investigate the use of ERASMUS+ via this group to determine if it can be used to support short exchange visits of professionals (full MDT) between the healthcare providers in our network.

Provision of continuous support from the Coordination Team (e.g. ERN Monitoring, ERN Evaluation, etc.)

- Coordination team support continues to be scored highly. The comment relating to the quality of the members speaks to a more fundamental issue of the application process, which is not fully in the remit of the Coordination team itself.

Organisation of regular meetings and similar (e.g. annual Strategic Board Meeting, monthly Workstream meetings, etc.)

- Likewise, the organisation of meetings also scores highly again. One comment refers to the fact that the 2024 ERN eUROGEN Strategic Board Meeting was wholly virtual, unlike previous years. This is dependent upon the necessary budget becoming available in future years or, otherwise, the willingness of HCP members to fund their representatives attending. The QIG will take forward the work to determine the situation for 2025 as soon as possible.

33. For Questions 3 -12, the following areas saw an increase (in excess of 0.4 or more) in their mean scores between 2023 and 2024:

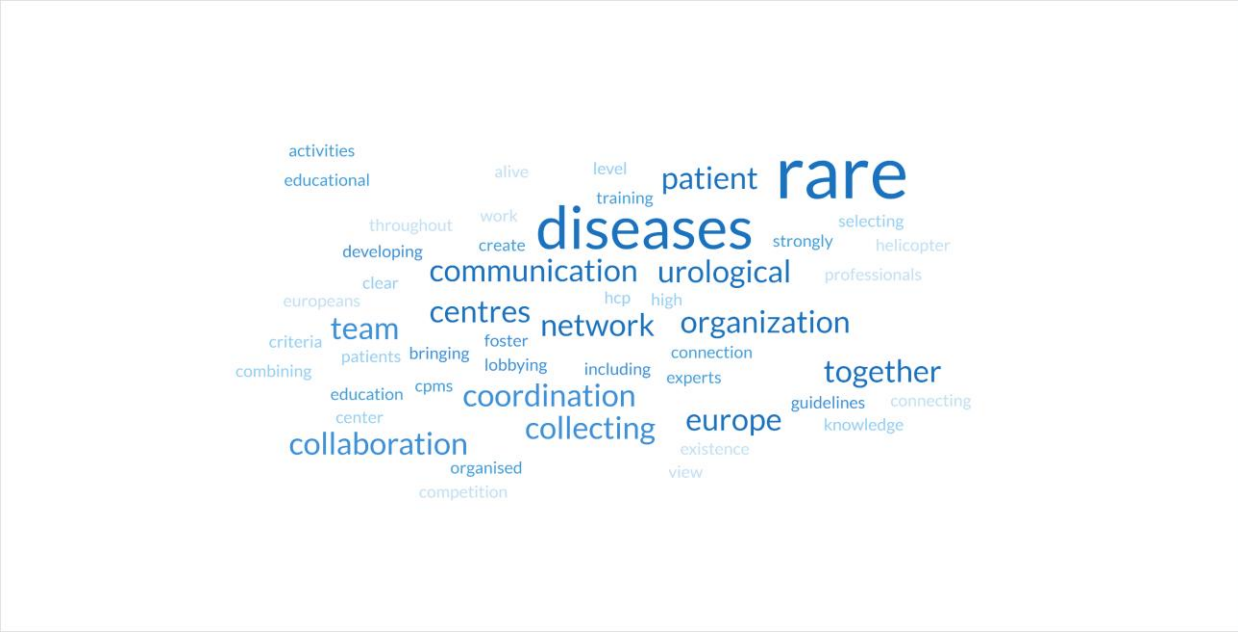
Clinical Practice Guidelines and clinical decision-making tools

- The increase in the score here is unsurprising as work package 7 on clinical guidelines was a deliberate prioritisation following the feedback from the network and the 5 year Evaluation which noted that ERN eUROGEN's output on clinical guidelines could be improved.

Publications (e.g. scientific papers, supplements, etc.)

- A positive improvement in the scoring for 2024, but more to do as evidenced by the comments. The QIG can perhaps think about how we might encourage more joint publications.

34. Turning to the SWOT analysis, question 13 asked members to detail what they saw as the strengths of the network currently, giving the word cloud below:



- As can be seen, the network is seen as having strengths in terms of communication and collaboration across Europe, working together as a team to help treat rare uro-recto-genital diseases and complex conditions.

35. Likewise, question 14 asked members to detail what they saw as the weaknesses of the network:

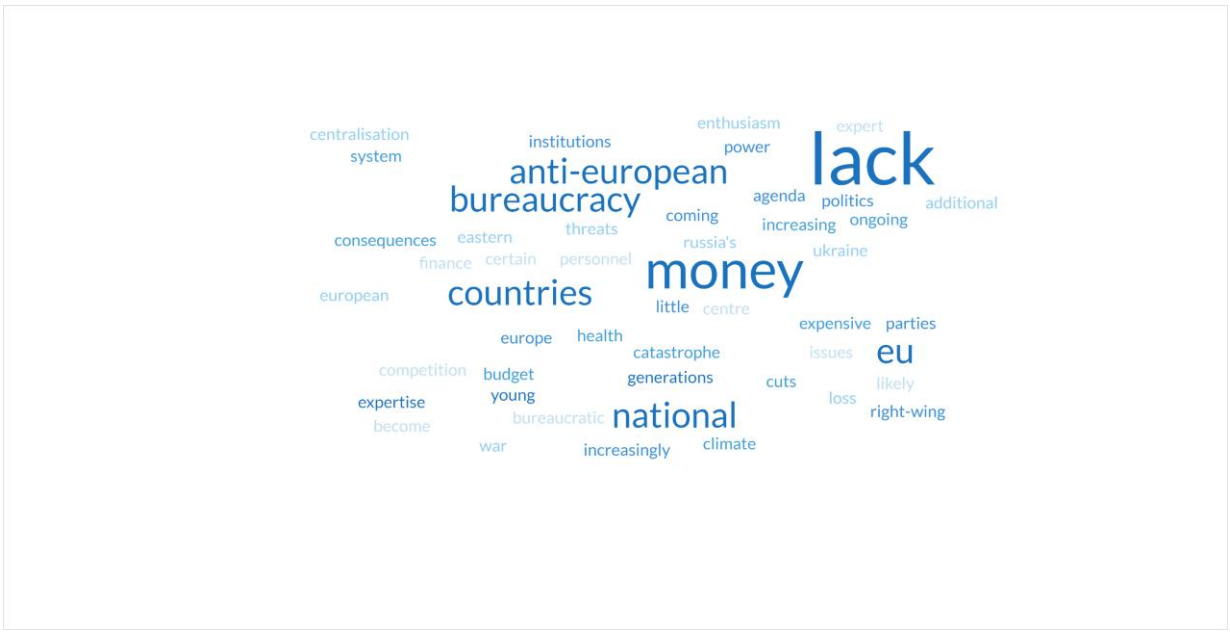
- This is more difficult to summarise, but working through the comments, it is clear that the lack of time and requirements for membership, e.g. providing patient numbers, as well as the inactivity and perceived lack of expertise of some centres, are primarily seen as weaknesses for the network at this current juncture. The QIG will discuss how improvements can be made going forward to get more experts involved in network activities. The geographical scope of our ERN, currently covering 20 Member States, could be improved by a new call for full members or Affiliated Partners and this view has been communicated to DG SANTE. In addition, expanding the

disease areas covered by the existing members and adding completely new disease areas to the scope of ERN eUROGEN's activities would also be helpful in increasing the number of clinicians available to work with the network.

36. Question 15 asked members to detail what they saw as the opportunities for the network at the moment:

- The main messages were around the opportunity for centralisation, alongside the strengthening of national and regional cooperation.

37. Conversely, question 16 asked members to detail what they currently saw as the threats to the network:



- The two main themes here were a lack of money going forward, as well as the political shift to the right across Europe, which may make cooperation more difficult and thus hinder our ability to take advantage of the opportunities identified above.

38. Finally, we asked the members to rate their overall satisfaction with their membership in the network for the last 12 months, as well as providing any final comments. This score positively, with no individual score below 5. In terms of the comments, the main theme was improving communication and reducing bureaucracy, something the QIG will need to focus on.

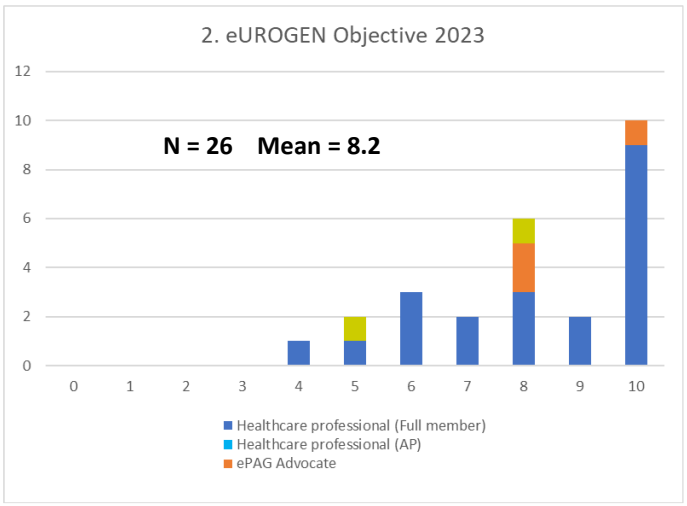
3. NEXT STEPS

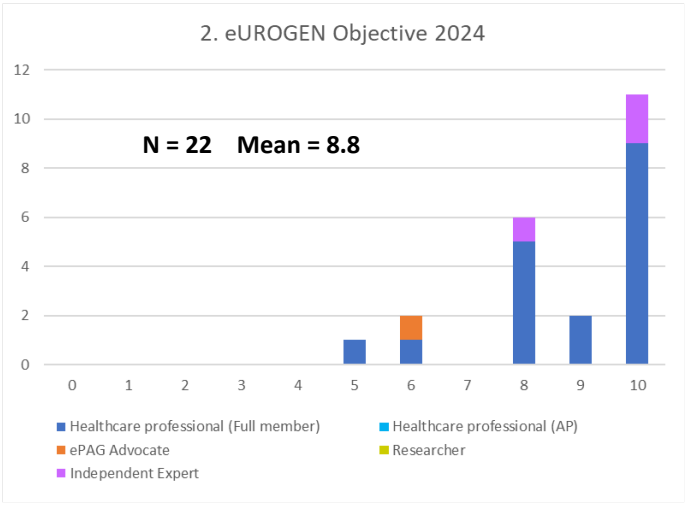
39. The results will be further considered by the ERN eUROGEN Quality Improvement Group to identify any actions for improving particular areas or issues identified by the survey, some of which have been noted above.

4. ERN EUROGEN QUALITY IMPROVEMENT SURVEY RESULTS & SWOT ANALYSIS (SEPTEMBER 2024)

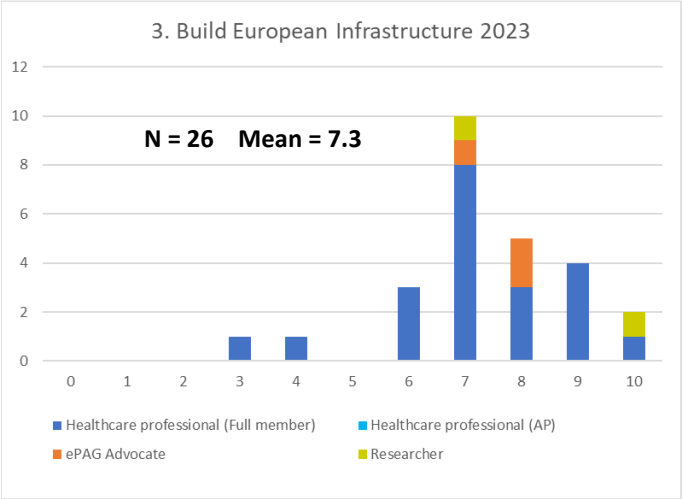
2. Please rate your agreement with the current mission of ERN eUROGEN, as stated below, taking into account the mandate of the ERNs provided by the European Commission (where 0 represents no agreement and 10 represents full agreement):

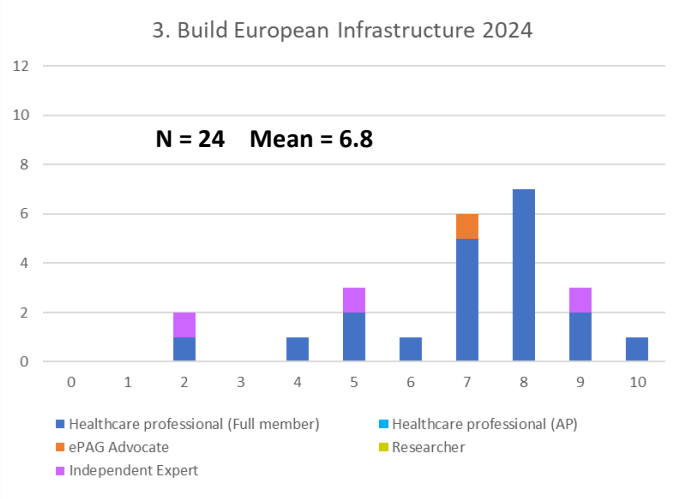
The mission of ERN eUROGEN is to develop a framework to provide faster specialist evaluation and more equitable access to high-quality diagnoses, treatment, and care for patients with rare urogenital diseases and complex conditions who need highly specialised assessment and surgery. Please rate your agreement with the current mission of ERN eUROGEN, as stated above, taking into account the mandate of the ERNs provided by the European Commission:





3. Building a European-wide infrastructure for rare urogenital diseases and complex conditions.

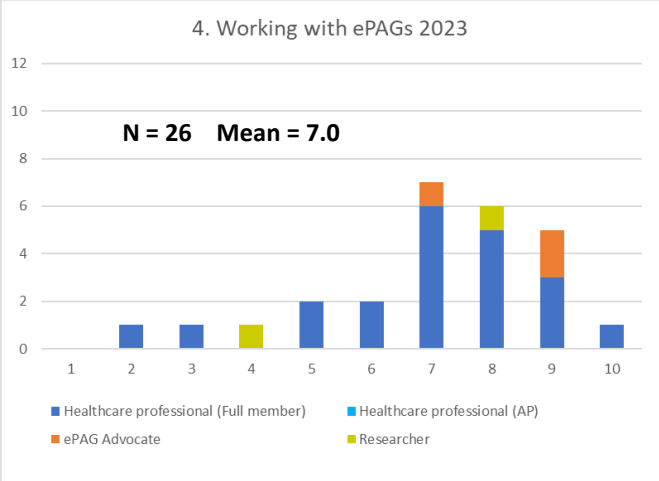


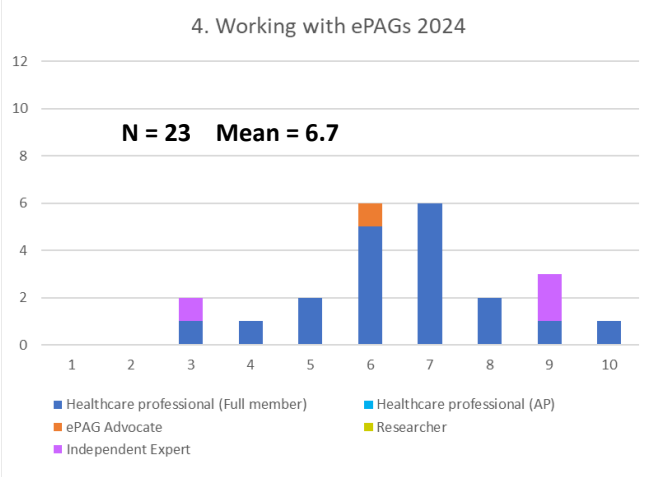


Comments (2024 only; commenter's score in brackets):

- Only a very selective group of clinics is participating, not representative at all. (2)
- In my special area exchange between centres is low. Tools for easier communication are needed. (4)
- "Concerning European wide real centres of expertise: the operational criteria are not taken seriously enough (especially defining minimal numbers of patients seen and procedures performed, controlling that they are really met, and excluding centres not meeting the criteria). Many clinics proceeds with occasional surgery, now under the name of an ERN, but without any real improvement.
  Concerning the European wide discussion of cases through CPMS: it is very hard for the experts to find time for these discussions beside their own clinical and scientific work, making the discussions often less fruitful, because of a lack of participants. A decent financial compensation would surely help.
  A third problem: The other clinics do not send any more patients to the now ERN centres than they did before, instead they go on with performing occasional surgery, producing preventable catastrophes. At least for Germany this is statistically proven. Legally binding minimal numbers as introduced in Germany for neonatology and adult surgery, are necessary to really change the picture." (5)
- I think we are still quite far away from having "built" an efficient infrastructure. Just a virtual "infrastructure", maybe... (5)
- Based on my experiences in workstream 1, no answer possible for WS 2 and 3. (7)
- Great efforts have been made - but even wider coverage (countries involved) would be great, if these countries have HCPs that meet the criteria. (8)

4.Working in partnership with patient representatives.

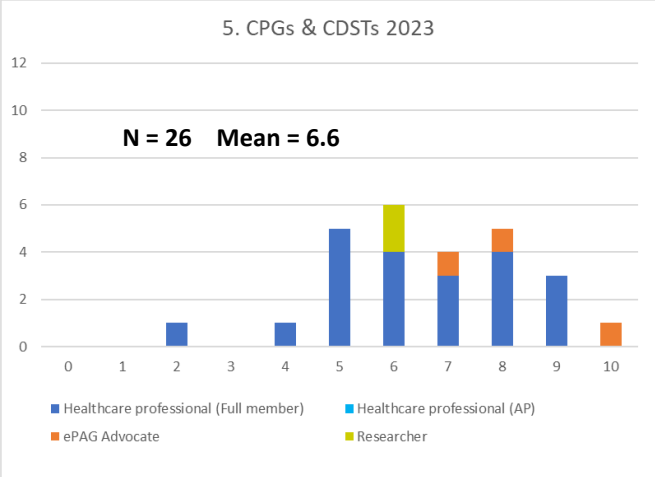


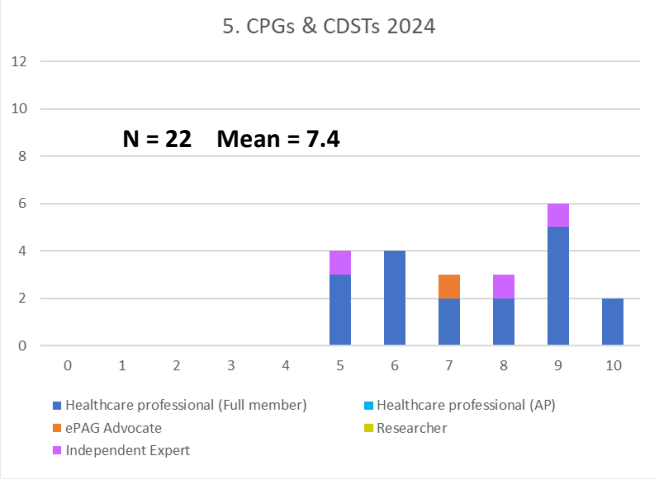


Comments (2024 only; commenter's score in brackets):

- Only very partially. (3)
- Only some patients representatives involved. should be extended. (6)
- The ERNs would not have been founded if the patient organisations (EURORDIS) would not have kept on pressing for it. It is not appropriate that they only have an advisory role. They should become board members in all ERNs. (6)
- True , but limited to few diseases. (6)
- It is needed to have more patient representatives from different diseases. But the work very time consuming. Improvement: in my opinion it is needed to have some kind of remuneration. (8)
- Unfortunately not all disease areas have active patient organisations. Potentially eUROGEN could play a role in supporting the development of organisations, which would lead to involvement of more representatives. (8)

5. Clinical Practice Guidelines and clinical decision-making tools.

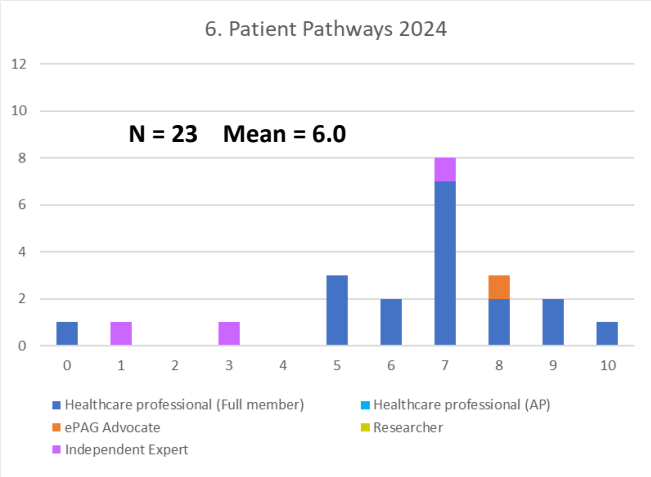


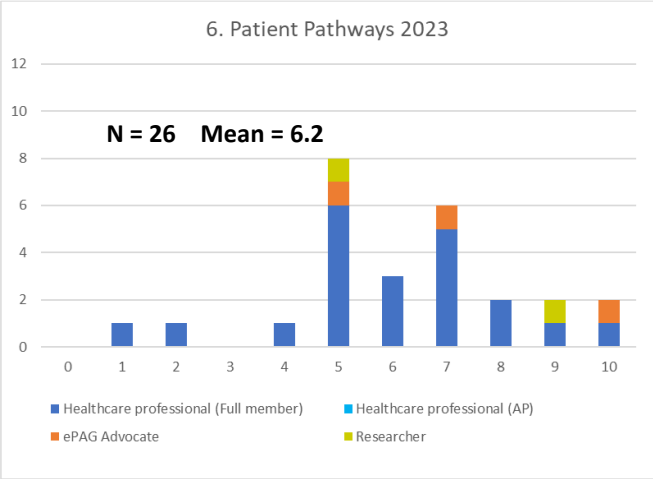


Comments (2024 only; commenter's score in brackets):

- Yes but only for those who participate. (5)
- Answer regarding workstream 1. (7)
- Great efforts with the available means. Hopefully more resources become available (financial support but also cooperation with specialist societies). (8)
- The work done in this field promises to have a lasting impact both on health care, and politics. (9)

6. Development of patient pathways

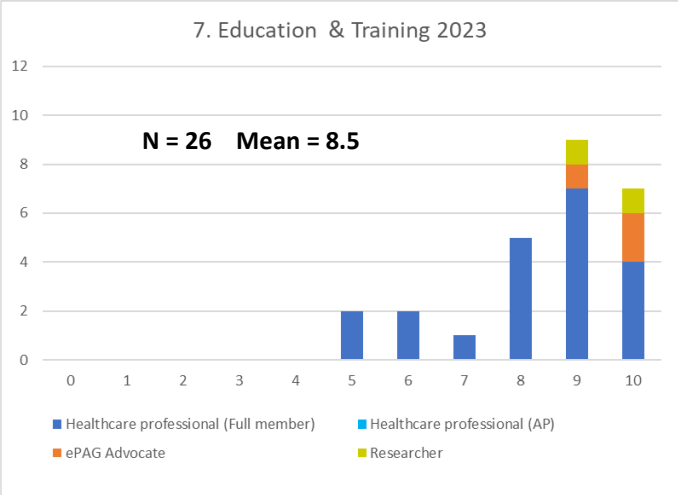


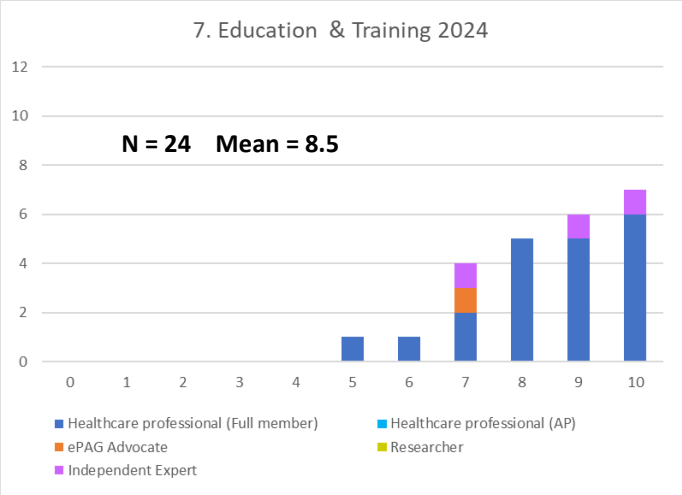


Comments (2024 only; commenter's score in brackets):

- This is in agreement with point 3. (3)
- Again, great efforts with the available means. (7)
- As there are so many rare and ultra rare diseases, development of guidelines, patient pathways, training activities et cetera will always cover only a minor part of them. But the number is increasing! (9)

7. Educational and training activities (webinars, ERN Exchange Programme, etc.)

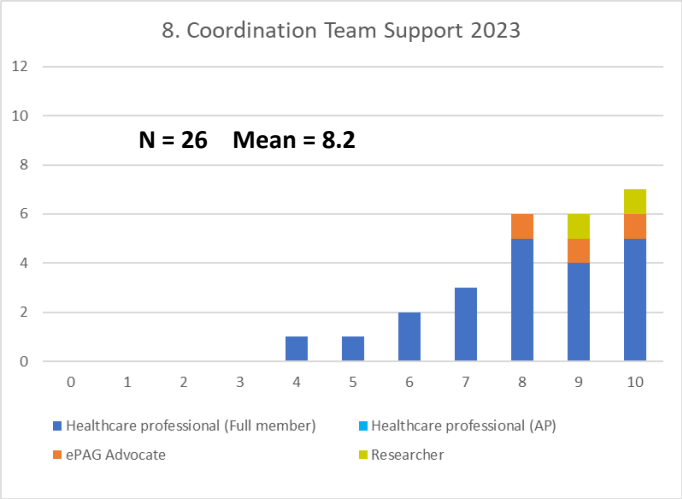


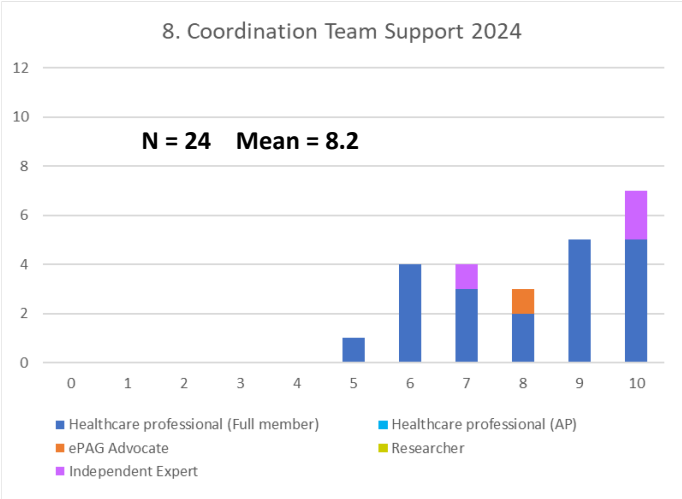


Comments (2024 only; commenter's score in brackets):

- There is a risk in providing training, including surgery, to the general public: colleagues might feel encouraged to do occasional surgery, producing preventable catastrophes, because they were taught by us on the Internet. (5)
- Improvement: more discussion at webinars (7)
- That goes well but that is not unique for eUrogen, every scientific organization does so (7)
- More exchange programs and workshops for FEAPU fellows would be of great improvement. (8)
- Very active webinar programme. The loss of the exchange programme is a great shame (financial causes unfortunately). Worth prioritizing in future fund acquisition proposals. (8)
- I would aim to a more rigorous lecturer selection. (9)

8. Provision of continuous support from the Coordination Team (e.g. ERN Monitoring, ERN Evaluation, etc.)

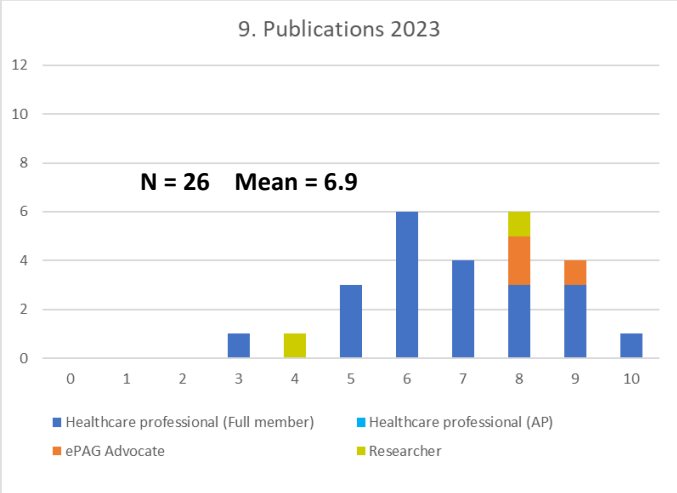


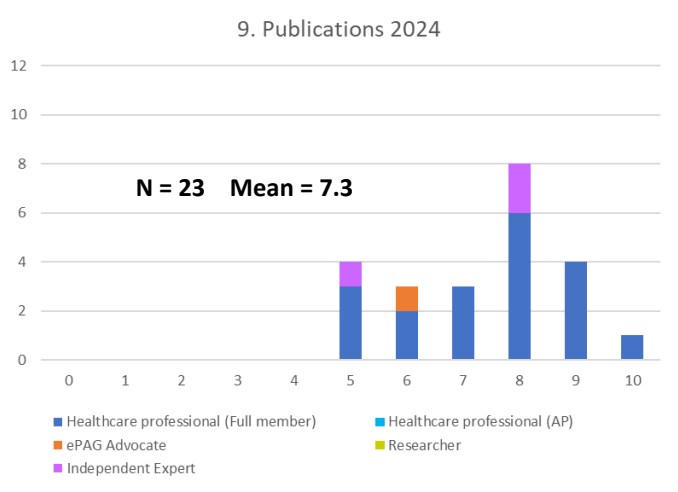


Comments (2024 only; commenter's score in brackets):

- The support from the coordination team is really cherished and appreciated and of great help. Unfortunately at least in eUROGEN the impression is that the first goal is to have many clinics included, regardless of their patient numbers, results and active participation. The coordinating team should put more emphasis on quality instead of quantity. (7)
- Support is okay. (7)
- Fantastic team: always available and helpful. (10)

9. Publications (e.g. scientific papers, supplements, etc.)

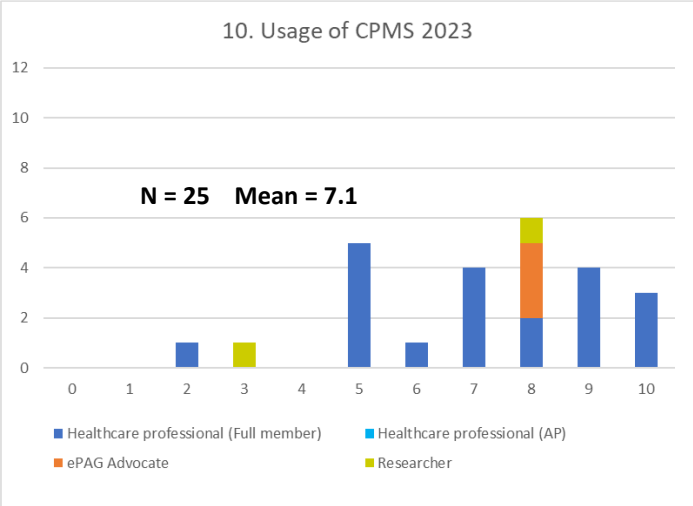


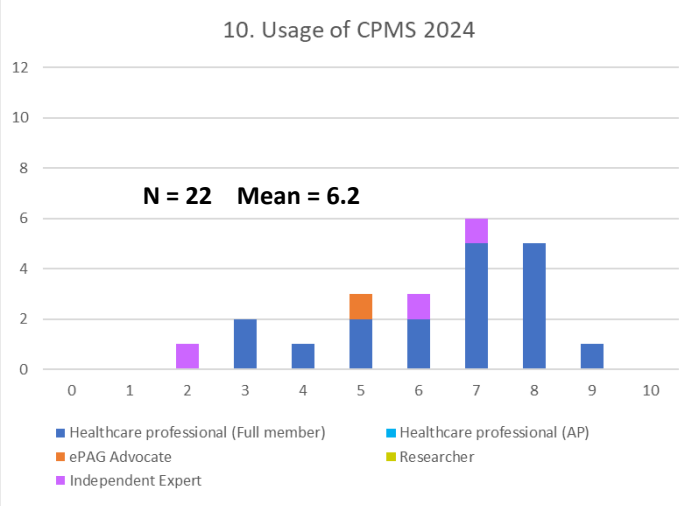


Comments (2024 only; commenter's score in brackets):

- No publications in my area. Most centers are inactive, because there are no incentives for active involvement. (No score)
- That is ok too, but not very exclusive, like webinars. (5)
- More eUROGEN initiated papers could be published. The webinar platform is a great stepping stone and could lead to cooperative publications. Reviews at first. The Registry can drive retrospective publications but also prospective studies. It feels like a great potential is there which is not fully harvested yet. Fantastic book though! (7)
- Very useful publications on partly beforehand completely ignored important topics are another fruit of the ERNs. (8)

10. Usage of the Clinical Patient Management System

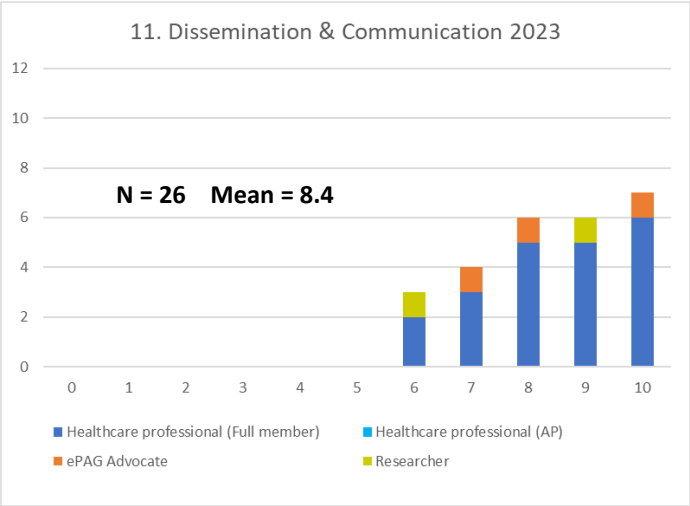


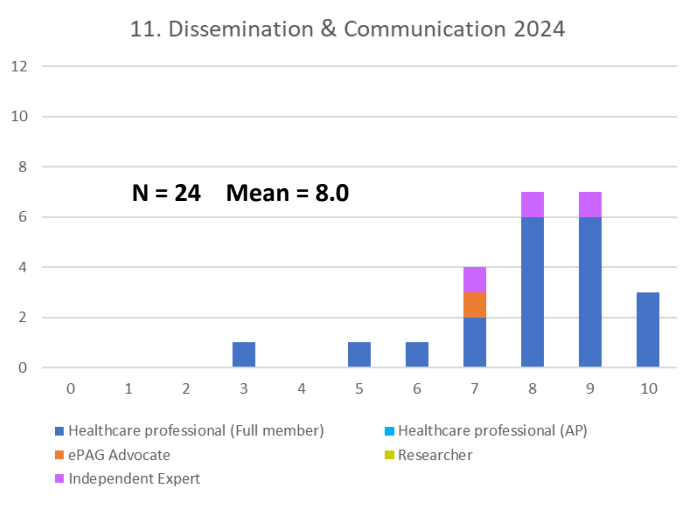


Comments (2024 only; commenter's score in brackets):

- CPMS is difficult to use. I hope the new CPMS is simpler. (3)
- See above, 3b: it is very hard for the experts to find time for these discussions beside their own clinical and scientific work, making the discussions often less fruitful, because of a lack of participants. A decent financial compensation would surely help. (4)
- From the patient perspective it is not clear for me, if the patients had benefit - what happens after the cpms. (5)
- Worked in the beginning but is not representative of what those clinics who don't know about ERN need. (6)
- Insight in expertise by health care professional would help to construct panels. (8)

11. Dissemination and communication from ERN eUROGEN (e.g. website, newsletter, etc.)

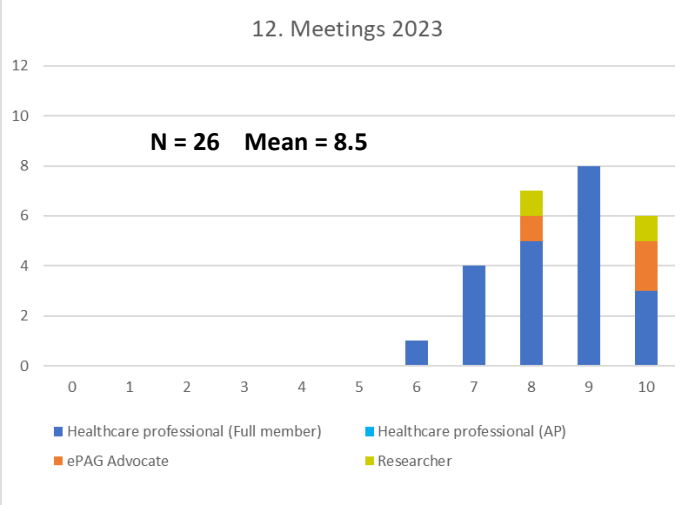


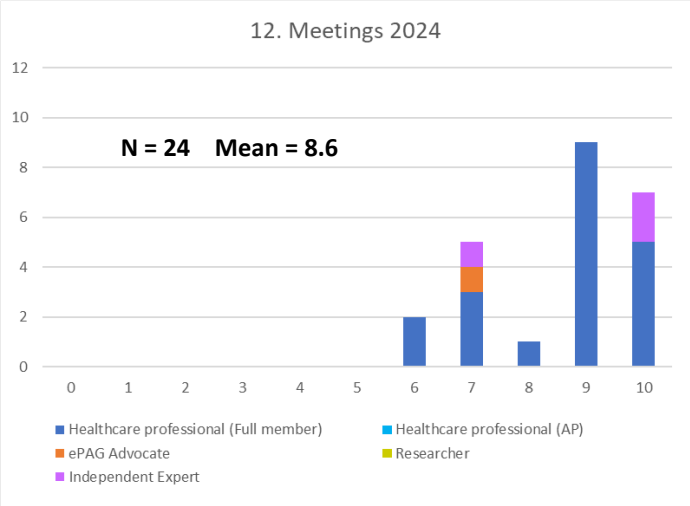


Comments (2024 only; commenter's score in brackets):

- There is so many important scientific and administration will stuff to read, I hardly ever get to the website, newsletter and Plaza. (3)
- Very transparent communication - the website could be more user friendly. (7)
- Okay But for whom? (7)
- Great as is! (10)

12. Organisation of regular meetings and similar (e.g. annual Strategic Board Meeting, monthly Workstream meetings, etc.)





Comments (2024 only; commenter's score in brackets):

- Until now, excellent. Because of the monthly WorkStream meetings via Internet, the annual strategic board meeting absolutely has to be in presence. It is a pity that we will have it only while the Internet this year. Discussing and solving controversial points is nearly impossible this way. (9)
- Like clockwork and reliable. (9)

13. In your opinion, what are the greatest strengths of the ERN eUROGEN network? (2024 responses only)

- Foster and including patient organization; developing guidelines; lobby work for rare diseases; bringing experts together
- Strongly organised
- CPMS and training/education
- Educational activities
- Create connection between HCP and patients, selecting high level centre with clear criteria
- Communication knowledge on rare diseases
- Combining competition
- Still alive
- Europeans work together
- The existence of the network itself.
- Spin en the web with a helicopter view in Urological rare diseases throughout Europe
- Connecting professionals
- Wide network with competent centres. Active coordination team.
- The focus on rare disease, the European support and the Coordination Team!
- Communication
- The strong role of the patient representatives
- Collaboration
- Collecting expertise on rare urological conditions
- Collecting and facing different experiences from all over europe, stimulating collaborations
- Selection of highly qualified centres, internationality, scientific soundness, reputation
- Pan-European organization

14. And its greatest weaknesses? (2024 responses only)

- Self-reporting of so called "centre of excellence" for rare diseases

- Too weak if members of the networks do not fulfil the rules and regulation e.g. not fulfil the case numbers; in other words - less possibilities if there are not real experts inside the networks
- Taking clinics in as full members which do not have sufficient patient numbers and against the advice and experiences of national patient organisations knowing them very well.
- Asks a lot of commitment from participants ('pro deo time') in a highly 'concurrential' field (too little time).
- There are many working groups, but I am unaware of the results.
- Slowness
- Partnerships between expertise areas, lack of centralisation in many countries and therefore are many rare diseases still treated in non ERN/eUROGEN hospitals with much less expertise
- National law permit to indicate as centre of excellence that are not corresponding to eUROGEN criteria
- Too much paper work
- Implementation of activities
- Not being known by the young physicians
- Patient exchange and no criteria in numbers of patients treated to become expert centre
- Distance and need for video conferences instead of physical meetings. However that probably cannot be changed
- The professionals that we intend to serve are not there. Help in individual cases on the spot not organized yet
- Strict criteria to adhere to, difficulty to match with local regulations (E.g. privacy issues, bureaucracy)
- Pluralism of countries
- Many inactive centres.
- Dependency from HCPs for several planned activities can be a weakness
- Too many rules and permission to be asked. Many action results into too much paperwork that discourage from going on
- Proper contribution needs plenty of time.
- A lot of promise and potential is there and could / should be developed
- Research

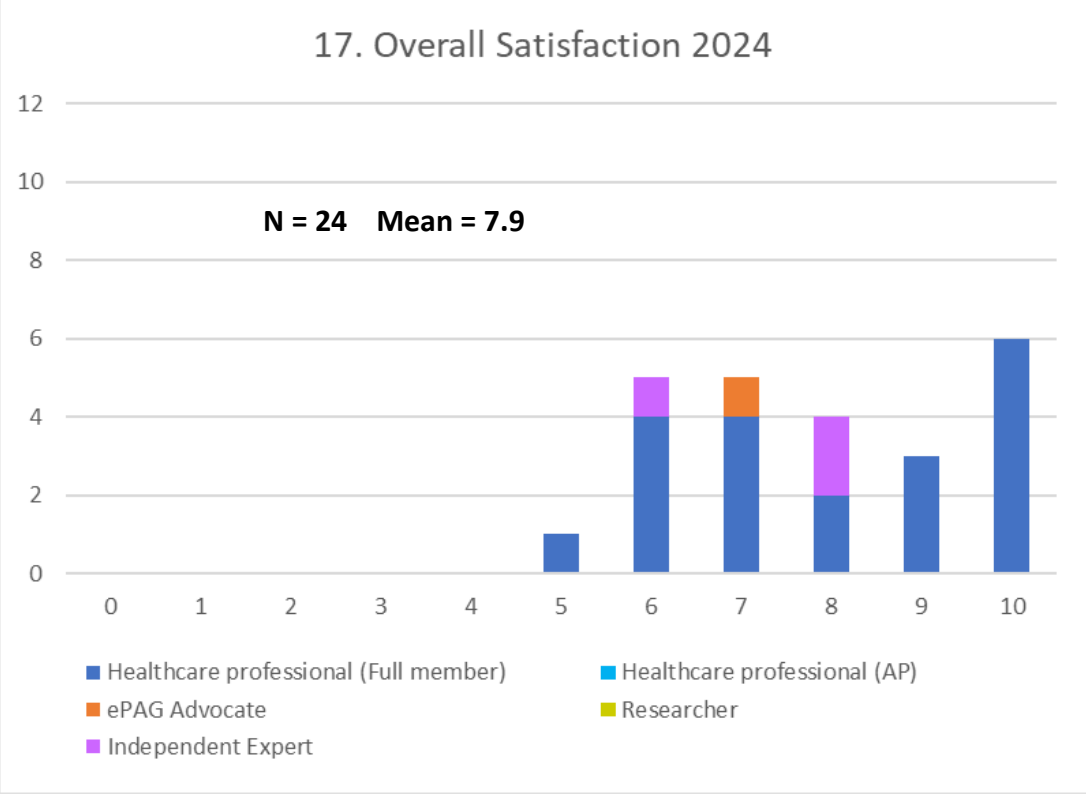
15. What opportunities do you see for the network to embrace in the future? (2024 responses only)

- Improve standardisation, extend guidelines and optimising care for children, adolescent and adults
- Creating awareness for rare diseases, developing further guidelines, strengthen the patient organisations
- Encouraging the HCPs to form regional and national networks, to realise centralisation of care which until now did not take place (see 3b: he other clinics do not send any more patients to the now ERN centres than they did before, instead they go on with performing occasional surgery, producing preventable catastrophes. At least for Germany this is statistically proven. Legally binding minimal numbers as introduced in Germany for neonatology and adult surgery, are necessary to really change the picture, as long as we do not have this, forming regional and national networks might help.)
- To agree on European protocols for all complex urological pathologies
- Becoming a key player in rare disease management in EU
- I would wish more opportunities to learn from other experts/exchange opinions, the educational online events are great, but an in person learning experience would be even more beneficial
- To move up different national health system forward an high level of healthcare as suggested by Eurogen
- Simplification of healing pathways
- Continued efforts and broadening activities
- Information for everybody for free
- Centralisation of care
- Expansion and simplification of CPMS
- Goals are still valid
- Guideline leadership, clinical condivision of complex cases
- development
- More cooperation within centres in Europe and globally
- Improve research and guidelines in rare diseases
- Sharing expertise, not only by word, but also by hand. Training and education
- Implementing European database without any national regulation/legislation

16. And what hindrances are on the horizon that may become an issue for the network? (2024 responses only)

- Lack of expertise of young generations
- Too little money , much bureaucracy, anti-european politics
- Right-wing parties increasingly coming to power all over Europe and in the EU institutions, which have a national, anti-European agenda.
- Increasing budget cuts in the health system because of the expensive consequences of the ongoing climate catastrophe and Russia's war against Ukraine and threats against additional eastern European countries."
- Loss of enthusiasm
- Lack of centralisation in certain countries
- Too many bureaucratic issues
- Finance
- Lack of personnel
- Competition to become an expert centre
- Bureaucracy
- Money most likely
- Keeping all centres involved
- Money, lack of local support of hospital administration
- Securing Continuity of funding. If this occurs, this may have a dramatic impact on the performance of the network.
- Lot of rules in national and EU level mean increased need for manpower
- Finances, as always
- More and more paperwork

17. Please rate your overall satisfaction level with your membership of ERN eUROGEN in the last 12 months



18. Other comments (2024 responses only):

- Would like to be more involved
- The ERNs are a great, unique endeavour, which brought us to a point in caring for rare disease patients, and the cooperation with the patient organisations, which we would never have been able to reach without them.

- So far, the work in the ERN has been mostly bureaucracy. Interactions and knowledge exchange with other centres or caregivers through the ERN was limited. I think more emphasis should be put into improving communication: limit bureaucracy and unnecessary emails, organize interesting and specific meetings for each expertise area, offer support for patient recruitment in clinical trials...
- Communication between centres could be more easy to work properly.

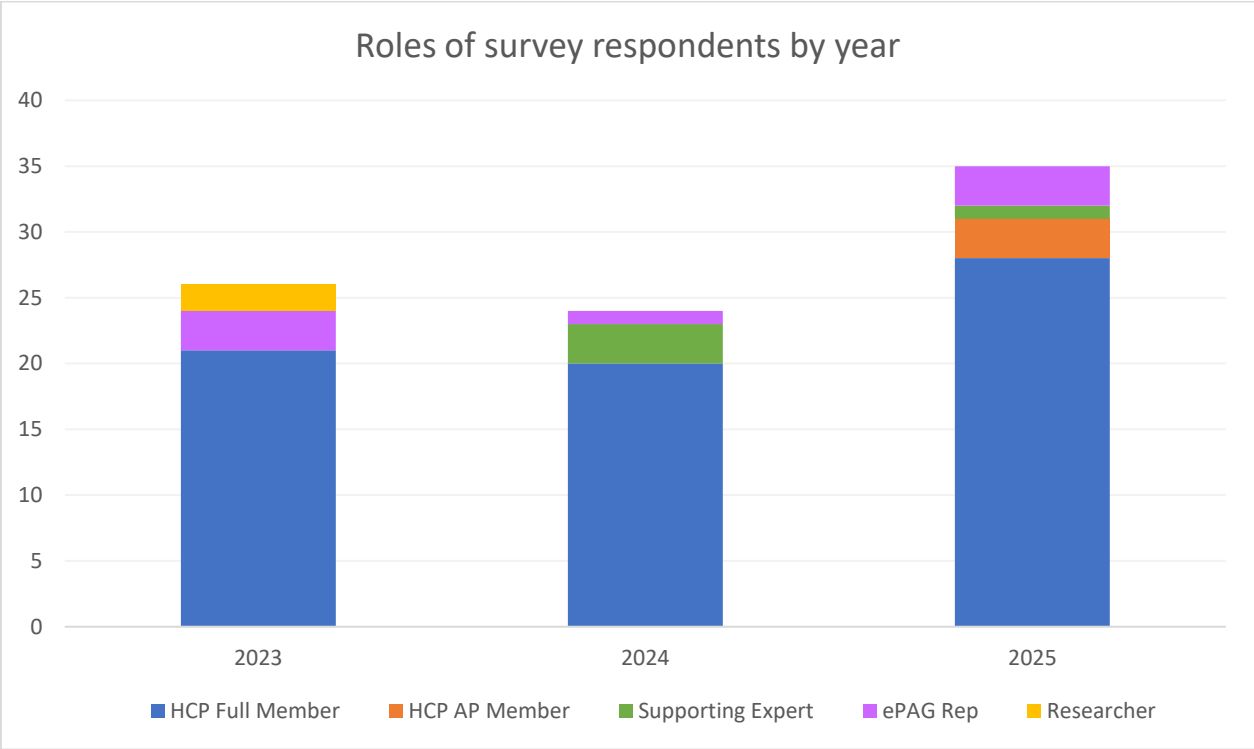
ANNEX B: ERN EUROGEN NETWORK SURVEY RESULTS 2025 (D1.4)

1. BACKGROUND

40. ERN eUROGEN first issued a network survey during the 2022-23 Bridging Grant. This is now undertaken as an annual process, in line with the requirements of the EC call for proposals.
41. For 2025, this anonymous survey again asked respondents to score the progress and development of the network across a range of areas of its work. However, for this year, the survey was expanded to help gather more in-depth feedback with regard to the activities of Coordination Team and the barriers faced by our members.
42. The network-wide survey was issued in September 2025 and this report sets out the feedback that was gathered. We received 35 responses in total (compared to 24 in 2024, and 26 in 2023). However, the questions were not mandatory and thus many questions have fewer than 35 responses.
43. The full results and comments are provided in **Annex A**, alongside a comparison to previous years where applicable.

2. NETWORK SURVEY RESULTS

Question 1. Respondent's role



1. 2025 saw more survey responses compared with the two previous years. This is a positive sign in itself in terms of HCP engagement, regardless of the results. A number of changes were made to the 2025 survey in an attempt to capture more nuanced feedback regarding both the major activities undertaken within the network and a number of the products produced and issued by the Coordination Team. Whilst this meant both that the number of questions increased and some questions were discontinued whilst others were created anew, it was felt that the benefits would outweigh the costs since the outputs would be much more useful.

2. The main section was also reorganised by Work Package to better align with other network activity, such as monthly workstream meetings and the monthly performance report.

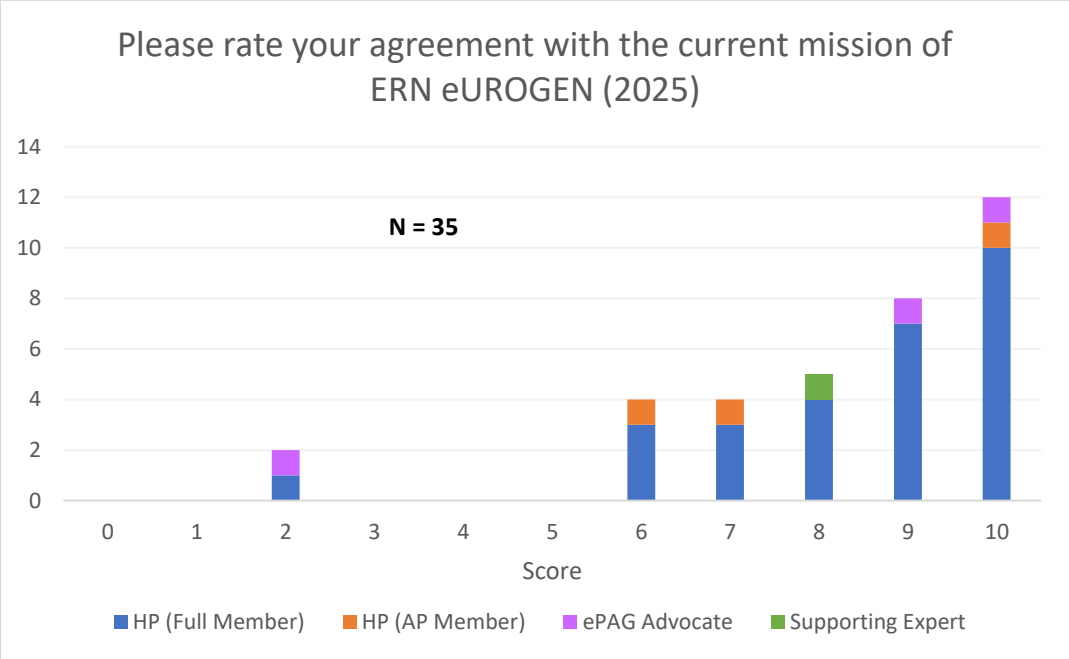
3. As with previous years, the majority of respondents work in a full-member HCP. It is another positive sign in that there were a number of respondents from Affiliated Partner centres.

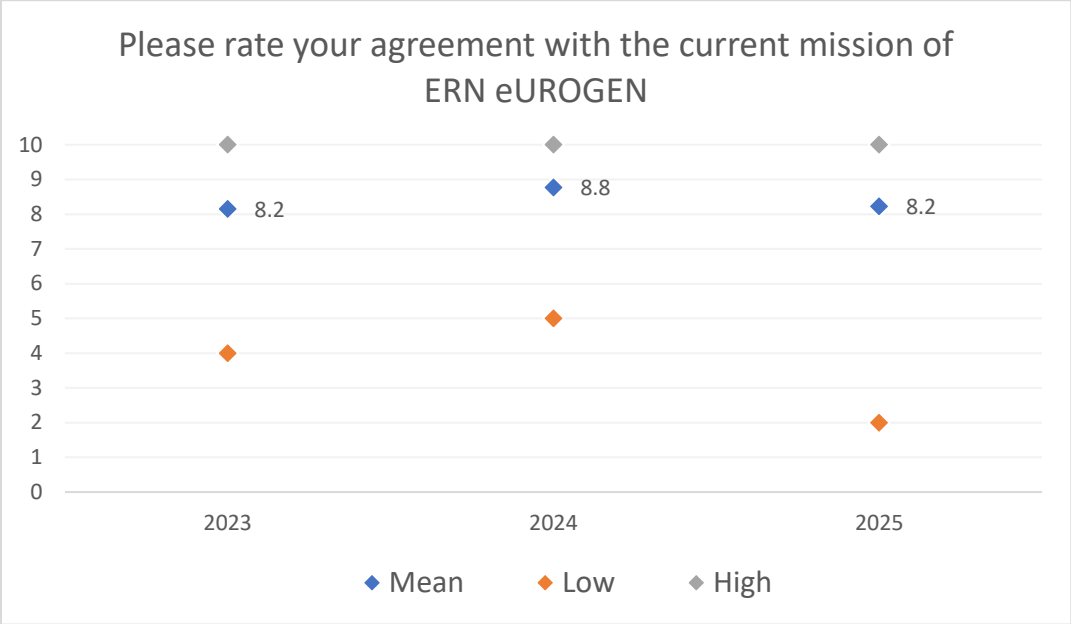
Part 1: Work Packages

Work Package 1: Coordination

Question 2. Please rate your agreement with the current mission of ERN eUROGEN, as stated below, taking into account the mandate of the ERNs provided by the European Commission (where 0 represents no agreement and 10 represents full agreement):

The mission of ERN eUROGEN is to develop a framework to provide faster specialist evaluation and more equitable access to high-quality diagnoses, treatment, and care for patients with rare urogenital diseases and complex conditions who need highly specialised assessment and surgery. Please rate your agreement with the current mission of ERN eUROGEN, as stated above, taking into account the mandate of the ERNs provided by the European Commission:



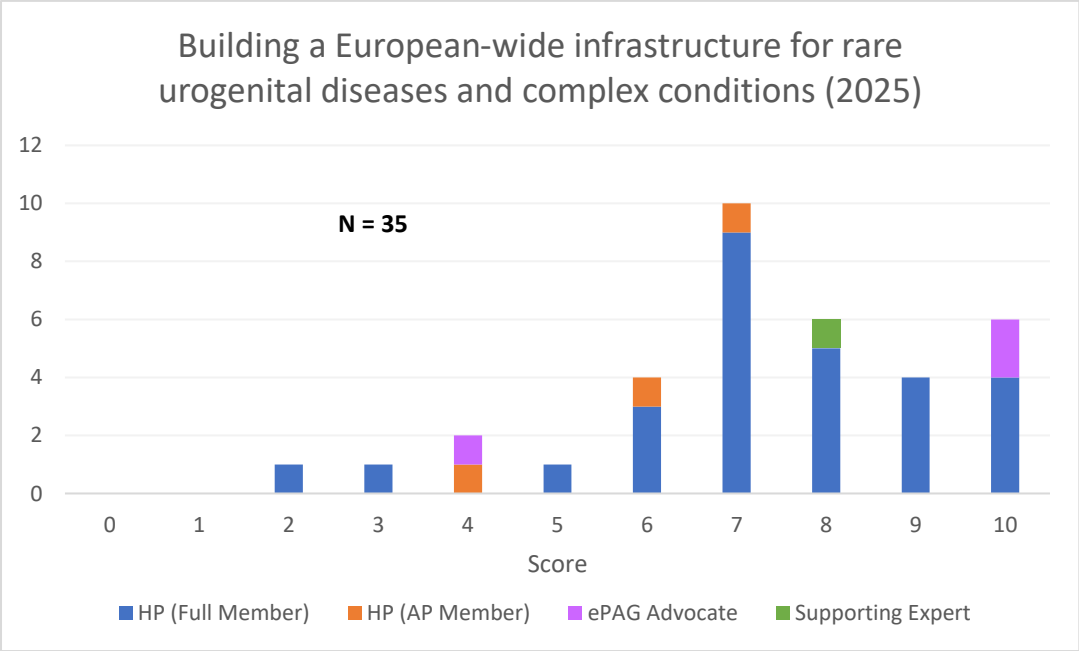


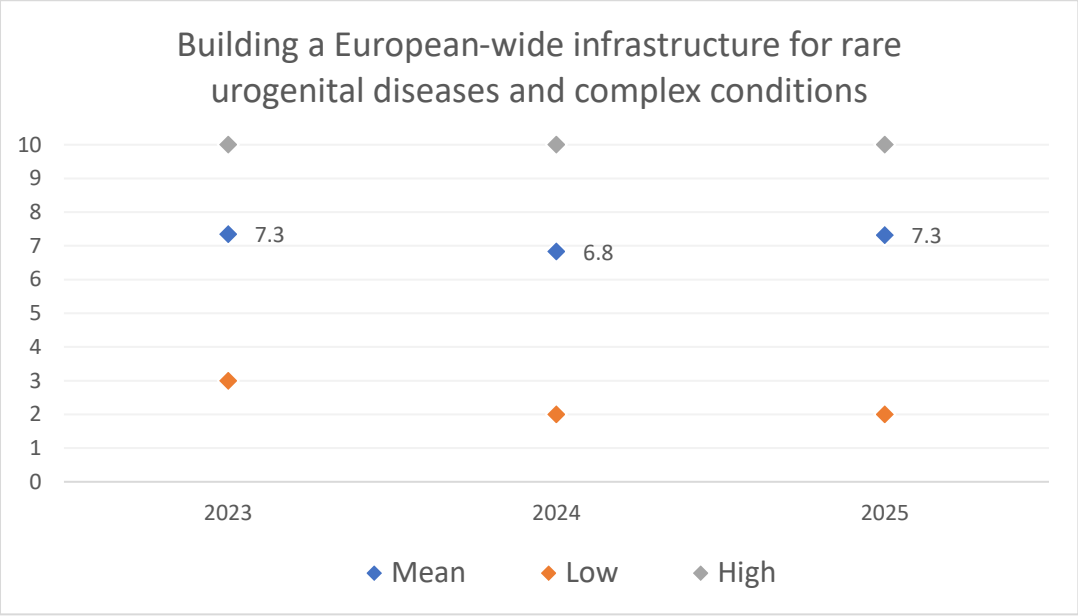
4. All 35 respondents answered this question and, apart from two low marks, the remainder were all 6 or higher, with a modal score of 10.

5. The low scores were actually the lowest we have seen across the 3 years of the survey. Respondents were not given the opportunity to elaborate on their scores for this question. This will be rectified in the 2026 survey. Despite these scores, the mean score was equal to 2023.

6. Questions 3 to 5 rate the achievement of the activities and results delivered by ERN eUROGEN in the last 12 months for each of the stated aims (where 0 represents no achievement, and 10 represents full achievement).

Question 3. a) Building a European-wide infrastructure for rare urogenital diseases and complex conditions:





b) Any specific comments on this area (requirements, improvements etc.)?

Score	Comments (2025 only)
10	The biggest achieve is always to improve in the future
8	8 countries are missing and this should be solved by a new EC call for affiliated partners
8	Some members seem more motivated to work together, others less so
8	Important progress has been made in building the network and establishing a common structure. However, further work is needed on practical implementation and ensuring more active engagement from all member centres to reach full impact.
7	Some countries are over-represented and some underrepresented. A more even spread should be considered to allow for equitable access
7	Guidelines should also exist in a more pocketsize version
4	Only those centers that can manage the administrative load are present, which don't have to be the best ones
3	More visibility and information about eUROGEN certified centers in patient care, so centralization can take place

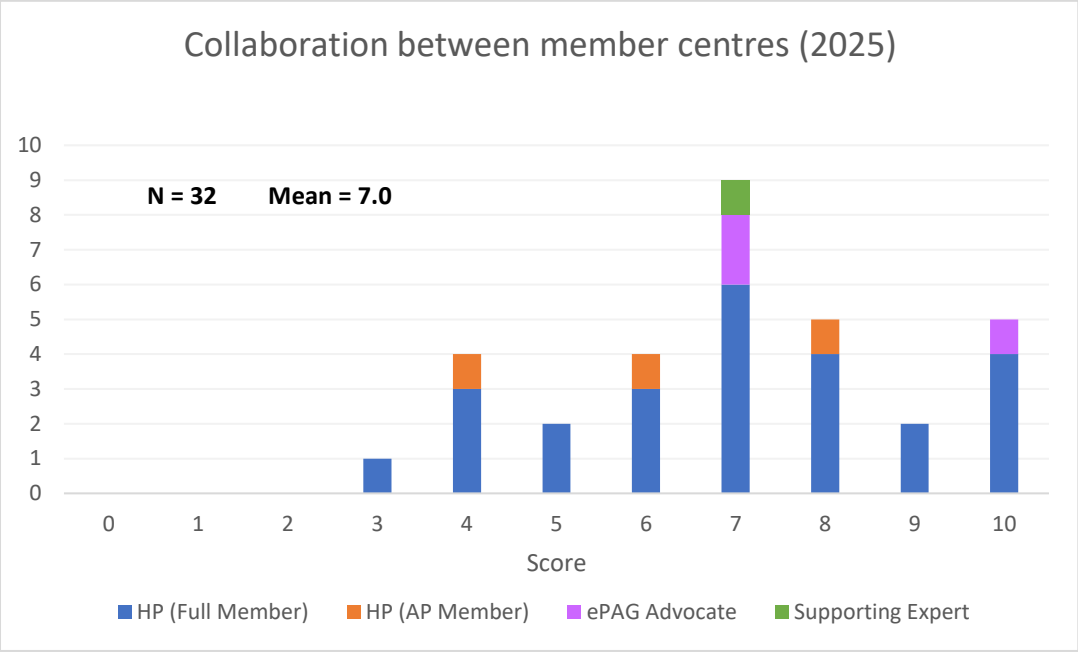
7. The results regarding our efforts to build a European infrastructure are more mixed, with a mean of 7.3 and a modal score of 7.

8. However, these scores show an improvement from 2024 and back to the levels of 2023. The comments below suggest that we still need to do more to encourage more active engagement by a number of HCPs. This was also reflected in the 2024 survey, and is an ongoing issue for the network as many HCPs, as will be seen below, continue to feel that they do not have the necessary resources to undertake the range of network activities.

9. Other respondents point out the need to widen the geographical coverage of the network, and make it a more even spread between countries. As pointed out, this should be helped by the forthcoming call for additional Affiliated Partners to fill existing gaps in the networks.

Consideration by QIG: How to improve communication between member HCPs, as well as encouraging greater participation more generally in the network.

Question 4. a) Collaboration between member centres (joint scientific papers, research, studies, etc.):



b) Any specific comments on this area (requirements, improvements etc.)?

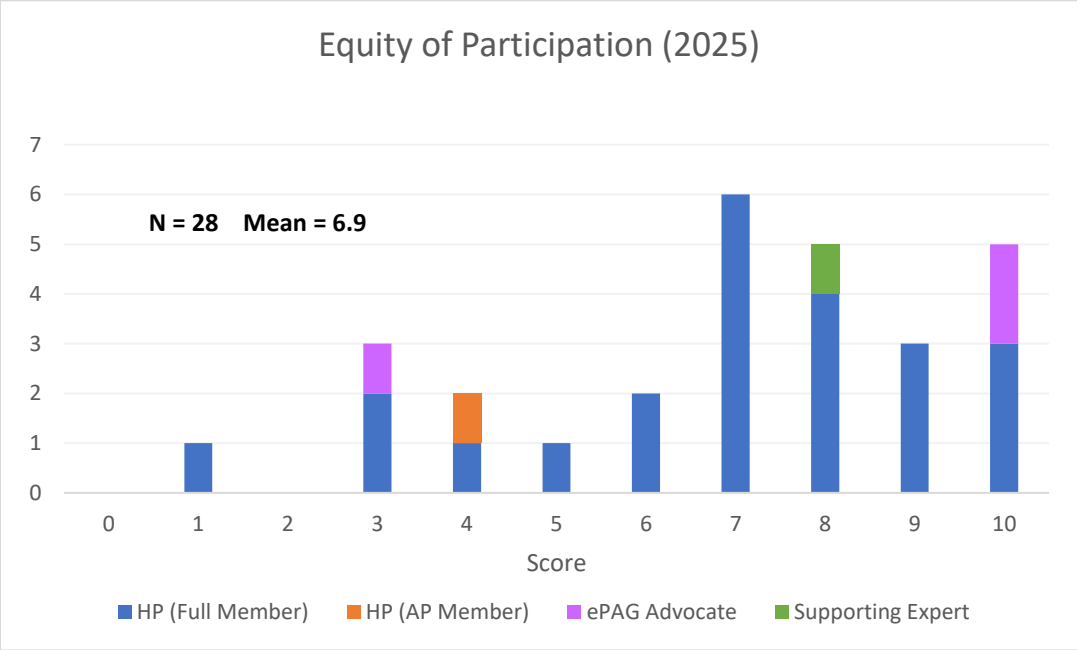
Score	Comments (2025 only)
10	Better information in regional hospitals so that they can refer patients more quickly to specialist centres.
9	I think there should be more opportunities for participation between centers in an easy way.
8	Registry is still developing on local approval and would be the first option to connect all for clinical studies
8	Some members seem more motivated to work together other less
8	guideline ARM: a milestone.
7	First steps have been taken - it hasn't taken flight yet. Maybe the initiatives could be centralized, liaised through the coordinating team, who can then spread the word?
7	There has been good progress in collaboration, and we value the joint efforts made so far. At the same time, there is still potential to further strengthen joint research and publications. More structured initiatives and facilitation from the coordination team could help increase scientific output across the network.
7	As an affiliated partner in UK would be good if could look at better arrangements to allow closer working
5	Working groups focusing to the research needs development
4	Only those centers that can manage the administrative load are present, which don't have to be the best ones
3	Time, lack of funding

10. This was a new question for the 2025 survey, attempting to delve more into the answers to the previous question on building a European-wide infrastructure.

11. The spread of results is quite similar, with an identical modal score, although with a slightly lower mean score.

12. Whilst the comments provide a number of opinions on how things might be improved, there is no overall consensus as to how this might be achieved.

Question 5. a) Equity of participation (e.g., do all regions/countries have an equal voice in decisions and access to opportunities within the network?):



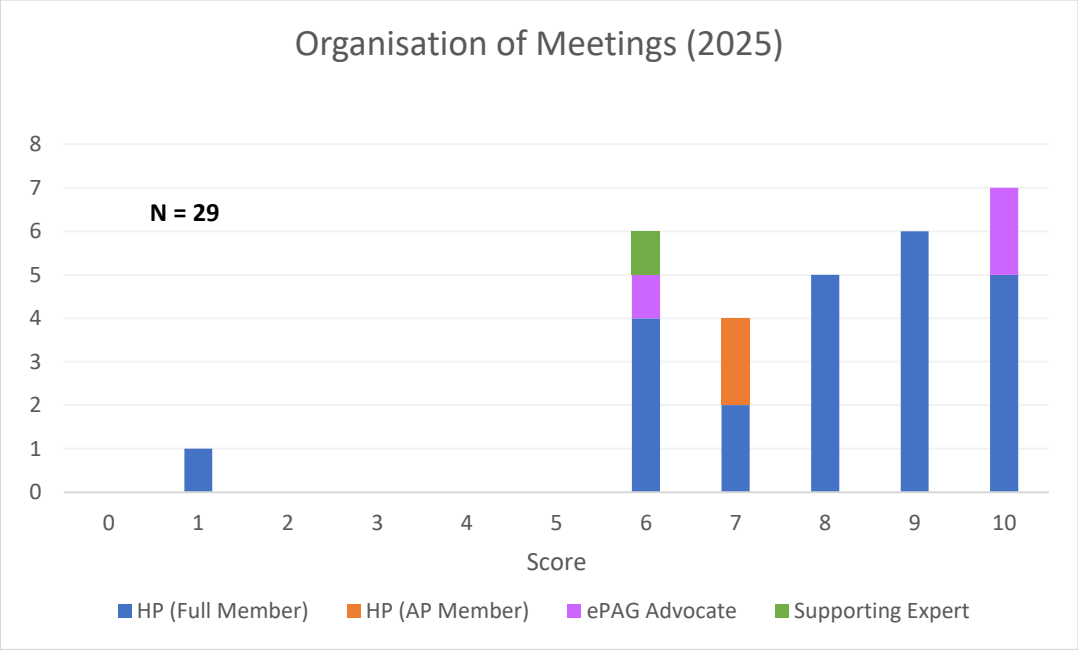
b) Any specific comments on this area (requirements, improvements etc.)?

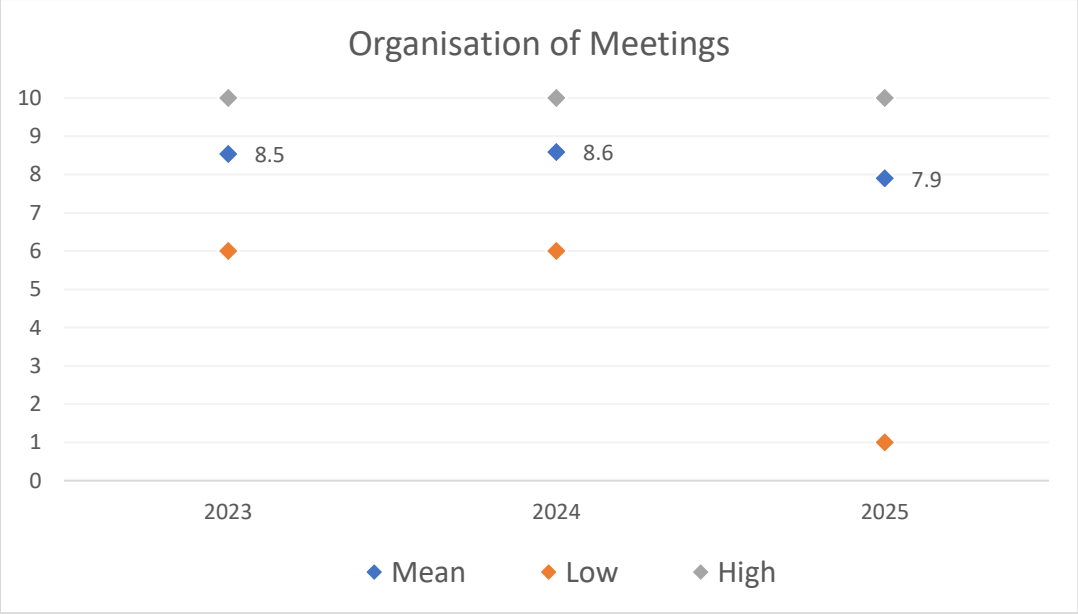
Score	Comments (2025 only)
8	New affiliated partners needed
7	The voice is equal by principle, but representation is not - this causes inequality
7	Overall, participation across countries and regions has been good, and we appreciate the inclusive approach of the network.
3	It takes a long time as a relative new member to gain access to knowledge about how everything works. It is also obvious that many members have known each other for many years making collaboration easy for them
3	Difficult to get time and support out of clinical work
n/a	Smaller countries with few cases and sparse experience should send their patients to bigger countries instead of trying to become full members.

13. This was again a new question for the 2025 survey, and also attempts to gather more specific opinions on the issues raised previously in Q.3.

14. This also gives a spread of responses. The comments do not focus on one particular issue but we intend to consider them individually to see how we can improve.

Question 6. a) Please rate the organisation of regular meetings and similar (e.g. annual Strategic Board Meeting, monthly Workstream meetings, etc.) delivered within ERN eUROGEN in the last 12 months (where 0 represents no achievement, and 10 represents full achievement):





b) Any specific comments on this area (requirements, improvements etc.)?

Score	Comments (2025 only)
9	Annual meeting rescheduled till 2026
9	Strategic Board Meeting

9	The meetings are very well organised and provide valuable opportunities for exchange. As active participants, we appreciate the structure and regularity. It could be useful to continue developing formats that allow for even more clinical discussion and sharing of best practices.
6	Lots of administration.

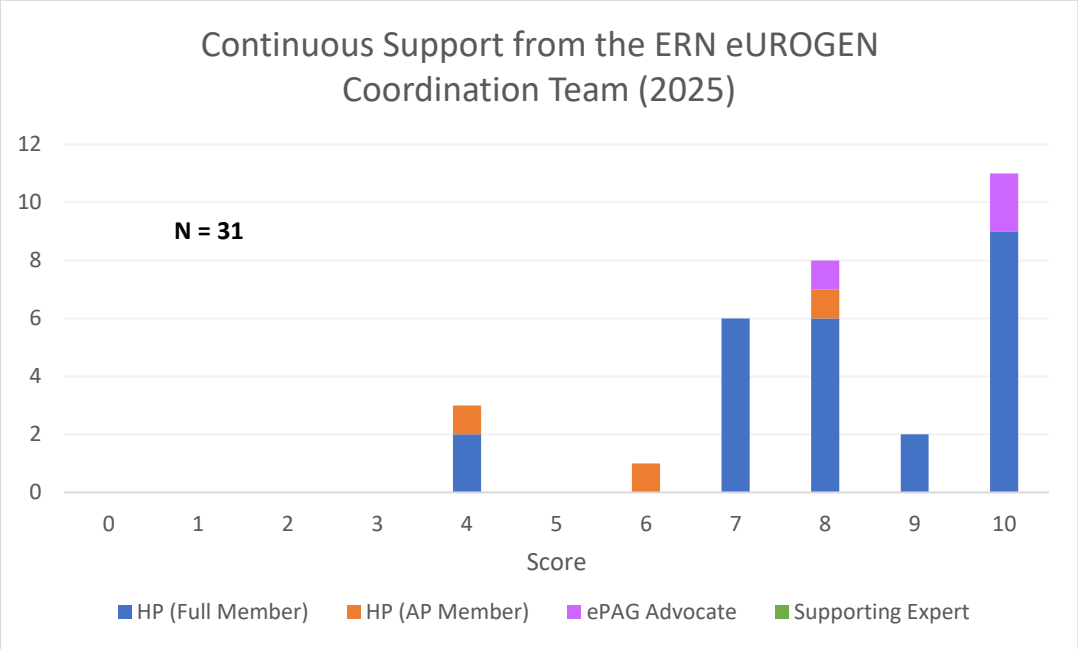
15. Whilst this question received a predominantly positive respone, the mean score was lower than previous years.

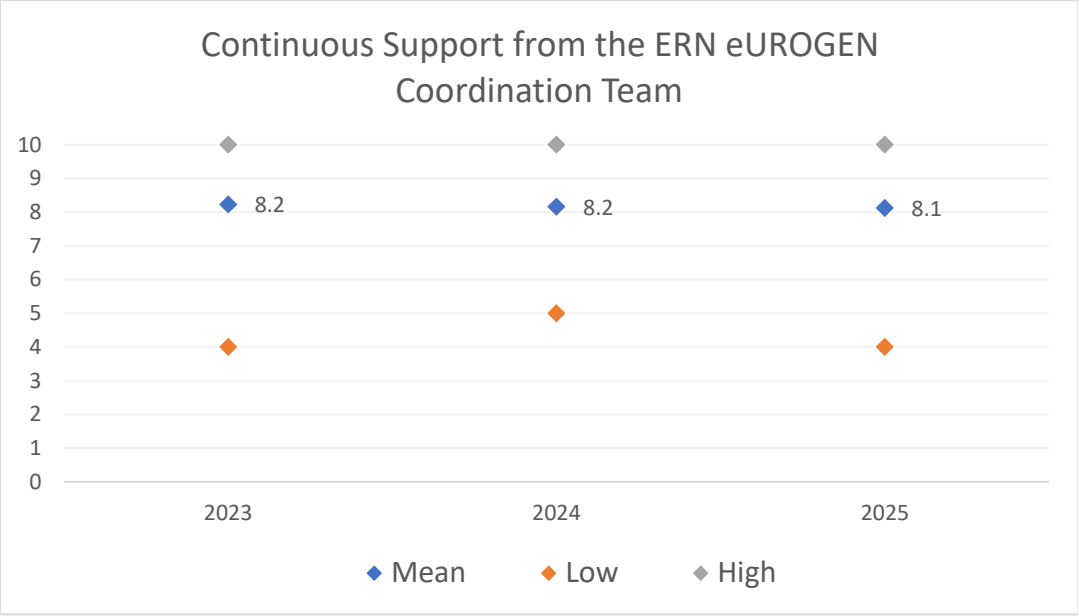
16. This is partly explained by the one low score, which is perhaps an error. No comment was left by this respondent and thus, if it was intended, we do not know the reason.

17. A slightly reduced score might also be the result of issues with the monthly worlstream meetings for Workstreams 2 and 3.

18. In terms of the comments, the lowest-scoring respondent who commented only mentions "lots of administrration". It is unclear what this refers to for this question as the bruden for these actions falls on almost wholly on the Coordination Team.

Question 7. a) Please rate the provision of continuous support from the ERN eUROGEN Coordination Team to the Network in the last 12 months (e.g. ERN Monitoring, ERN Evaluation, Elsevier books, etc.):





b) Any specific comments on this area (requirements, improvements, issues, etc.)? Is there anything else the Coordination team could do to support or help facilitate your network activities?

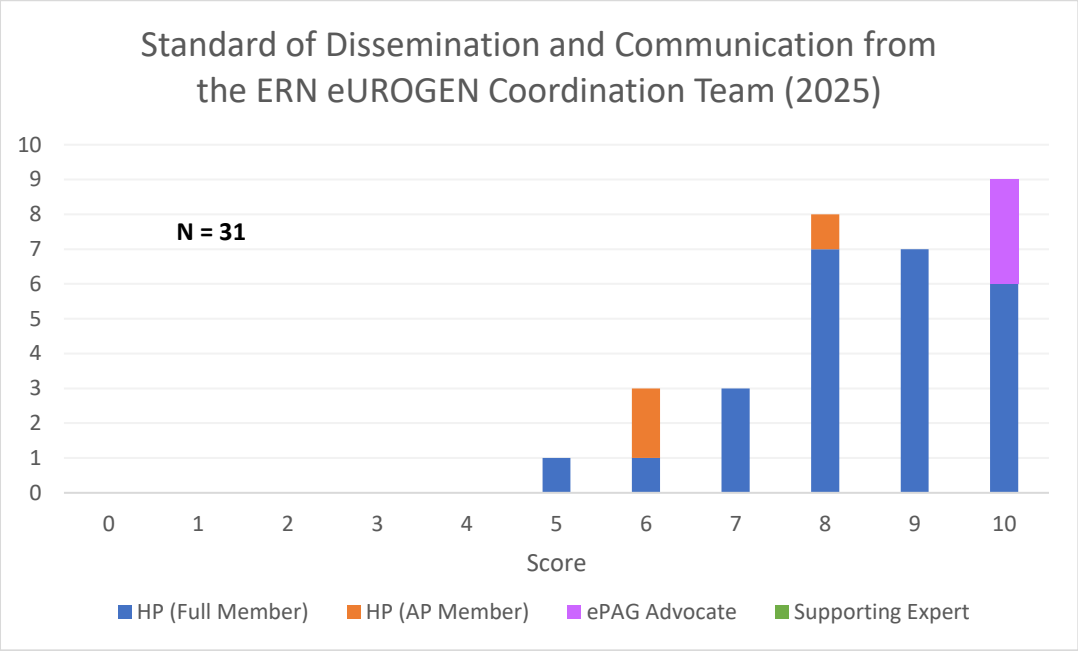
Score	Comments (2025 only)
10	A fantastic team!
10	Please organize the annual meeting always in person, not only virtual!
10	The support from the coordination team has been very strong and consistent, which is greatly appreciated. Clear communication and resources such as the monitoring and evaluation materials are helpful.
8	It is important more Translate information

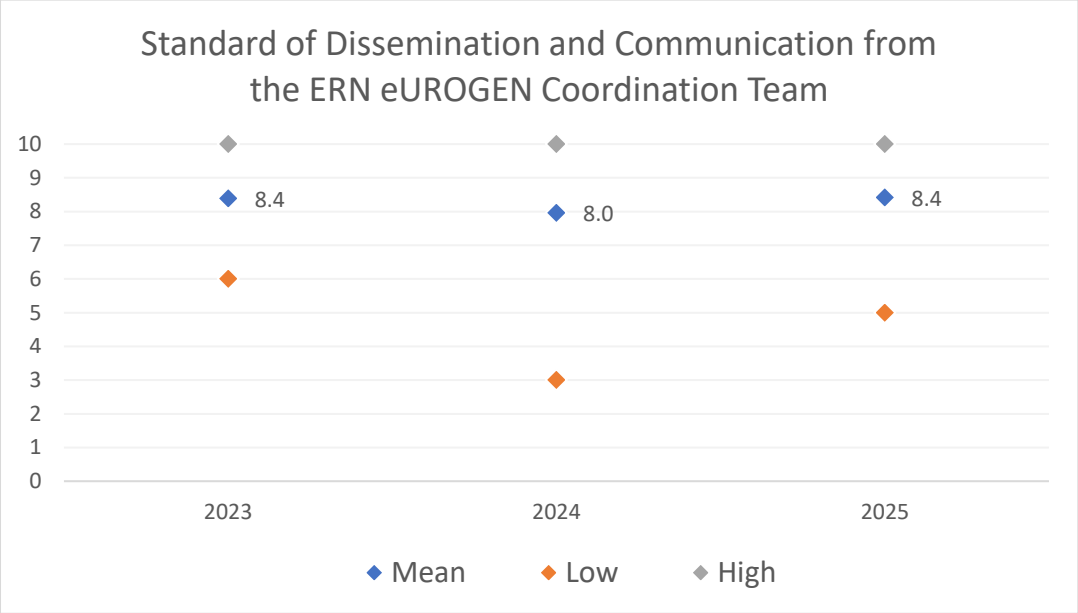
19. The support of the Coordination Team for other activities is viewed positively, as in previous years, with a modal average of 10.

20. The lowest-scoring respondent that commented mentions the importance of translation for these communications. However, this is not a priority for the network where it communication with our clinicians is involved (rather than, for example, producing patient-related information). This is because, as stated in the application process, HCP representatives are expected to communicate in English.

Work Package 2: Network Dissemination & Communication

Question 8. a) Please rate the standard of dissemination and communication from the ERN eUROGEN Coordination Team to the Network in the last 12 months (e.g. website, newsletter, emails, etc.):





b) Do you have any issues you wish to raise with regard to our dissemination or communication activity, suggestions for improvement, or examples of things that went particularly well?

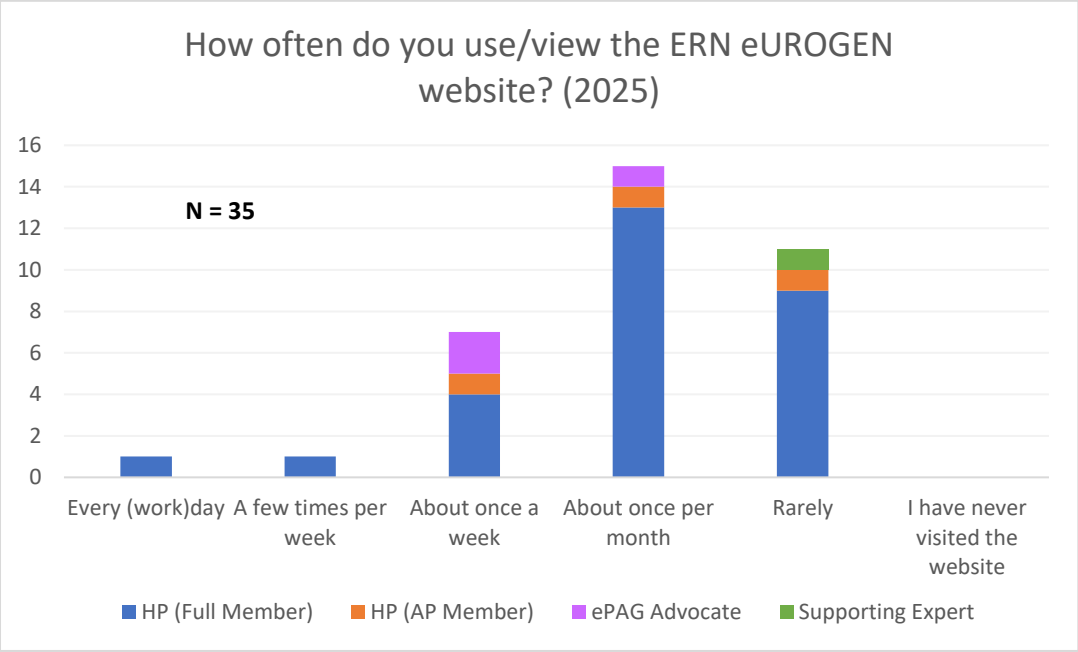
Score	Comments (2025 only)
9	The communication from the coordination team has been clear and regular, and the newsletter and emails are especially helpful. To strengthen this further, more concise clinical summaries and highlights of practical outcomes would make the information even more useful for busy clinicians. We have also identified terminology as an area where communication could be improved. Administrative language is often used instead of clearly naming the specific patient or diagnosis groups being referred to. Using clearer clinical terminology would make it easier for clinicians to understand and act on the information provided. Reporting quality indicators is one way of communicating, but meeting minutes and general updates are also important channels where this could be applied.

8	The pathologies covered are very diverse. For example, my interest is testicular cancer. The needs vary greatly depending on the type of pathology.

21. The standards of the dissemination and communications from the Coordination Team is rated highly, as in previous years.

22. The comments received below are interesting and we shall take them into consideration via the network Quality Improvement Group.

Question 9. a) How often do you use/view the ERN eUROGEN website?



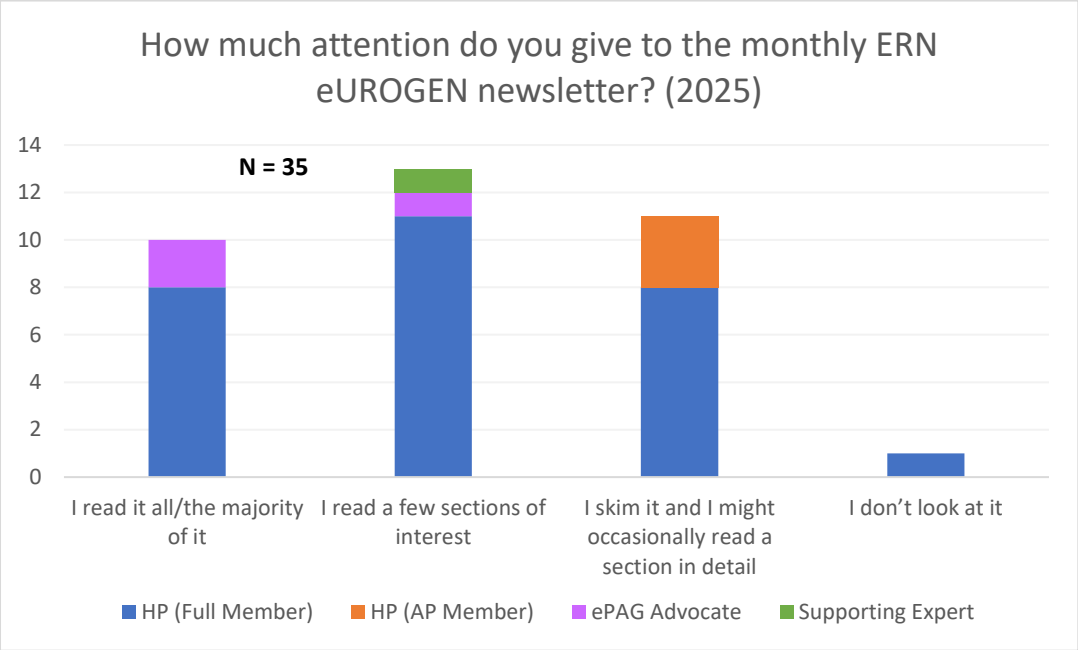
b) Are there any specific changes you would like to see made to the structure or content of the website?

Score	Comments (2025 only)
About once per month	There should be greater sectorization by pathology

23. Whilst our network members are only a small percentage of the website visitors, it is good to see some of them using the site weekly, and almost half of respondents visiting monthly.

24. We will take into account the comment regarding greater sectorisation by pathologies.

Question 10. a) How much attention do you give to the monthly ERN eUROGEN newsletter?



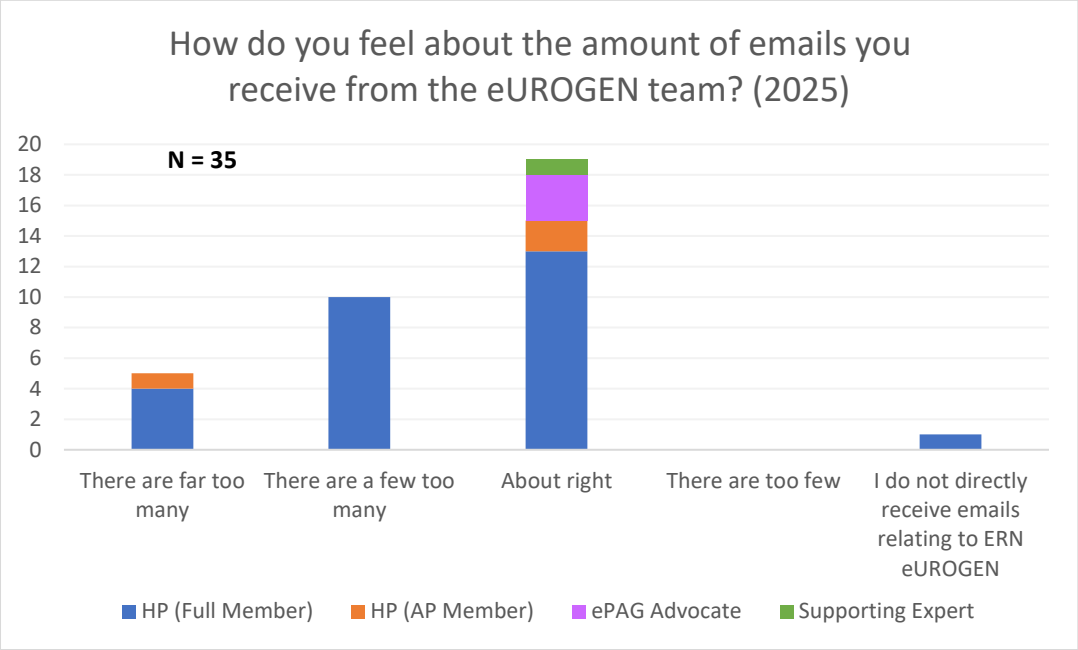
b) Are there any improvements you feel we could make to the newsletter (e.g. additional sections, format and style etc.)?

Score	Comments (2025 only)
I read it all/the majority of it	Very clear information delivery method
I read it all/the majority of it	The newsletter is informative and helpful. A shorter summary of key highlights at the beginning could make it even easier for busy clinicians to quickly grasp the most important updates.

25. The ERN eUROGEN newsletter is viewed by all but one of the respondents, with almost 30% of them reading the majority, if not all, of it.

26. We take note of the comment regarding a short summary of key highlights and will consider whether this can add value for the majority of recipients.

Question 11. a) How do you feel about the amount of emails you receive from the ERN eUROGEN Coordination Team?



b) Do you have any specific feedback on the emails received (e.g. too detailed, not detailed enough, confusing or unclear etc.)?

Score	Comments (2025 only)
There are a few too many	Content and readability is great!
There are a few too many	The information flow remains high, but it is more coordinated now compared to previous years, which is a positive improvement. Our main input would be to make it clearer who the emails are addressed to – whether they are directed at the clinical urologist in the team, the administrator, the hospital's legal representative, etc. Involving national structures such as the CSD (Centre for Rare Diseases) could strengthen this process.

27. More than half of the respondents consider the number of emails received from the Coordination Team is about right. Whilst we note that around 15% feel that there are too many, we are happy to see a comment indicate that things are improving. The suggestion to make the intended recipients of emails clearer will gladly be considered.

Question 12. Any other comments or suggestions on this area?

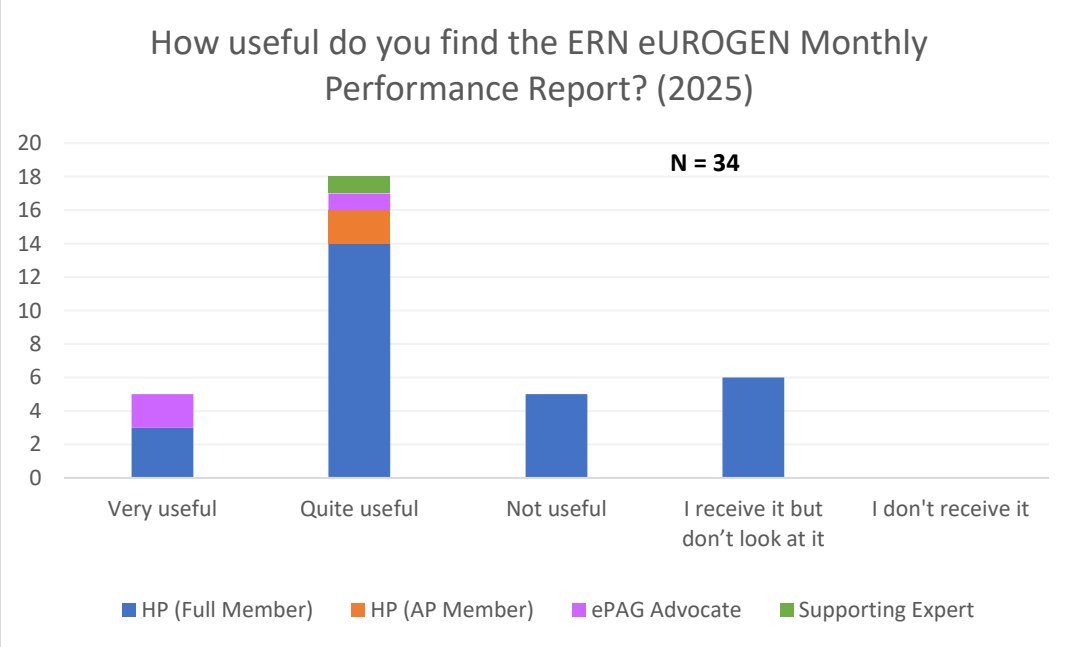
No comments

Work Package 3: Evaluation

Question 13. If you are personally involved in the provision of the annual monitoring data to the Coordination Team, do you have any comments on this process (e.g. resources required, the added value of the process, clarity of communications, suggested improvements, etc.)?

Comments (2025 only)
If automation would be possible, or if this could go through the hospital and not through the specialists, that would be awesome!
This might need discussion. Sometimes it is not fully clear what diagnoses are included. For example there many kind of spinal deformities that may cause neurogenic bladder.
It's painful, but crucial: no changes proposed
Sufficient
The process seems clear, but it requires significant time and resources at centre level.

Question 14. a) How useful do you find the ERN eUROGEN Monthly Performance Report?



b) Any specific comments on the report (suggestions for inclusion, improvements, etc.)?

Score	Comments (2025 only)
Quite useful	The report provides a good overview of network activities. A brief summary of key indicators and clinical highlights at the beginning would make it even more user-friendly for busy clinicians

I receive it but don't look at it	Trends over a longer period of time would be more interesting than monthly reports

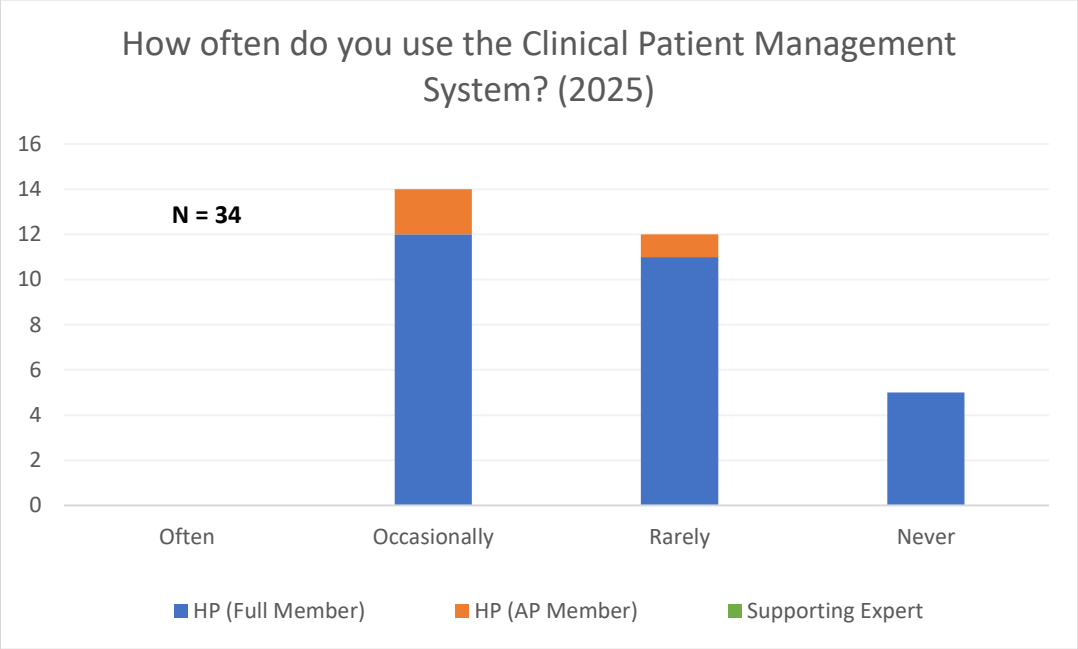
28. We understand that the annual data collection process is quite resource-intensive for HCPs. However, there were few comments that suggested any obvious improvements or alternatives. Indeed, it appears that HCPs understand the need to undertake this exercise.

29. Automation is always something that is being investigated through various projects, but its implementation is not feasible as yet.

30. However, for the 2025 data collection (undertaken in Q1 2026), we will be streamlining the process for HCPs to help reduce the burden and confusion that has arisen in the past by asking them to complete all contributions via a single link.

Work Package 4: CPMS & Care

Question 15. a) How often do you use the Clinical Patient Management System?



b) What are the biggest barriers that you face in using CPMS more frequently or at all, if any, e.g. resourcing, accessing the system, hospital/legal restrictions etc.? Please explain.

c) And what support or tools do you need/want to overcome these issues?

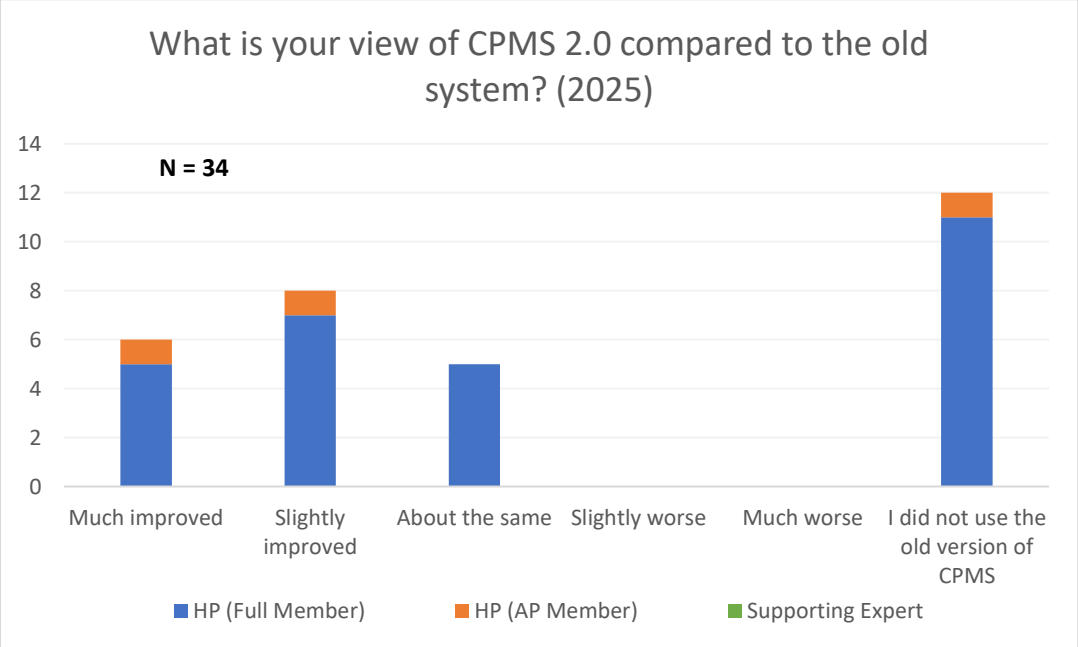
Score	Comments b) (2025 only)	Comments c) (2025 only)
Occasionally	Wow I'll do more	
Occasionally	Complex to use	
Occasionally	Knowledge on area of expertise of the specialists in WS2	An overview by the coordinating team
Occasionally	No barriers and easy to use once it is set up on your devices. No direct clinical work personally, so less activities	None
Occasionally	Hospital legal restrictions for the moment	
Rarely	Difficulty in management	
Rarely	Resourcing. Apparently we get soon permission to participate the registry. Then we need an educational event.	
Rarely	Time: our own time, but more important: the real experts often are too busy to answer, and the ones answering often do not provide helpful insights, out of lack of experience	We do not know, sorry
Rarely	It is a complex system. Create a simpler, more fluent and time-saving system	I need time for it.
Rarely	The main barrier is that other communication channels are already established and feel easier to use in daily clinical work. In addition, limited time and resources make it challenging to integrate CPMS regularly.	Simplification of the interface, stronger integration with hospital IT systems would help overcome these barriers and encourage more frequent use.

Rarely	Too complex to use, login and to organise event with all necessary parties	
Never	My hospital has as of yet not consented to us using it! I have at least three patients I need to discuss!	I think support will be good
Never	No spare time	Monetary help for the centers so they can have study nurses (or equal) in helping with the documentation etc.

31. we asked our members how often they use CPMS. We can, of course, use the reporting system in CPMS 2.0 to look at how often clinicians log in, but it is not necessarily a straightforward question. Clinicians will tend to log in more regularly whilst cases are ongoing in which they are involved, but may then have significant periods without the need to access the system. Therefore, it is probably not surprising that the most popular response was 'occasionally'.

32. As a follow-up to these questions, we asked what barriers they faced in using the platform, to which we received about a dozen responses that mentioned the complexity of the system, the lack of time (of both those requesting the advice and the experts), as well as hospital restrictions.

d) What is your view of CPMS 2.0 compared to the old system?



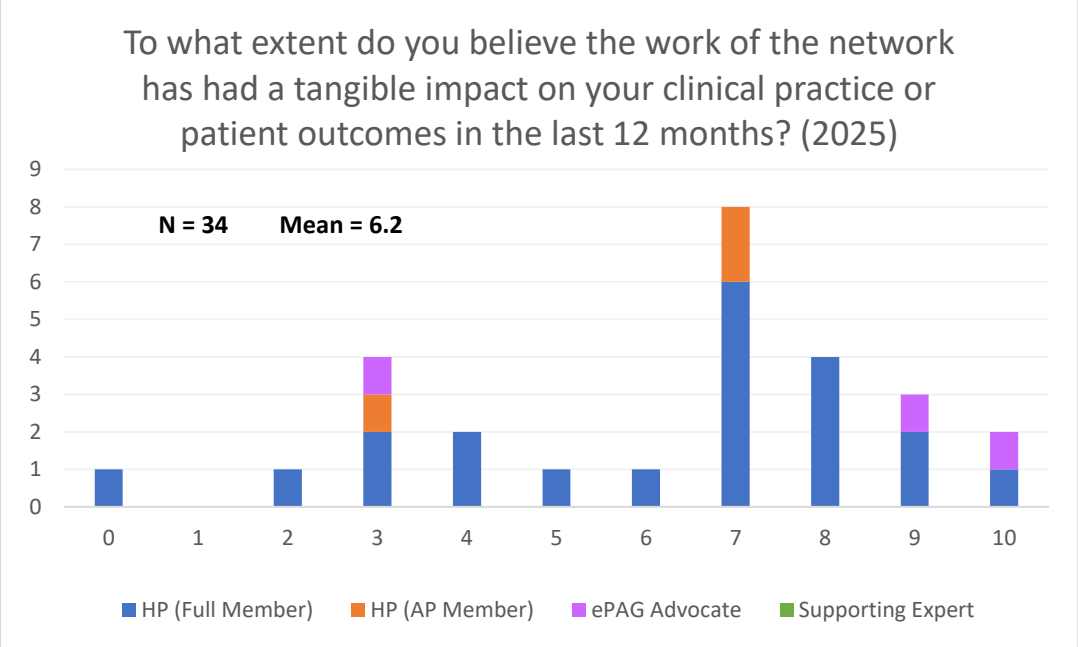
33. We also asked for their views on the new version of CPMS compared to the previous one. It is clearly positive that no one reported a decline in their assessment. If we ignore the 40% who did not have a point of comparison as they did not use the earlier version, almost 75% of respondents saw an improvement in the platform.

34. Those who lacked the resource to use CPMS typically had not used the old system. Those highlighting the complexity felt that there had been a slight improvement or it was about the same, although we do not know how extensive their use of the new system has been. Even a respondent who rated CPMS 2.0 as much improved had the following to say: "The main barrier is that other communication channels are already established and feel easier to use in daily clinical work. In addition, limited time and resources make it challenging to integrate CPMS regularly." It is obvious that we still have challenges ahead to change the entrenched views and behaviours of some clinicians

35. e) Any other comments on this area (requirements, improvements, issues, etc.)?

No relevant comments.

16. a) Please indicate to what extent you believe the work of the network has had a tangible impact on your clinical practice or patient outcomes in the last 12 months (where 0 represents no impact, and 10 represents a full impact):



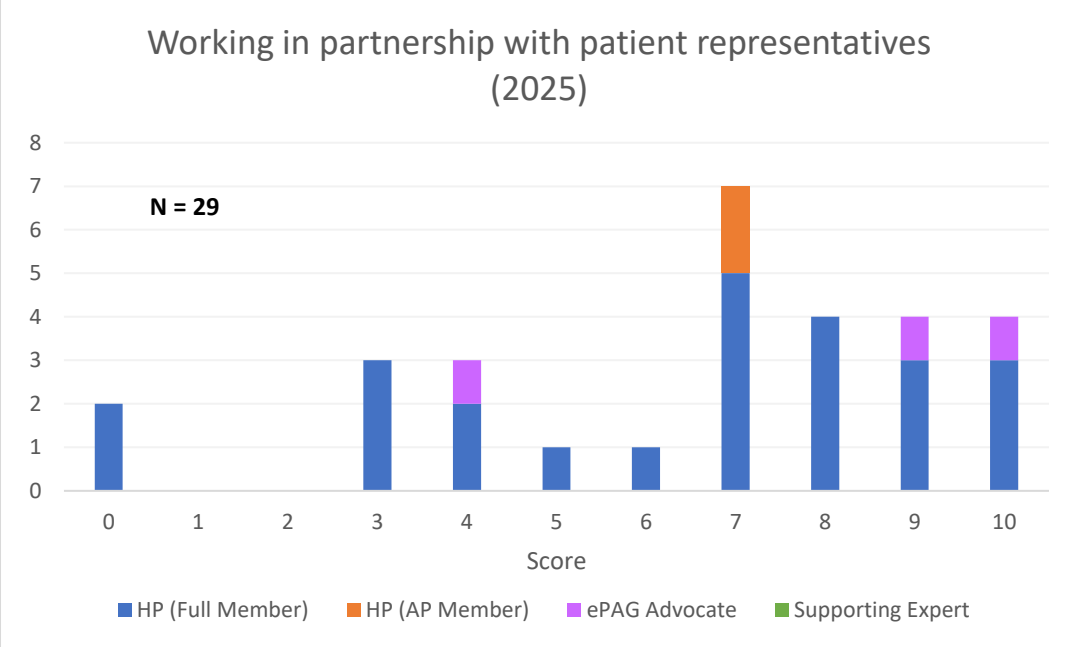
b) Any specific comments on this area?

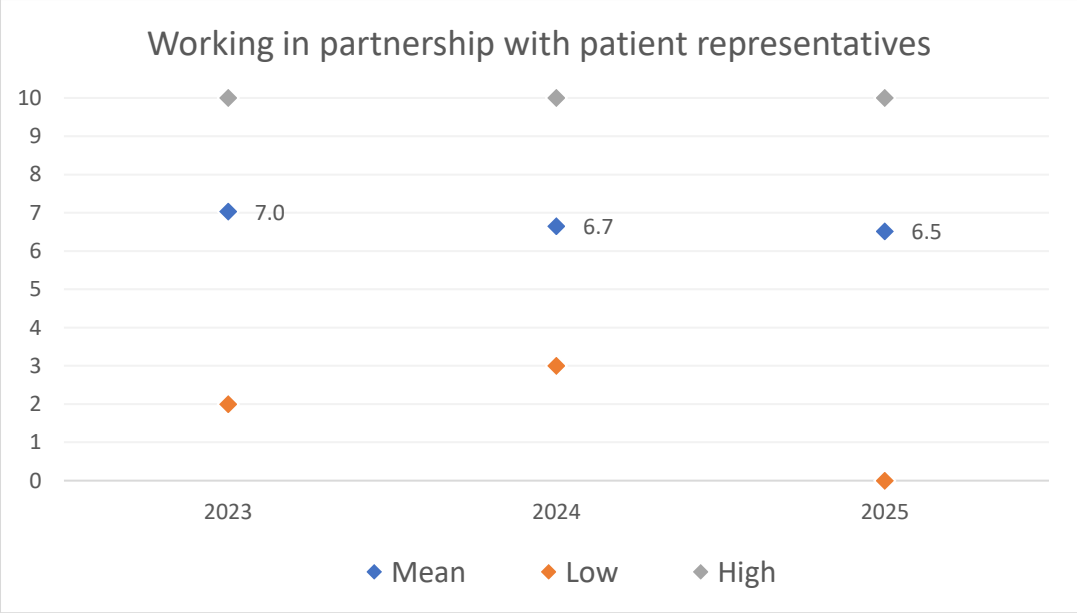
Score	Comments (2025 only)
10	For our association it was to get in touch beyond our borders
7	The few CPMS cases we discussed have influenced decision making
6	The network has provided valuable opportunities for collaboration, knowledge exchange, and access to expertise. While the direct impact on day-to-day practice and patient outcomes is still developing, we already see important foundations being laid. With further implementation of tools, pathways, and CPMS, the potential for significant impact is clear.
3	We learned from the network to manage more ARM with perineal fistulas conservatively. Yet, we are frustrated that new members were accepted and tolerated in ERN who lack sufficient patient numbers and dedication to the network, and to see that the ERNs did not lead to centralisation nationwide, occasional surgery goes on unchanged.

36. This was a new question for 2025. The mean score seems quite low. However, the commenter who rated this as '6' makes the point that the tools to facilitate a direct impact on day-to-day practice are still being put in place. The issue raised by the commenter who gave a '3' is an important one for the network, though the question of centralisation will depend heavily on the integration of ERNs at national level, e.g. through JARDIN.

37. However, it seems advisable that the network try to establish what else could be done in this space going forward to try to ensure an improvement.

17. a) Please rate the achievement of the activities and results delivered by ERN eUROGEN in the last 12 months with regard to working in partnership with patient representatives (where 0 represents no achievement, and 10 represents full achievement):



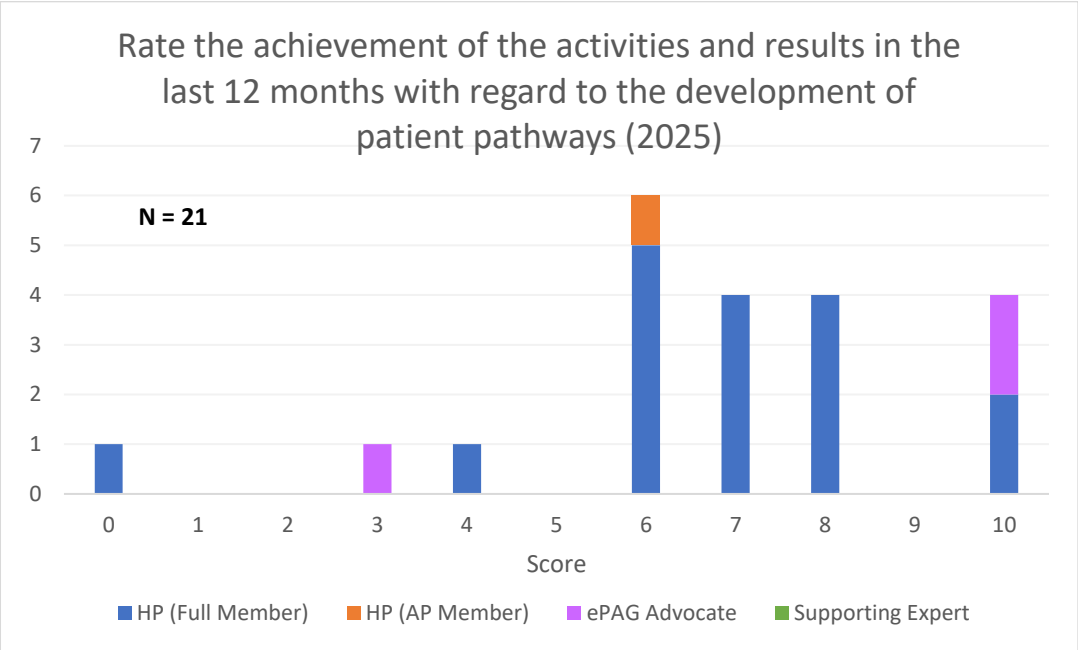


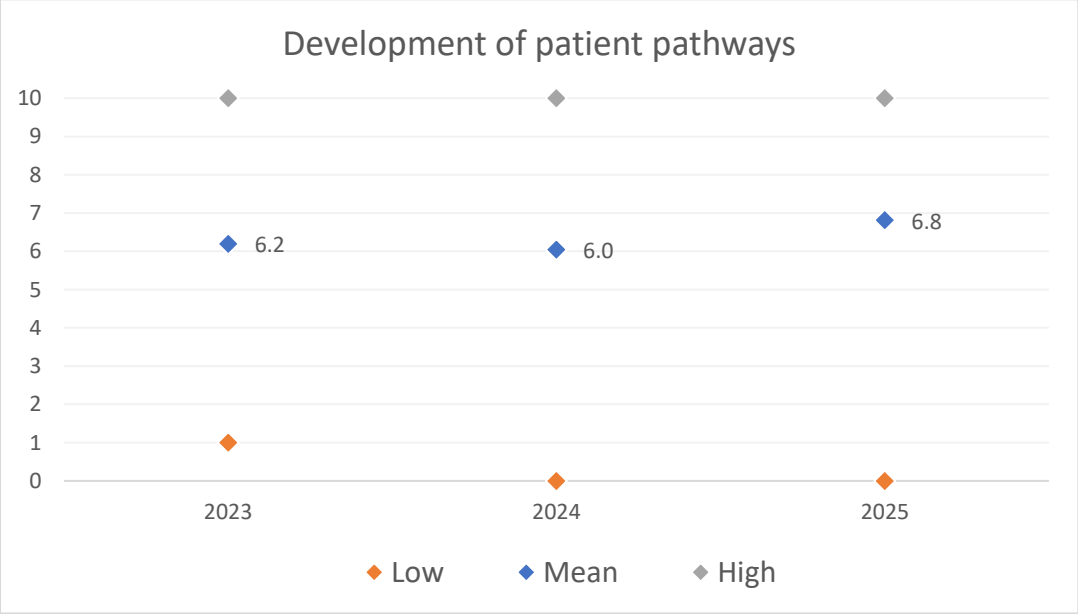
b) Any specific comments on this area (requirements, improvements, issues, etc.)?

Score	Comments (2025 only)
10	We applied for a nationwide minimal number of 5 ARM reconstructions per clinic and year in Germany, which would have been impossible without the role model of ERN-eUROGEN
7	Unfortunately patient representatives are hard to find for disease areas in WS2
7	Patient representatives are actively engaged and bring important perspectives. It would be helpful to further strengthen their integration in clinical and research activities to ensure maximum impact.

38. This question shows a decline in the mean for the second year running, although scores are quite spread and both the median and mode are 7. Unfortunately, none of the lower-scoring respondents left explanatory comments. Those that dod comments left helpful remarks regarding the need for additional patient representatives for WS2 and further embedding all patient reps into additional activities of the network.

18. a) Please rate the achievement of the activities and results delivered by ERN eUROGEN in the last 12 months with regard to the development of patient pathways (where 0 represents no achievement, and 10 represents full achievement):





b) Any specific comments on this area (requirements, improvements, issues, etc.)?

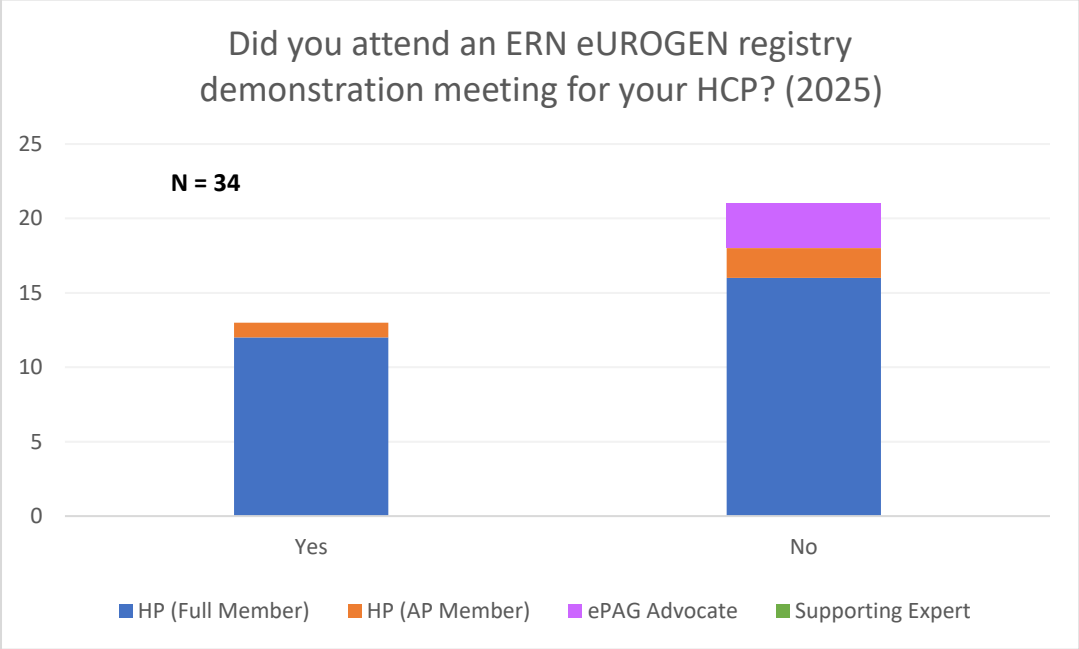
Score	Comments (2025 only)
10	guideline ARM: a milestone, patient journey ARM, also!!!

n/a	Progress has been made in developing patient pathways, which is very valuable. The next step will be to ensure that they are fully implemented and widely adopted in clinical practice

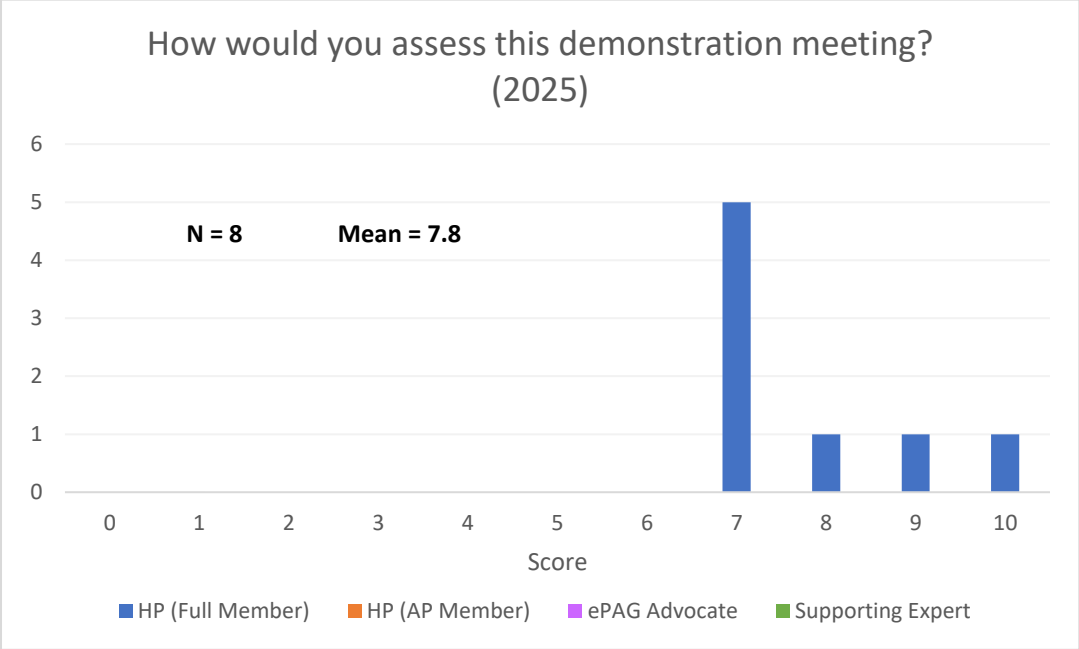
39. This question scored higher than the previous two years, although its mode is 6. However, there were only a few low scores, and no comments associated with these. As the comment made by a non-scoring respondent states, we now need to try to ensure the adoption and implementation of these pathways.

Work Package 5: Registry

19. a) Did you attend an ERN eUROGEN registry demonstration meeting for your HCP?



a) (i) If Yes, how would you assess this demonstration meeting?

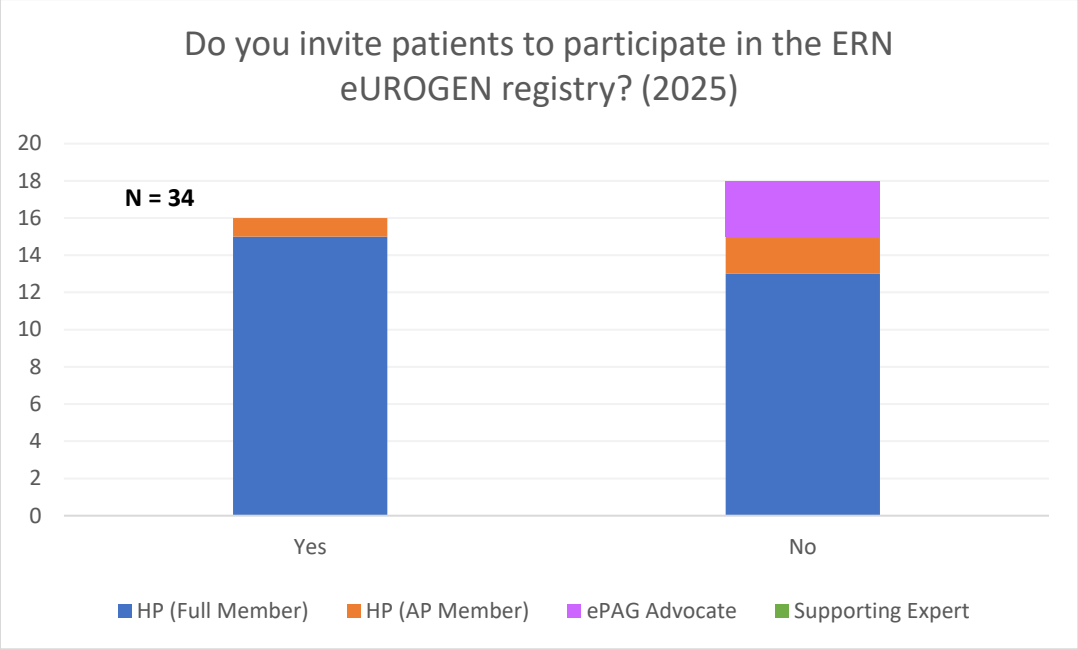


a) (ii) What information, if any, was lacking during this demonstration meeting or what other suggestions for improvements do you have?

No comments.

40. With regard to the registry demonstration meetings, these were positively received with a mean score of 7.8.

b) Do you invite patients to participate in the ERN eUROGEN registry?

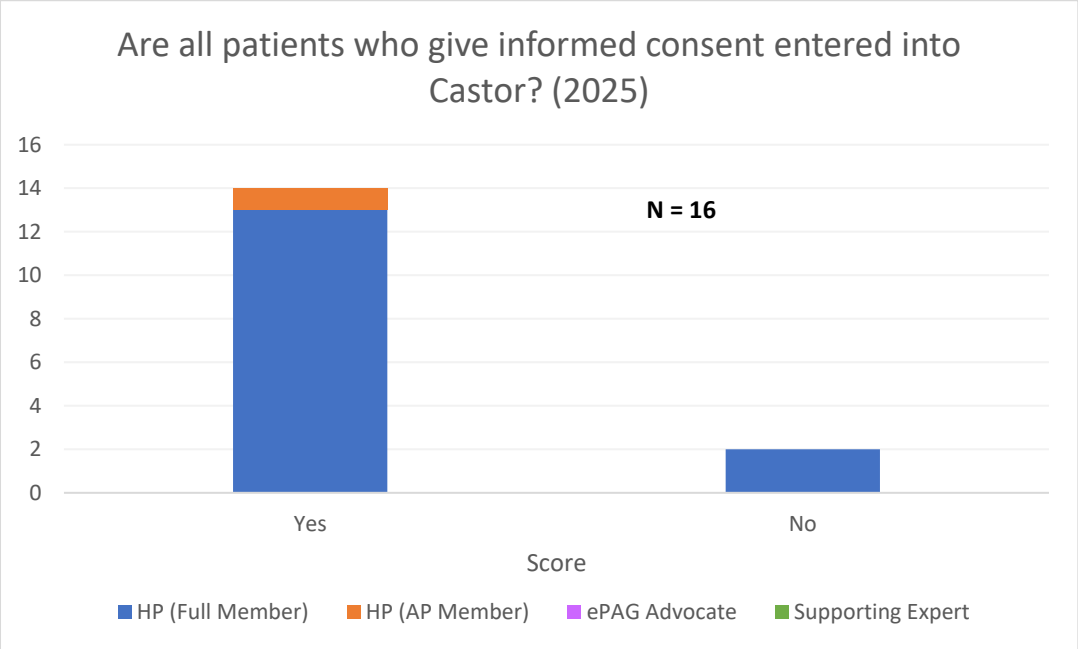


b) (i) What obstacles do you encounter when inviting patients?

Comments (2025 only)
Language
Language
Fear for privacy , difficulties to understand the value of a remote evaluation
Lack of time on our side, scepticism on side of the patients cause people fear that they could be bothered
Too complicated information

41. Of those who do not currently invite patients to participate in the registry and responded as to why, language barriers seem an important issue.

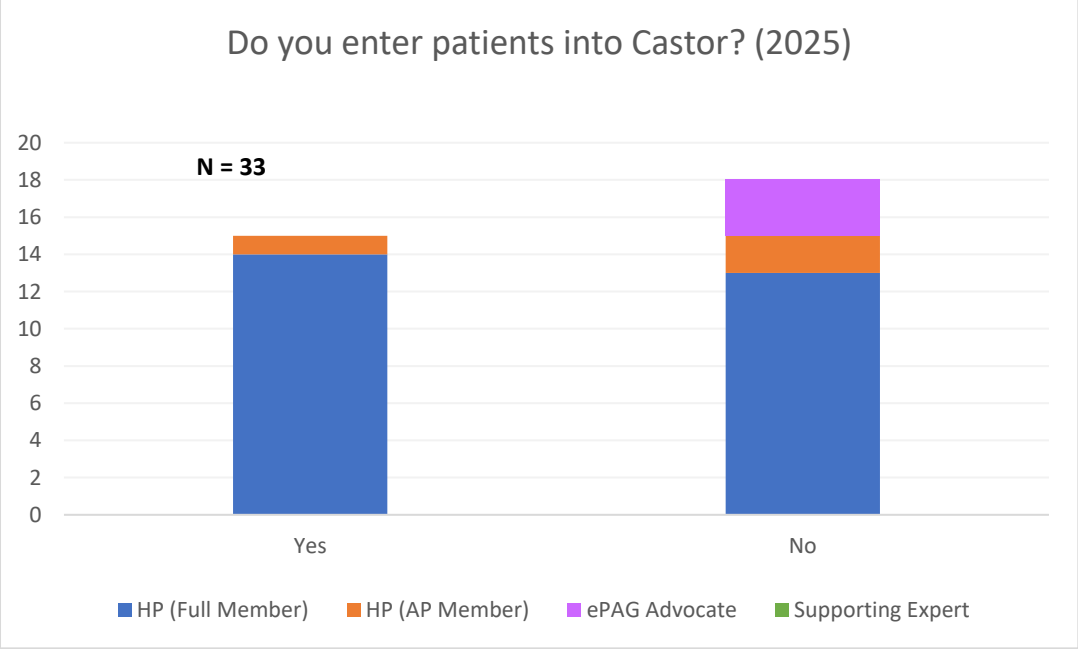
b) (ii) Are all patients who give informed consent entered into Castor, the ERN eUROGEN registry database platform?



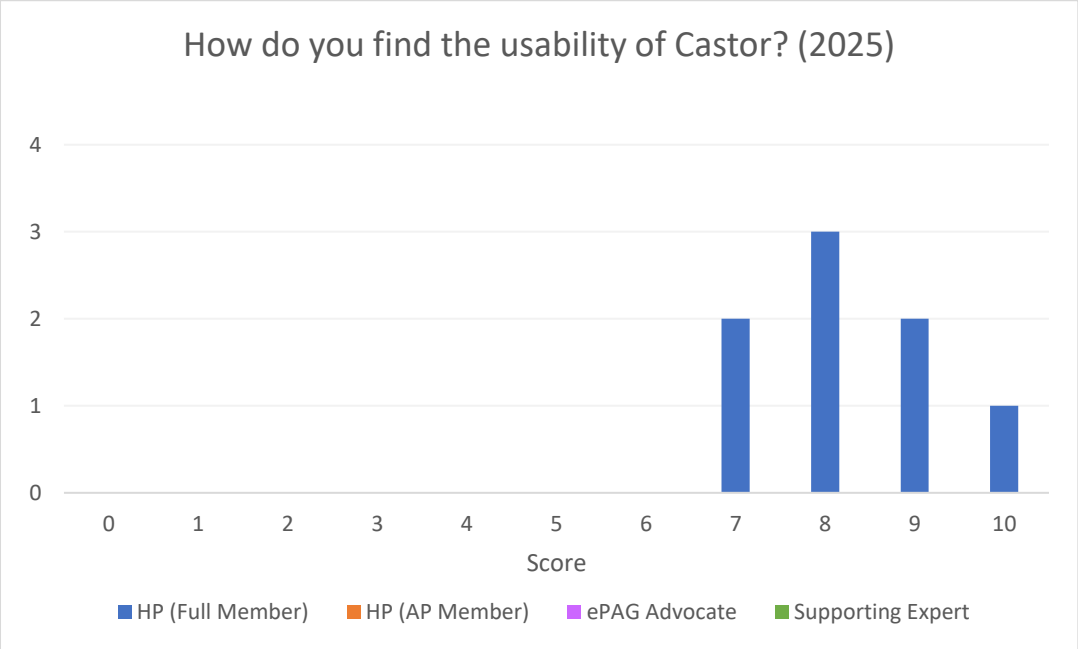
b) (iii) If no, why not?

Comments (2025 only)
No time, no study nurse
No enough time on the top of our daily activities.

c) Do you enter patients into Castor (ERN eUROGEN registry database platform)?



c) (i) How do you find the usability of Castor?

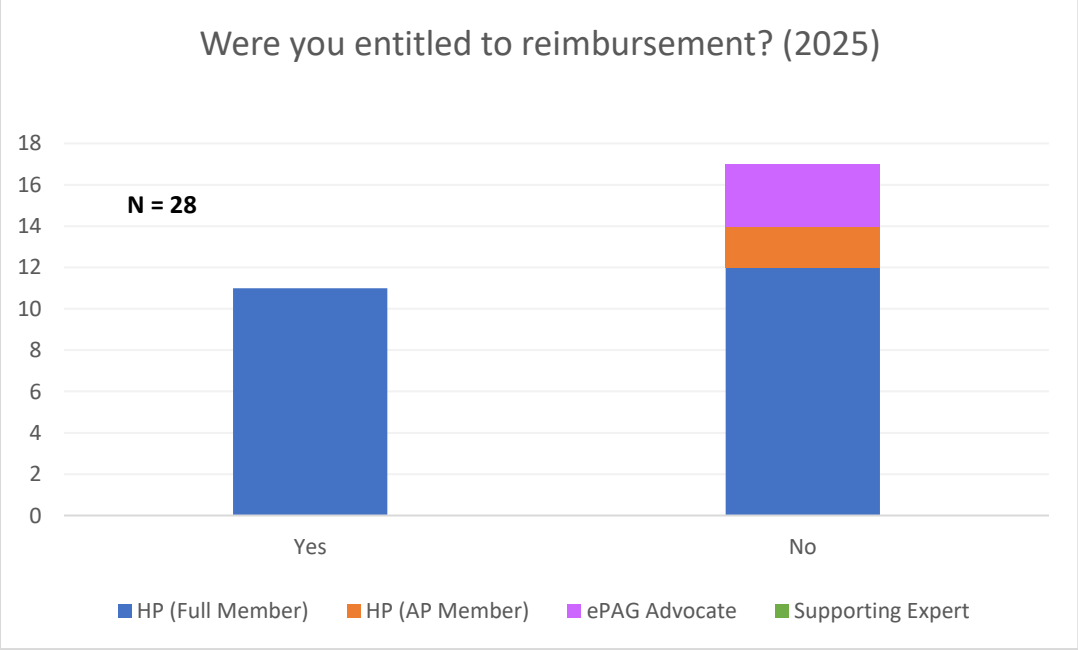


c) (ii) How could we further improve your use of Castor?

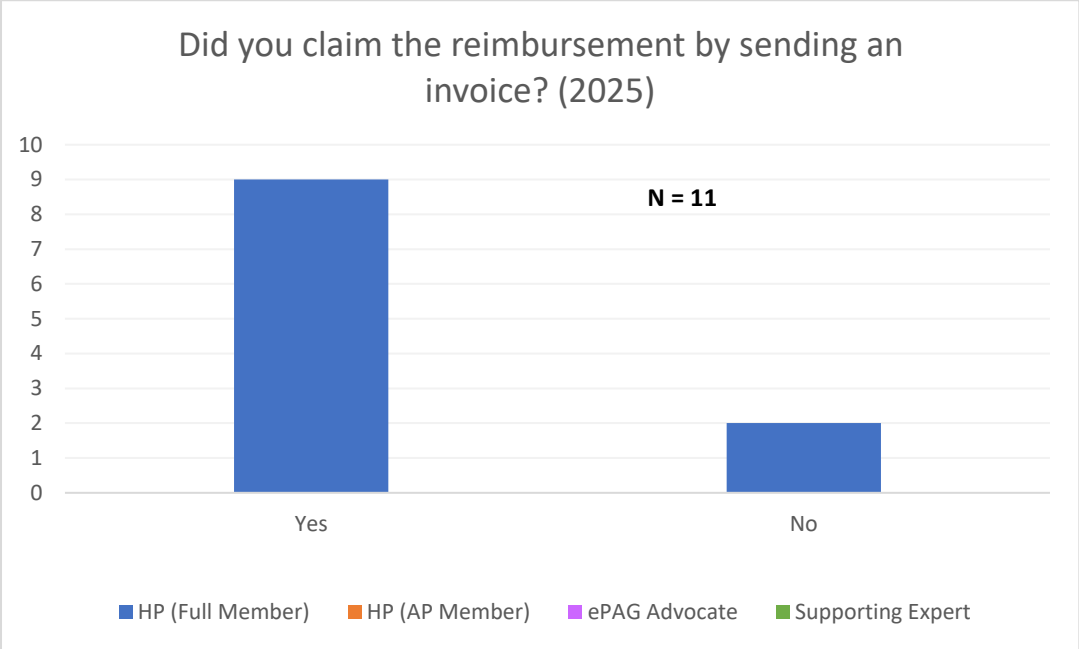
Score	Comments (2025 only)
10	more specific filters for research purposes

42. For those who input patients into Castor, they appear to find the system user-friendly.

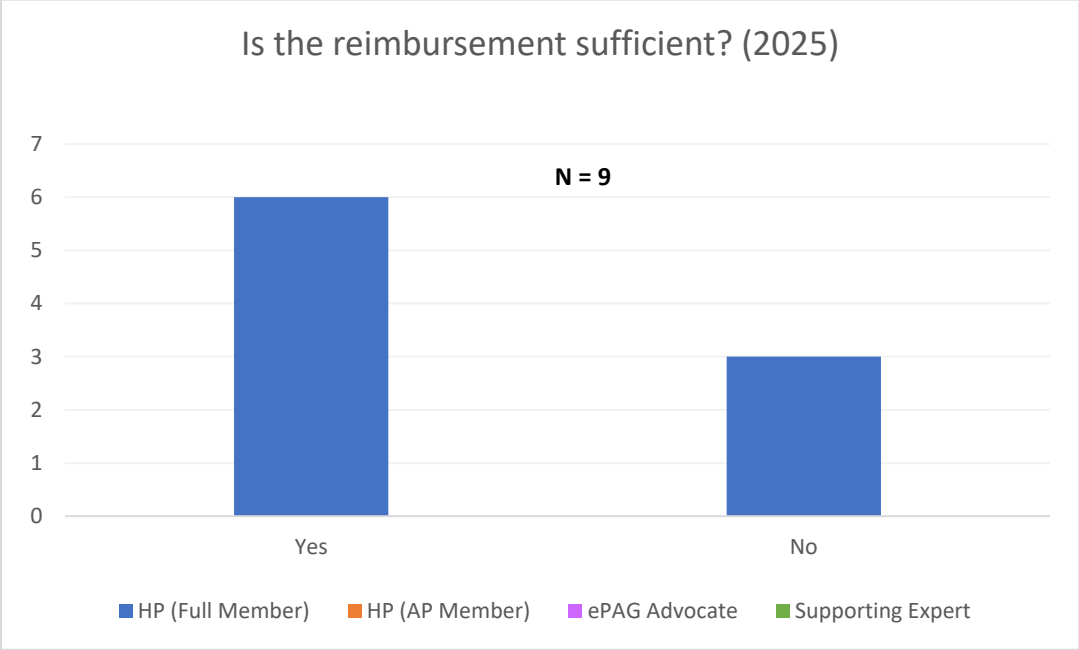
d) Were you entitled to reimbursement?



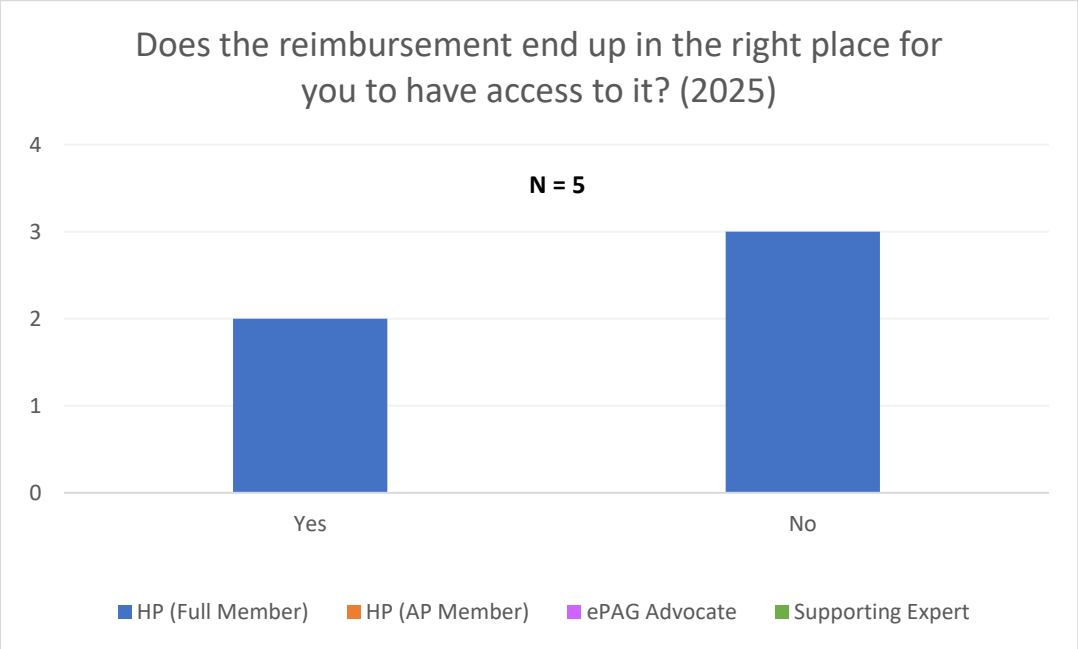
d) (i) If Yes, did you claim the reimbursement by sending an invoice?



d) (ii) If Yes, is the reimbursement sufficient?



d)(iii) If Yes, does the reimbursement end up in the right place for you to have access to it?



d) (iii) If No, why not?

Comments (2025 only)
Does not cover the work
if it would really pay the time we invest it would be easier to make it sustainable with or against our administration
Takes longer time

43. For those who were entitled to reimbursement, the majority of them sent invoices to claim this, and most of these considered the reimbursement to be sufficient. However, for the few who responded regarding whether the reimbursement ended up in the correct place for them to use it, it was felt that it didn't.

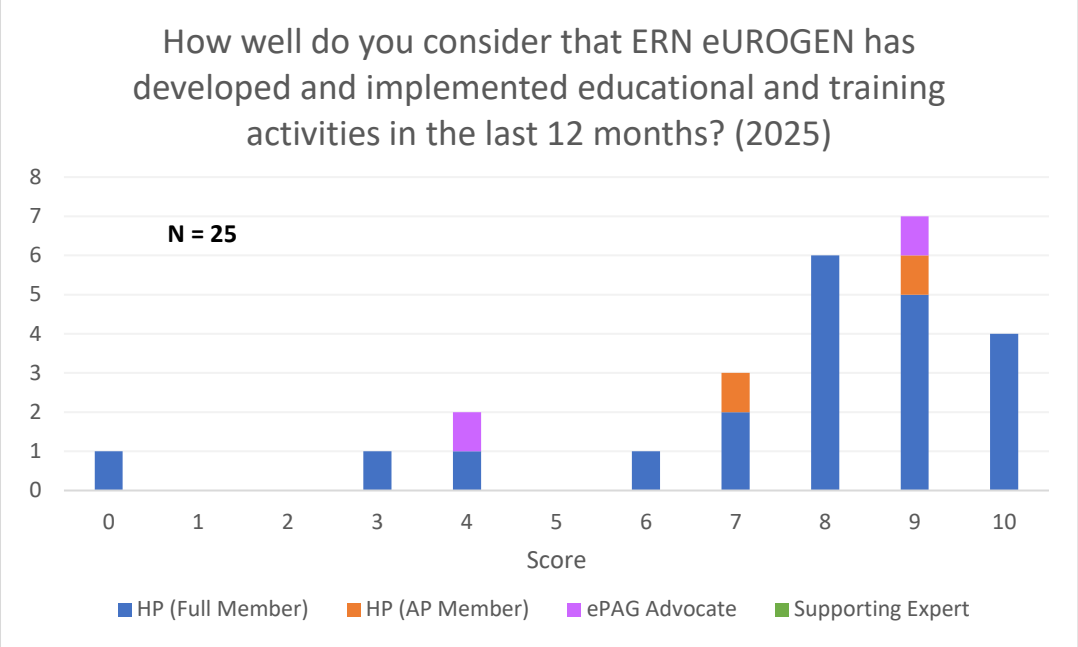
e) What else can we do to help you with the registry?

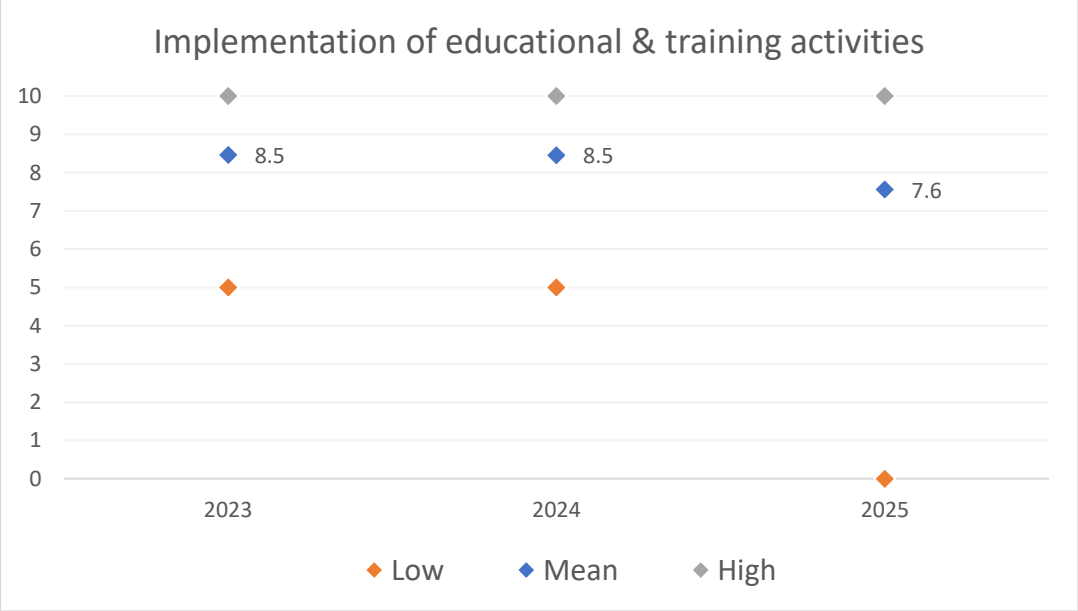
Comments (2025 only)
Study nurse!
Structured financial support for data entry into the registry
When we get local permission to join the registry, we need an educational session on line
Translate questions
Involving national structures such as the CSD (Centre for Rare Diseases) could strengthen implementation, streamline processes, and support patient inclusion.
Nothing, we need time to open the registry in Our Hospital
Don't know at this moment

44. There are various issues that respondents identified in terms of support which our Registry team will consider going forward.

Work Package 6: Education & Training

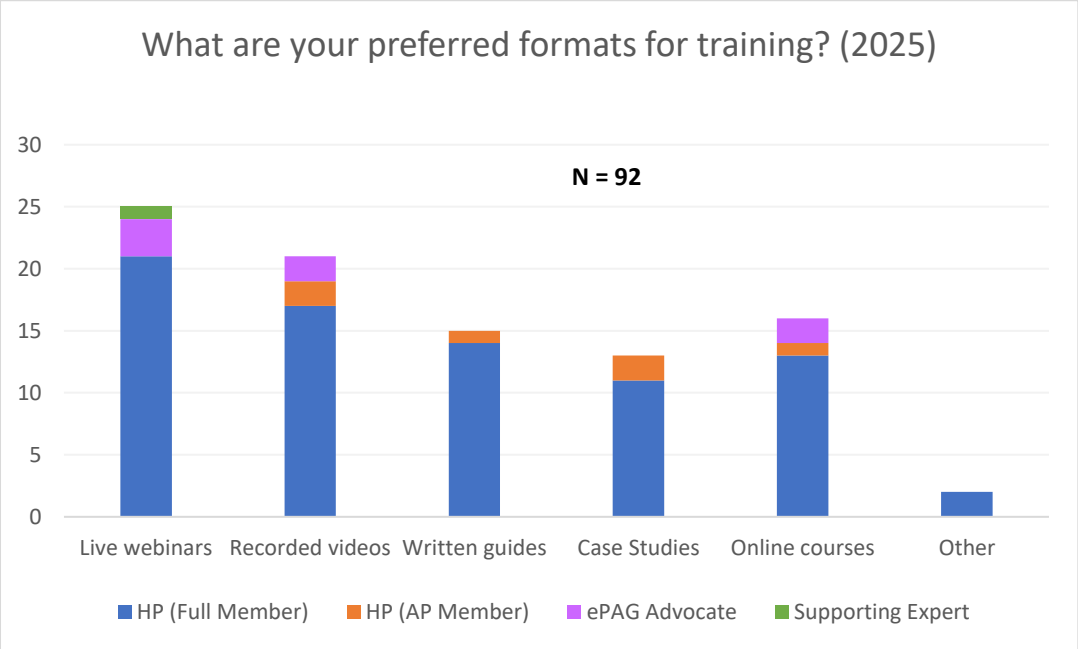
20. a) How well do you consider that ERN eUROGEN has developed and implemented educational and training activities (e.g. the ERN eUROGEN webinar programme) in the last 12 months (where 0 represents no achievement, and 10 represents full achievement)?





45. Whilst still receiving a high rating, with a mode of 9, the mean score was down compared to previous years. Part of this was due to a '0' rating from one respondent. We did not provide the opportunity to comment on this question and thus such an option will be made available going forward.

b) What are your preferred formats for training? (Select all preferred options)

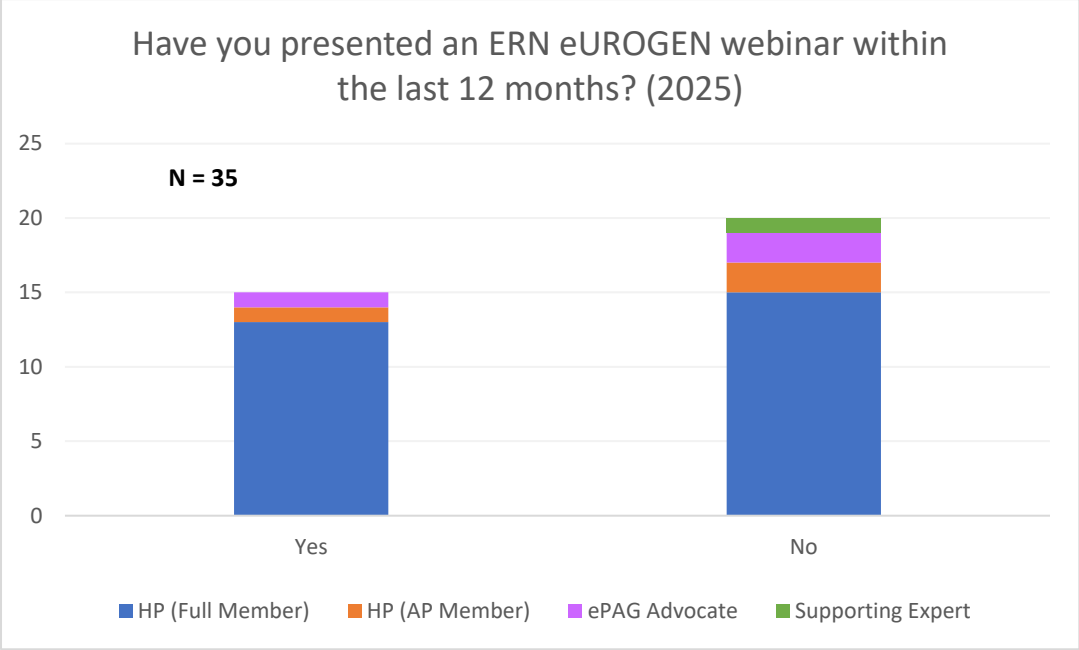


c) What additional training or educational courses or products do you believe ERN eUROGEN needs to help produce going forward? Any other comments around education & training?

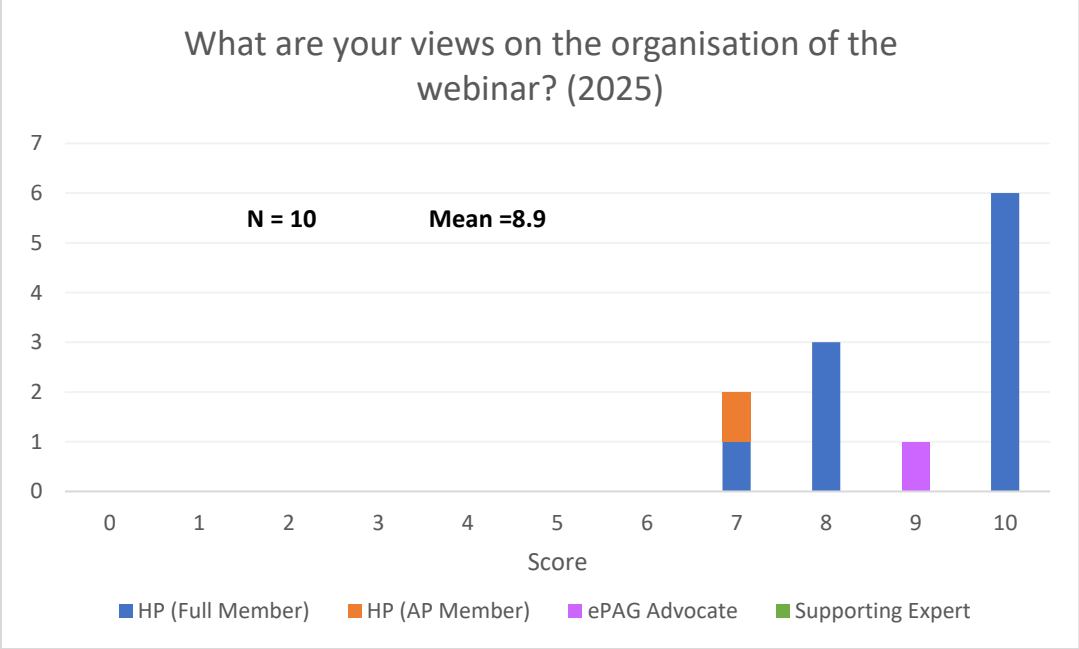
Score	Comments (2025 only)
10	A course in feminizing surgery for i.e. CAH patients needed since our colleagues who formerly operated the girls when very young now are retiring and the girls are teenagers asking for surgery which almost no one knows how to do
10	Step by step assessment tools and surgical techniques with tip and tricks.
9	Instead of live webinars, I would suggest creating pre-recorded educational videos that are all available in a dedicated education area, where people can also post their questions and answers. It is often difficult to attend live webinars due to scheduling conflicts
8	Theoretical and practical courses
4	Meetings in specific subjects
n/a	Complication guidelines
n/a	Further training focused on practical clinical cases, multidisciplinary teamwork, and rare disease pathways would be very valuable. Short, focused sessions are particularly useful for busy clinicians.

46. We allowed people to select multiple options for question 20. b), with live webinars being rated as the most preferred option. We, of course, also offer recorded videos via our YouTube channel, but we might also consider fully prerecorded events. We are also aiming to develop online courses for the EU Academy. The other given options were also rated as desirable and thus we will consider how we might develop these going forward.

21. a) Have you presented an ERN eUROGEN webinar within the last 12 months?

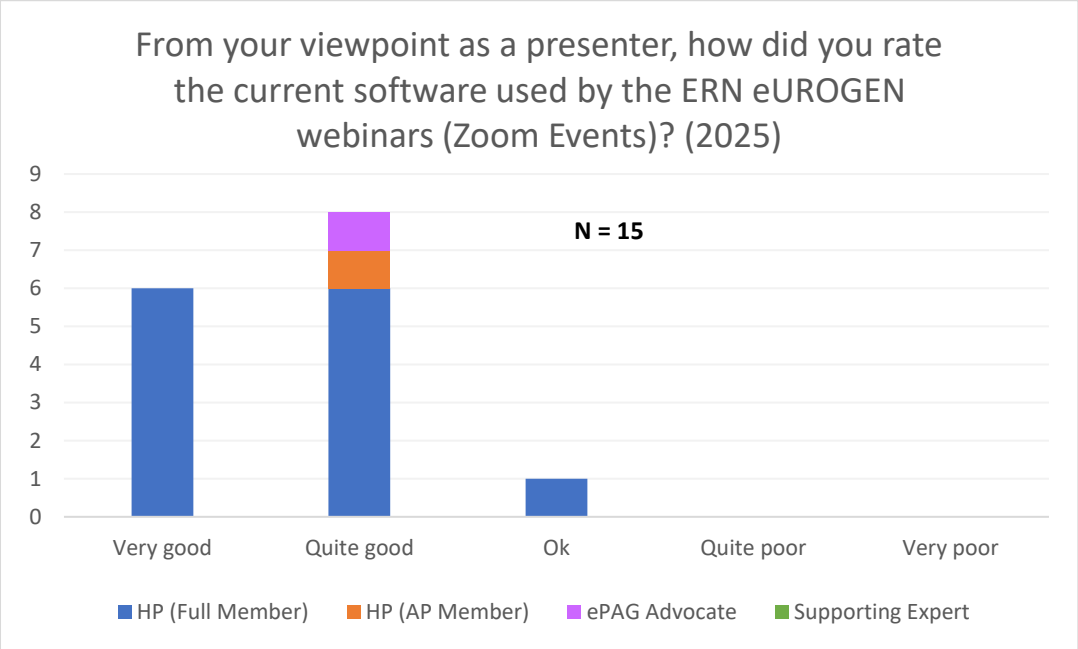


a) (i) What are your views on the organisation of the webinar (where 0 represents very poorly organised, and 10 represents very well organised)?



47. For those who have taken part in presenting a webinar in the past 12 months, they were content with the organisation of the session. Despite this, the Webinar team will continue to try to improve the organisational aspects of the whole process of booking and arranging sessions with the presenters.

a) (ii) From your viewpoint as a presenter, how did you rate the current software used by the ERN eUROGEN webinars (Zoom Events)?



48. The switch from using GoToWebinar to Zoom seems to have been a positive one for presenters.

b) Any other comments on the ERN eUROGEN webinar programme (requirements, improvements, issues, etc.)?

Comments (2025 only)
I believe that recording the sessions would make things easier for everyone and would also give each person the option to make their presentation in their own language, with English subtitles generated by Eurogen. There are many excellent people who hesitate to participate in webinars because they do not feel comfortable presenting in a language that is not their own
Zoom is blocked by some HCP's, even on own laptops when using HCP wifi
Facilitate simpler access

Collaboration with national centres such as CSD could help identify relevant training topics and reach more healthcare professionals across disciplines. It is also important to acknowledge the broader educational efforts carried out at our centre for these patient groups. Much of our work for patients with rare urogenital conditions takes place outside ERN eUROGEN.

We are actively engaged in other professional communities and contribute to educational initiatives, such as the ESPU webinar educational series. For example, in collaboration with the ESPU Educational Committee, we recently organised a European Masterclass on high-grade vesicoureteral reflux (VUR) in infants. The two-day course gathered 28 participants from several European countries and involved our entire uro-team.

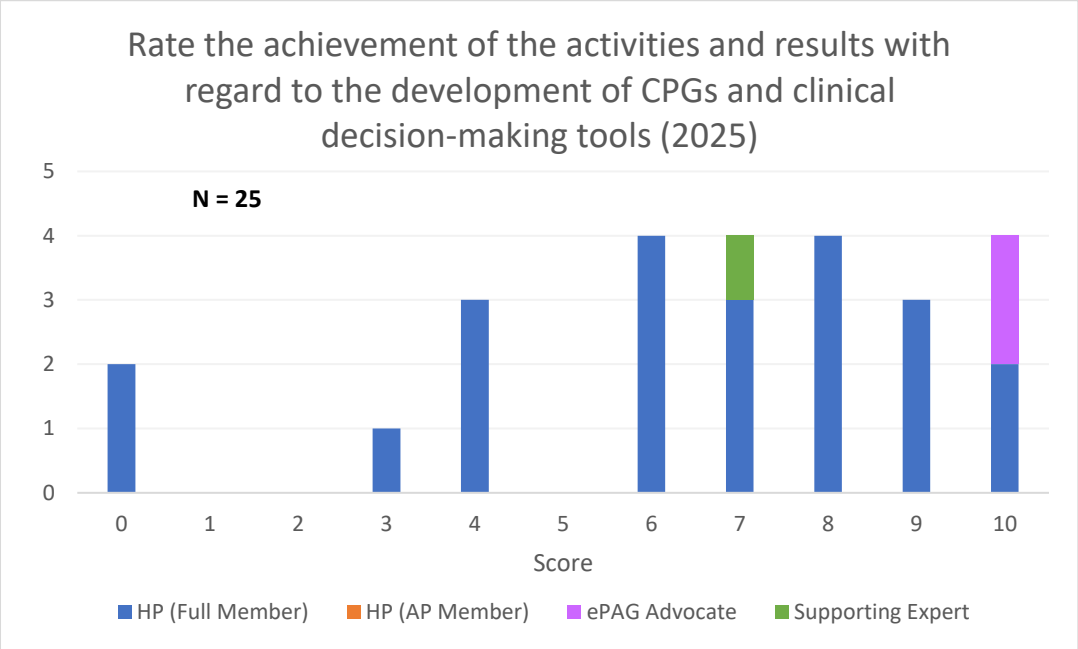
Looking ahead, we are also planning a workshop in 2026 focusing on spina bifida and bladder exstrophy in collaboration with ERN eUROGEN, which we are very excited about. As this will be a significant contribution to the educational programme, it could be valuable to allow some flexibility in participation requirements for other activities during periods when centres take on fewer but larger commitments. This would help ensure that major initiatives receive the focus and resources they require, while still contributing meaningfully to the network as a whole.

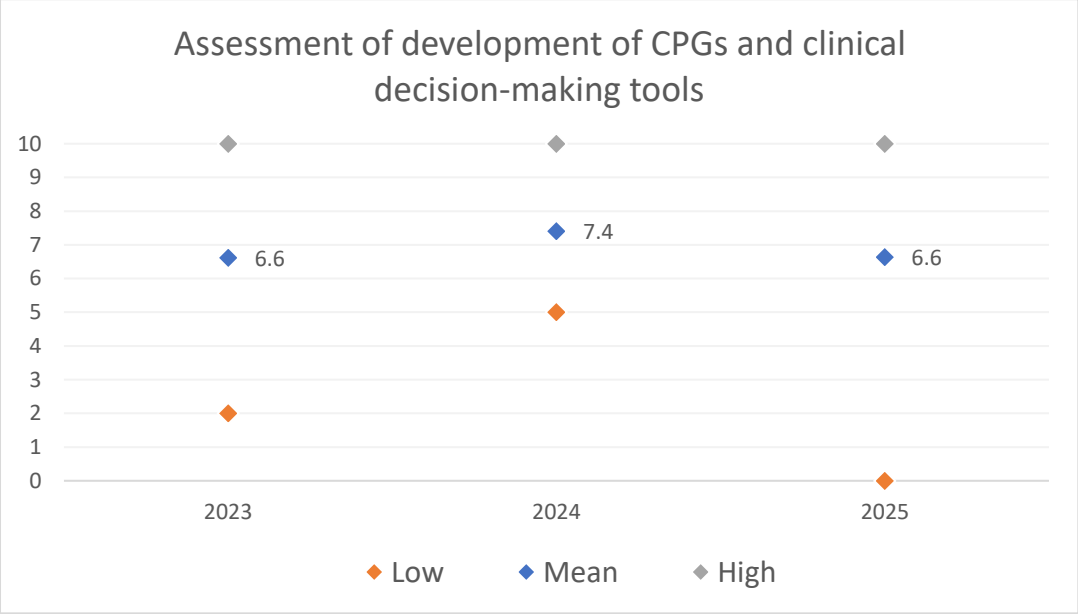
Strengthening synergies between ERN eUROGEN and existing educational initiatives like these could give ERN eUROGEN a more complete overview of member centres' ongoing work for these patient groups. It would also support a more balanced understanding of how centres contribute across different activities, ensuring that efforts are reflected fairly in quality indicators. This should ideally also be reflected in expectations of activity levels, as it may not be realistic to maintain the same level of engagement across all ERN areas during periods of high involvement in major initiatives, such as hosting an international workshop. We see this as an important point for open dialogue within the network.

49. The comments received regarding members' views of the webinar programme shall, of course, be considered going forward. With regard to the comment on Zoom, we have found issues with all webinar and meeting software in at least a few hospitals and, therefore, there is no perfect choice.

Work Package 7: Guidelines

22. a) Please rate the achievement of the activities and results delivered by ERN eUROGEN in the last 12 months with regard to the development of Clinical Practice Guidelines and clinical decision-making tools (where 0 represents no achievement, and 10 represents full achievement):





b) Any specific comments on this area (requirements, improvements, issues, etc.)?

Score	Comments (2025 only)
8	Future financial support is needed for professional support of GLN teams
4	Had to use the ARM guideline, very good, but there need to be a 'pocket' version
n/a	CSD could play an important role in supporting dissemination and implementation of guidelines at national level.

50. The mean score for the development of Clinical Practice Guidelines (CPGs) fell back to the 2023 level, which is a slight disappointment, particularly in the context of completing the CPG on Paediatric Neurogenic Bladder (D7.5) and the CDST on Posterior Urethral Valves (PUV) (D7.7) in Year 2 of the grant.

51. There were six scores of 4 or lower, including a 0. However, only one of these respondents provided a comment regarding the lack of a pocket version of the ARM guideline.

52. Overall, we feel that progress in this area has been very positive over the first half of the current grant period.

Work Packages 8 & 9: Capacity Building, Best Practice, & Other Activities with Ukraine

23. Do you have any suggestions or thoughts on how the network could better support Ukrainian clinicians (e.g. webinar topics, CPMS cases, offering them training in your HCP if funding is available etc.)?

Comments (2025 only)
Watch webinars later, and offer guidelines
Offer funding for HCP to gain experience in high volume centres

53. We only received two responses to this question. Perhaps, more than anything else, clinicians are unsure as to what help might be given, over and above what we are already delivering in terms of the joint webinar programme.

Part 2: SWOT Analysis

24. In your opinion, what are the greatest strengths of ERN eUROGEN? (2025 responses only)

Role	Comments
Full Member	Networking
Full Member	Collaborations
Full Member	Dissemination of information and collaboration between countries
Full Member	Could be a great organization
Full Member	Networking and cooperation
Full Member	Combining our knowledge about rare diseases and having registries on rare diseases
Full Member	The focus on rare diseases - and the coordinating team of course!
Full Member	EU multi-stakeholder network, strategic connections, registry
Full Member	Organization and communication
Full Member	Good possibility to networking and research and get equal treatment for the rare patients all over Europe
Full Member	To join efforts and experiences
Full Member	That it exists, with its ideal aspirations (operational criteria!), and shows the need for centralisation on a legal, international basis
Full Member	Strengths: possibility of discussing patients from around the world
Full Member	The unique collaboration across European expert centres, the pooling of knowledge for rare and complex conditions, and the opportunities for education, research, and improved patient care through shared expertise and multidisciplinary networking.
Full Member	Multinational and multi-institutional cooperation
Full Member	In my opinion, the greatest strengths of ERN eUROGEN lie in its comprehensive and patient-centred structure, which creates a unique ecosystem for tackling rare and complex urogenital diseases.
Full Member	Great staff, small amount of participants that can easily speak together
Full Member	Networking
Full Member	Learning from each other
Affiliated Partner Member	Potentially a good network
Individual Supporting Partner	Pan European, bringing people together across large geographic area
ePAG Representative	The network to bring knowledge and experience together

54. Members were asked to detail what they currently saw as the greatest strengths of the network.

55. Looking through the responses, and also at the word cloud, the emphasis is firmly around collaboration, cooperation, and networking to bring together knowledge on rare diseases for the benefit of patients. This aligns well with our aims.

56. Research is also mentioned a number of times and this is also something we want to see developed through the joint-working established within the network.

57. These results were very similar to those seen in 2024.

25. And its greatest weaknesses? (2025 responses only)

Role	Comments
Full Member	Administration
Full Member	Lack of support to develop all the activities to be a member
Full Member	The review was extremely cumbersome
Full Member	A large organisation difficult to find your way in
Full Member	it takes time and resources to put up patients and in the German healthcare system the eUROGEN activities all go on to our anyhow way to high long working hours
Full Member	Representation across Europe (some countries too much, some too little)
Full Member	Sustainability of funding
Full Member	Collaboration among centres
Full Member	Lack of working groups and research projects
Full Member	Some HCP don't understand the value, other have fear that EUROGEN would like to replace scientific societies
Full Member	No centralisation achieved, members without proper experience accepted in and tolerated.
Full Member	Weaknesses: Very long surveys without translation
Full Member	Coordination between European and national structures (e.g. CSD) is still developing.
Full Member	Lack of time to participate
Full Member	The lack of full integration into national healthcare systems remains a significant barrier. The issue of sustainable funding and resource allocation is a persistent weakness. The lack of a formal legal status for ERNs as a whole creates a level of ambiguity and complicates cross-border collaborations, particularly in areas like research and data sharing. A more defined legal framework would provide the stability and clarity needed for the network to operate at its full potential.
Full Member	Limited amount of funds for onsite meetings and courses or other activities
Full Member	Slow
Full Member	Too complex organisation
Affiliated Partner Member	Hardly any support to do the work, very difficult to become a partner
Individual Supporting Partner	Limitations placed on supporting partners
ePAG Representative	Don't know it yet

58. Next, members were asked to detail what they currently saw as the greatest weaknesses of the network.

59. These responses were more varied, pointing out a number of things that are, or might potentially be, lacking. The most crucial points are:

    - A feeling that there is a lack of resource to be able to meet the expectations of membership. This is an ongoing and fundamental issue for the network that will be discussed at the ERN eUROGEN Strategic Board Meeting in February 2026.
    - The perception that it is a large and complex organisation, alongside comments around the difficulty in becoming partner, which is something that is difficult for us to change as we always have to operate within the administrative and legal framework established by the Commission.
    - The issue of sustainable funding.
    - The lack of integration with national systems (something that JARDIN is trying to address).

60. Hopefully, some of these issues will improve in the next few years, though most of them either outside of our control as a network, or areas where we have limited influence.

26. What opportunities do you see for the network to embrace in the future? (2025 responses only)

	Implementing European database without any national regulation/legislation
Full Member	Research
Full Member	Patient focused studies
Full Member	Educational
Full Member	To get more known and accessible for healthcare professionals not involved with rare diseases. Case discussions come from other eUROGEN centres but the opportunity is hardly known by others
Full Member	National integration and patient participation in the registry activities
Full Member	Collaborative work with presentations and publications
Full Member	Research
Full Member	More common actions
Full Member	Increase quality by increasing obligatory minimal numbers
Full Member	Consolidate a global clinical network in Europe for rare pathologies
Full Member	Closer collaboration with CSD could enhance patient inclusion, registry data, and education.
Full Member	Mobilising members to participate
Full Member	There is a major opportunity to pioneer the deep integration of the ERN model into national healthcare systems. This involves moving beyond virtual consultations to establish formal referral pathways, influencing national guidelines, and creating a seamless patient journey from local primary care to the highest level of European expertise. By embedding its knowledge and standards at the national level, ERN eUROGEN can transition from a network of experts to a fully integrated, systemic solution for rare disease care. The network is perfectly positioned to embrace the digital health revolution and the power of artificial intelligence. There is a tremendous opportunity to leverage AI and machine learning for faster and more accurate diagnostics, potentially reducing the diagnostic odyssey for many patients. Furthermore, expanding the use of telehealth, remote monitoring, and patient-facing digital tools can empower patients in their own care and make expertise more accessible, regardless of geographic location.
Full Member	More guidelines and shared clinical decision making tools . More research projects. Invitation for specialists to travel and share experiences. Improvement of care for patients. Possibility of employ on site administrative people to dedicate to ERN activities.
Full Member	Research
Full Member	Simplify

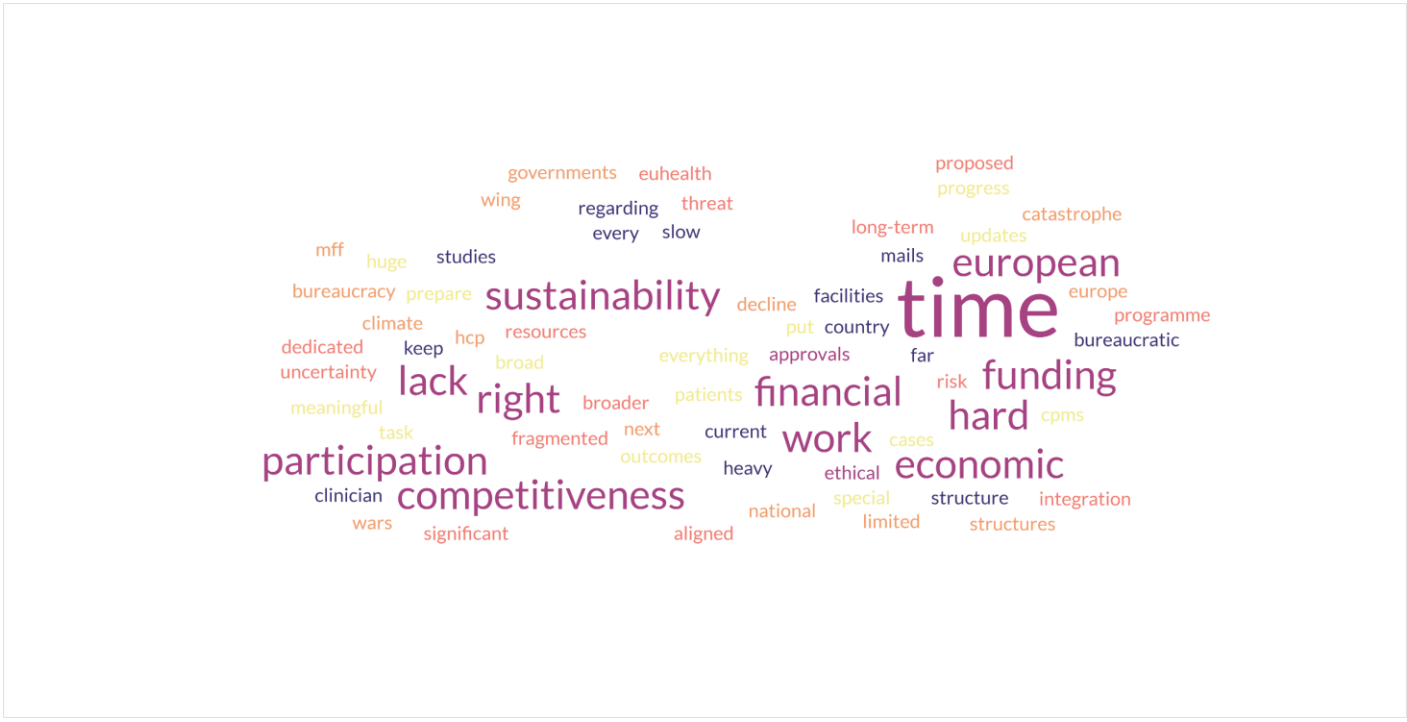
61. Part 3 of the SWOT analysis asked members to detail what they saw as the opportunities for the network going forward.

62. The main messages were around the opportunity for collaborative research, alongside the strengthening of national and regional cooperation.

63. These responses will be considered more carefully to see how we can try to incorporate these goals into our next grant.

27. And what hindrances are on the horizon that may become an issue for the network? (2025 responses only)

Role	Comments
Full Member	Ethical approvals in every country is far to slow and heavy for studies. We should work for facilities regarding this
Full Member	Current bureaucratic structure
Full Member	TIME! As a clinician it is hard to keep up with all mails and updates
Full Member	No time to put in patients and prepare special cases for CPMS
Full Member	The task is huge and broad - it may be hard to progress everything into meaningful outcomes
Full Member	Financial sustainability in the next MFF
Full Member	Lack of time. Bureaucracy
Full Member	Limited participation of HCP
Full Member	Right wing governments all over Europe-> lack of funding, economic decline, climate catastrophe and wars
Full Member	If European and national structures are not aligned, resources risk being fragmented.
Full Member	The uncertainty of long-term, dedicated funding is the most significant threat. The proposed integration of the EU4Health programme into a broader European Competitiveness Fund for the 2028-2034 budget, without explicit mention of ERNs or rare diseases, could undermine the network's financial stability and sustainability. A shift in policy that views healthcare primarily through the lens of economic competitiveness, rather than as a fundamental right, could jeopardize the very foundation of the ERN model.
Full Member	Jealousy of professional staff precluding exchange of experiences or participation to registries. Time demanding activities on the top of the already busy schedules of clinicians.
Full Member	Too much work
Full Member	Too little patient involvement
Affiliated Partner Member	No finances
Individual Supporting Partner	BREXIT
ePAG Representative	That the network size would cause losing overview. But that's more the fear, because it can also increase its strength.



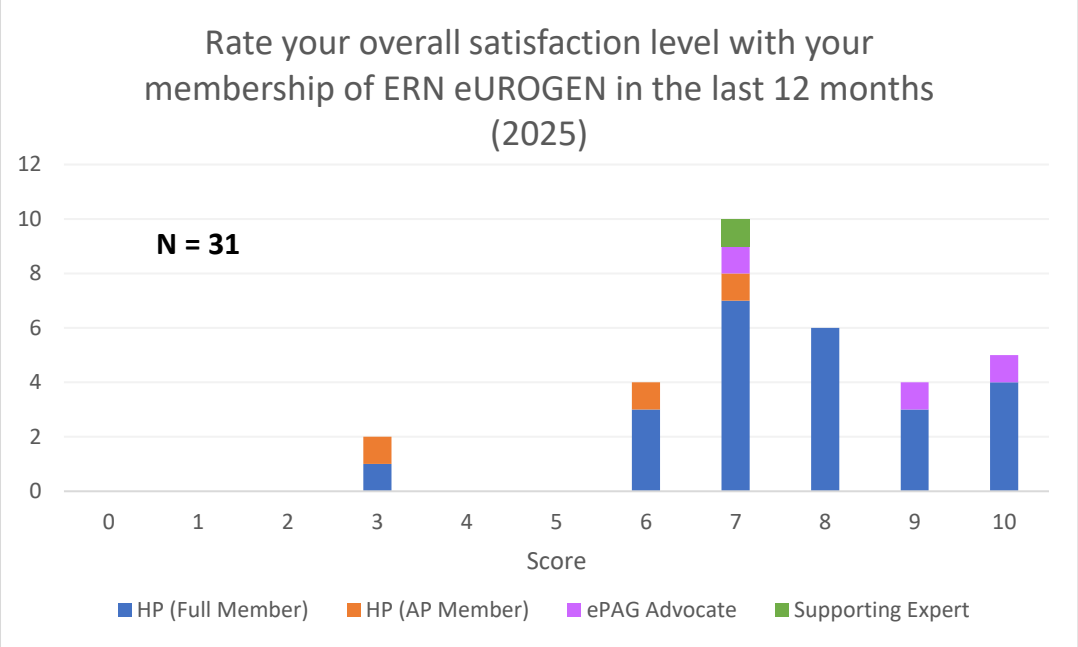
64. Finally, members were asked to give what they saw as the main threats to the network in the immediate future. The main points are:

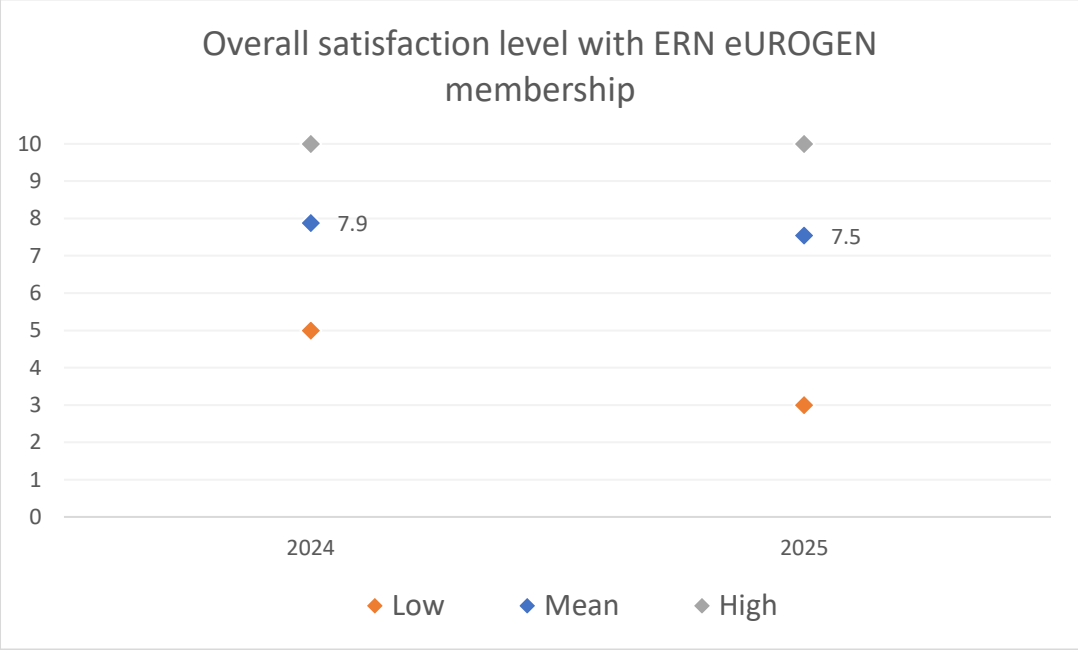
    - The restraints of the time that clinicians have available to dedicate to the network, coupled with the perception of bureaucratic structures which further slow progress and engagement.
    - Again, concerns over longer-term funding.
    - Political destabilisation.
    - A reminder that further patient integration is still necessary in the network.

65. As mentioned previously, we will be examining the question of membership expectations compared to the resource that members typically have available at our SBM in February 2026.

Part 3: Overall Opinions

28. Please rate your overall satisfaction level with your membership of ERN eUROGEN in the last 12 months (where 0 represents complete dissatisfaction, and 10 represents complete satisfaction):





29. Any other final comments regarding your engagement with or membership of the ERN eUROGEN network? (2025 only)

Score	Role	Comments

10	Full Member	Thanks for all the activities
10	Full Member	I would do it again - je ne regrette rien!
7	Full Member	Easily add more members to my team
7	Full Member	We value being part of ERN eUROGEN and see the network as an important platform for collaboration and expertise. However, at times the activities feel somewhat distant from daily clinical practice and patient care, with a relatively high administrative burden. A stronger focus on practical clinical impact and direct benefit for patients would make the membership even more meaningful.
3	Full Member	It takes many hours (monthly report/Castor/ registry/CPMS) and we have no help or spare time for this at all :-(

66. The mean satisfaction level with ERN eUROGEN membership fell slightly from 2024 to 2025, due predominantly to two respondents scoring this as only 3. One of these was a full member who commented regarding the lack of time to complete the necessary tasks that are asked of them.
67. However, it is important to stress that the majority of respondents gave a favourable rating, with a modal score of 7. One of those respondents gave a considered explanation, pointing out the need to focus as much as possible on practical clinical impacts. Our aim is to do this within the administrative requirements that we ourselves must meet, and we will continue to look at how we can further reduce any admin burdens on our members going forward.

3. NEXT STEPS

68. The results will be further considered by the ERN eUROGEN Quality Improvement Group to identify any actions for improving particular areas or issues identified by the survey, some of which have been noted above.

ANNEX C: EVALUATION OF ERN EUROGEN WEBSITE REPORT (T3.10)

1. BACKGROUND

1.1. Evolution of ERN eUROGEN website

- The ERN eUROGEN website (https://eurogen-ern.eu) was established at the same time as the network itself in 2017. The site was created by one of the network's main supporting partners, the European Association of Urology (EAU). Whilst the EAU remain the principal administrators for the site, both the ERN eUROGEN Performance Manager and Business Manager have had admin rights to enable them to update both the structure and content of the pages since 2019.
- This has enabled the network to ensure that the site is kept up to date, and identified changes can quickly be made in-house.

1.2. Recent changes/aims

- A major overhaul of the site design took place in late September 2023 to better arrange the information presented, update or remove old pages, and add new information as a result of the experience and changing priorities of the network.
- Subsequent to this, there have been frequent smaller updates to the layout and structure of the site. These have been prompted by:
  - The new Work Package structure of the Direct Operational Grant compared to the Bridging Grant
  - Improving the user experience
  - Comparison with other ERN websites

1.3. Feedback & continuous improvement

- We have regularly gathered feedback on the website from our members via our monthly and quarterly workstream meetings, correcting any identified errors and acting on improving layouts where the user experience indicated difficult in locating the required information that they were seeking.
- The ERN eUROGEN Business Manager regularly reviews the websites of other ERNs to identify best practices in terms of design and content.
- Furthermore, the ERN Communications Group created a spreadsheet where every ERN puts all their comms information (i.e., URLs and handles) so that other ERNs can easily find their website urls and thereby refer to them. It was also agreed that each ERN would include a page on their website with links to the other 23 ERNs. The ERN eUROGEN example can be found here: https://eurogen-ern.eu/about/other-erns

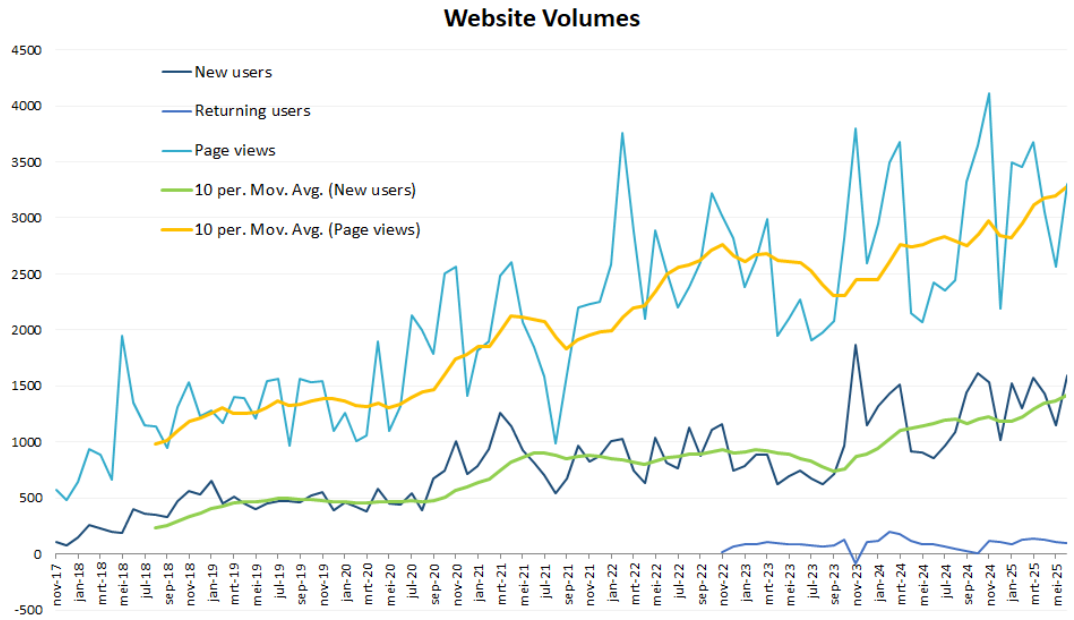
1.4. Evaluation

- No evaluation was undertaken at M12. Instead, it was decided to bring the website analysis more in line with many of the grant deliverable and deliver two reports during the grant period
- The analysis below was instead undertaken at M23 based on data to June 2025 (M21), predominantly to allow it to be done before a number of grant deliverables become due.

2. WEBSITE VISITORS

2.1. Visitor & Page View Volumes

Chart 1: ERN eUROGEN website - volumen of user visits (Nov-17 to Jun-25)



- As the graph above shows, the number of visitors to the ERN eUROGEN website has grown relatively steadily since 2017, albeit it with a good deal of variability from month to month.
- However, using a 10-month moving average to help show the longer term trends, performance has been strong since September 2023 when the website was given a significant overhaul.

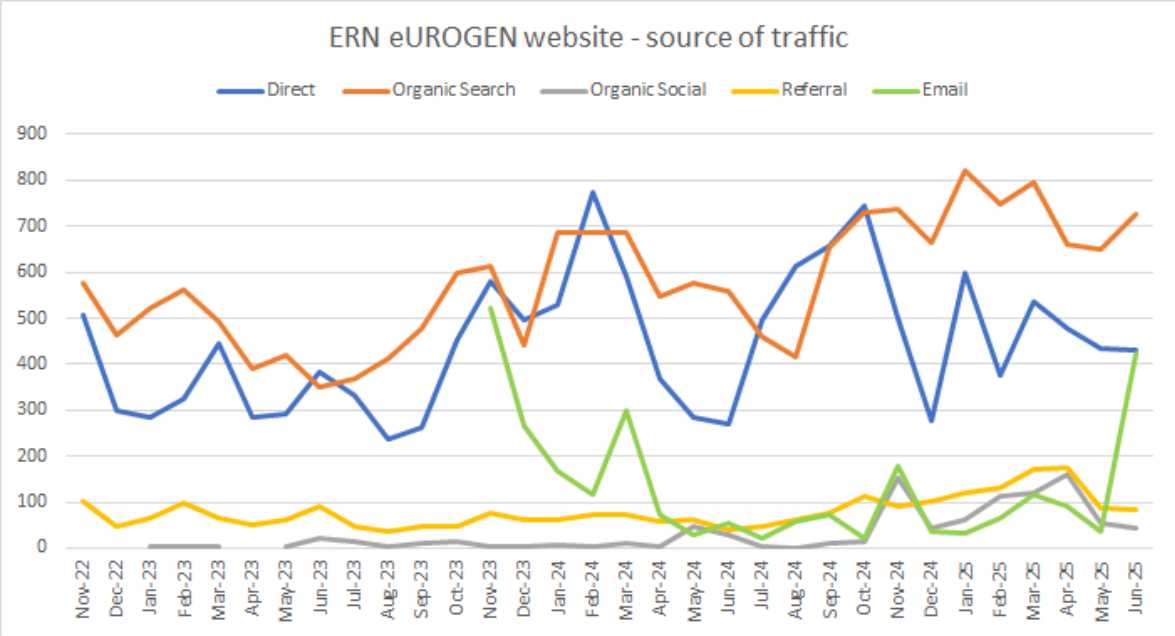
2.2. Session Channels

- The source from which visitors reach our website can be identified and tracked. The table below provides the definitions of the source channels that are shown in the subsequent graph.

Table 1: Definitions for source of traffic/channels for website sessions

Channel	Description
Direct	Direct is the channel by which users arrive at your site/app via a saved link or by entering your URL.
Organic Search	Organic Search is the channel by which users arrive at your site/app via non-ad links in organic-search results.
Organic Social	Organic Social is the channel by which users arrive at your site/app via non-ad links on social sites like Facebook or Twitter.
Referral	Referral is the channel by which users arrive at your site via non-ad links on other sites/apps (e.g., blogs, news sites).
Email	Email is the channel by which users arrive at your site/app via links in email.

Chart 2: Source of traffic/channels for website sessions (volume of user visits)



- The graph shows that, in the last 8 months, an increasing proportion of visitors have arrived at our site via search engine results, whilst the use of direct links has remained relatively steady in comparison.
- The use of links from social media platforms has shown a significant increase since October 2024. This is primarily due to more news stories being added to the website, which are then shared via social media. There has also been a focus to improve the design of posts by utilising specific graphic design software.
- Referrals have also shown a moderate percentage increase over the last 12 months.
- Users arriving via links in emails began in November 2023 when eUROGEN switched from using Mailchimp to Laposta for its monthly newsletters.

2.3. Visits by Country

- Looking at total number of user visits from Nov-22 to Jun-25, the top ten countries of origin of those users is shown in Table 2 below.

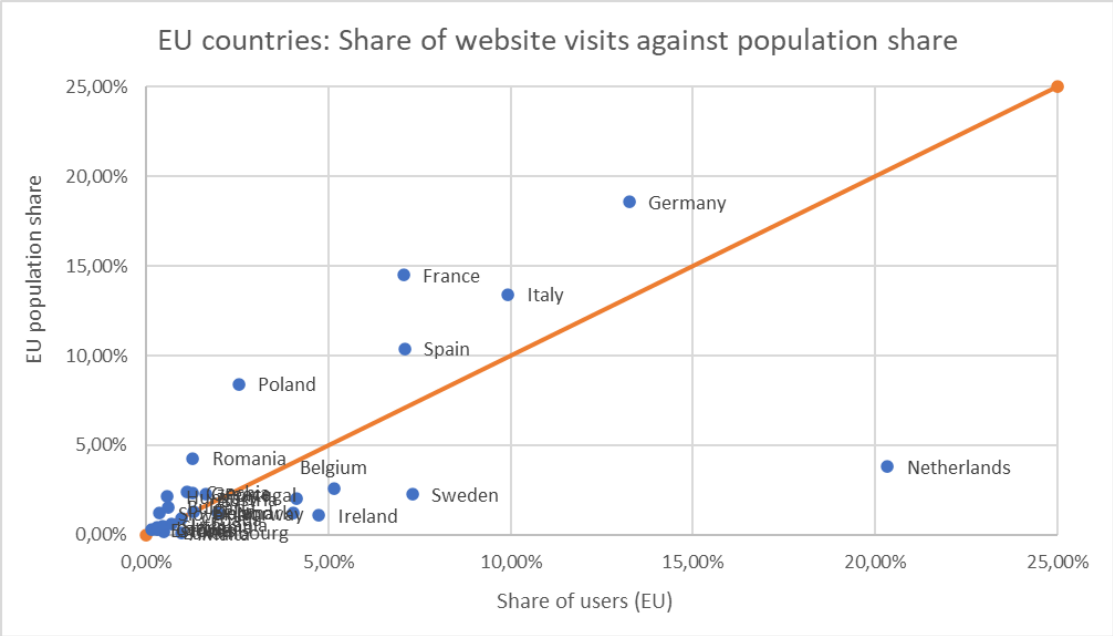
Table 2: Top countries for user visits (Nov-22 to Jun-25)

Country	Total users
United States	5317
Netherlands	4168
Germany	2717
United Kingdom	2512
Italy	2032
India	1826
Sweden	1496

Spain	1457
France	1448
Belgium	1055

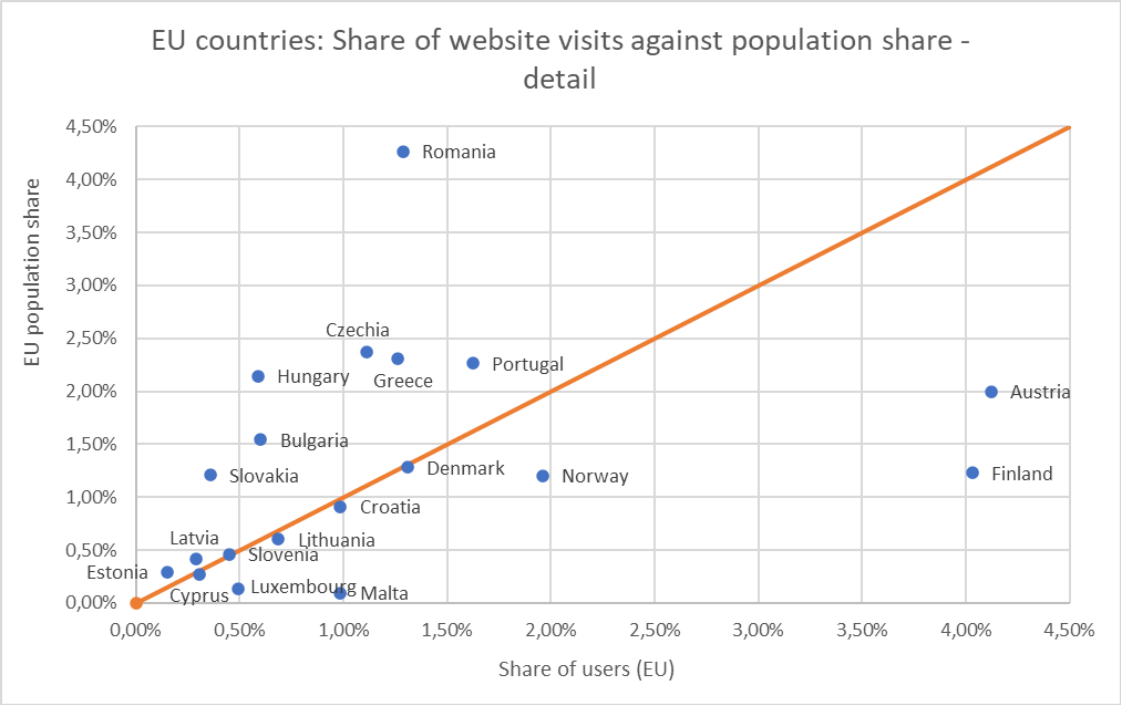
- This data must, of course, be caveated that it will be skewed if users are using VPNs. However, it doesn't immediately show anything too surprising. The high number for the Netherlands is probably explained by Radboudumc coordinating the network.
- Further analysis has looked at the user visits from EU countries and compared the relative shares from each country against their relevant population share.

Chart 3: A comparison of EU countries share of website visits against their population



- We can also look in more detail at those countries in the bottom-left of the graph.

Chart 4: A comparison of EU countries share of website visits against their population - detail from Chart 3



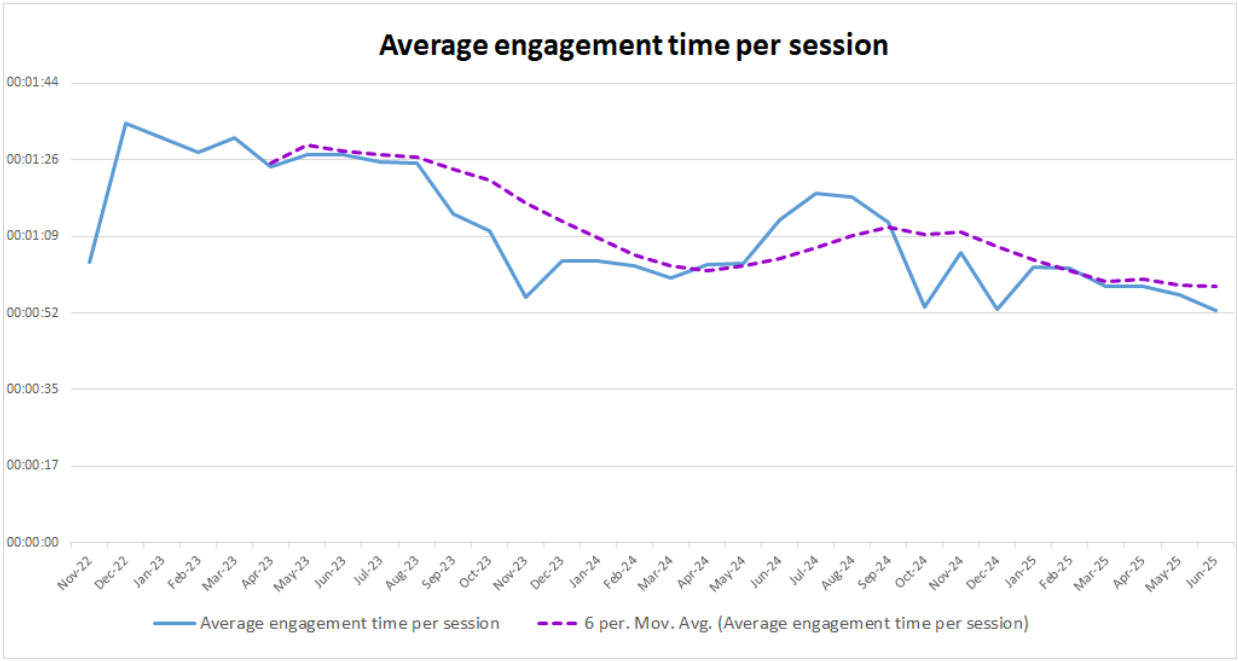
- Chart 3 shows that a number of larger countries have a noticeably smaller share of visits compared to their population (i.e. those above the orange line), particularly France, Poland, and Germany. For France, this may explained by the site being in English, although automatic translations are always available through one's browser.
- Other than that, there does not appear to be any obvious reason why engagement with the website should be lower in those countries compared to their population.
- In Chart 4, Romania is also a notable outlier, whilst Czechia, Hungary, Greece, Bulgaria, and Slovakia are also all above the line - countries where ERN eUROGEN currently has no HCP member. We expect Affiliated Partners to be nominated for those countries that are not yet represented within ERN eUROGEN in 2026, which should hopefully drive more engagement in those countries.

3. USER ACTIVITY

3.1. User Engagement Time

- In measuring the average length of time that a user spends on our website, we use the Average Engagement Time (AET) per Session instead of Average Session Duration, as the latter includes time when the website was not the focused window or tab of the user, thereby inflating the duration. On the other hand, AET only includes the session time when any of the following criteria are met:
  - The session lasts at least 10 seconds
  - The session includes one or more conversion events
  - The session includes two or more page/screen views

Chart 5: Average Engagement Time per Session

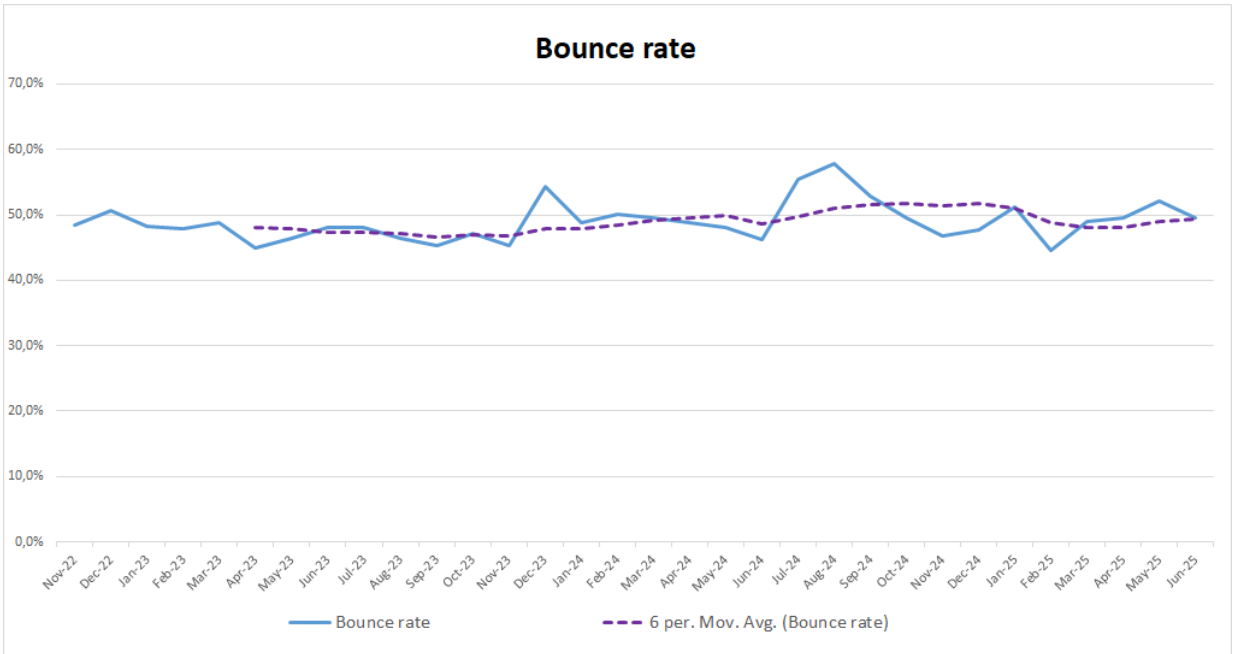


- The graph above shows that AET has reduced over time. It is quite difficult to determine exactly why this has happened, but one possibility might be the link to us driving more users to the website to view our webinar pages, which will be helpful but short interactions.
- We can try to assess this by looking at the engagement rates by pages. We would assume that the home page and webinar pages would have a much reduced engagement time compared to say, disease information pages or news posts.

3.2. Bounce Rate

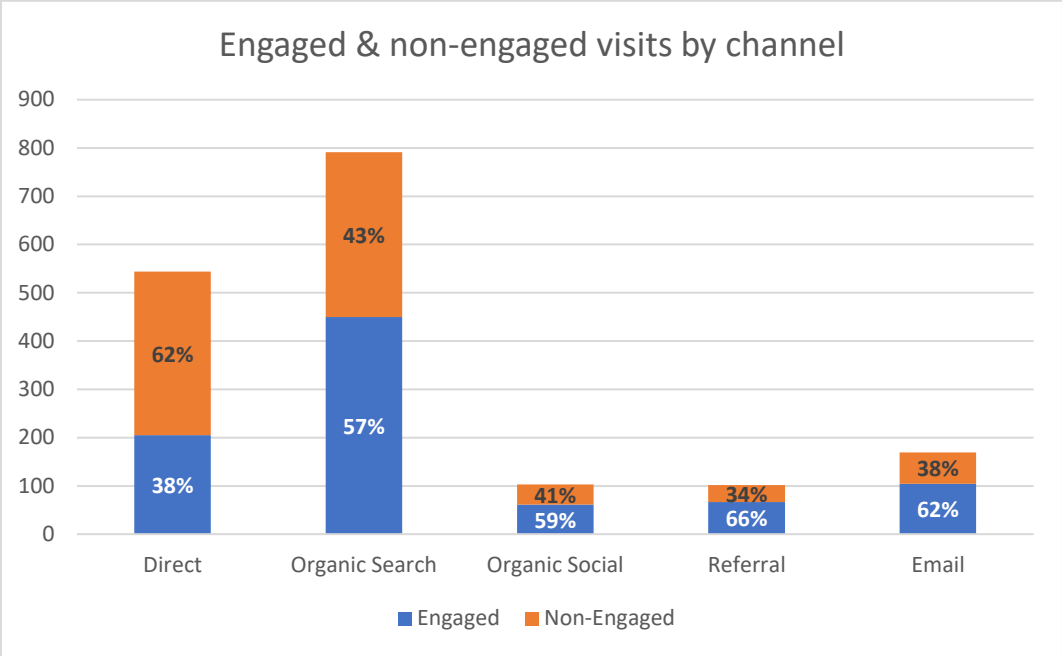
- Bounce rate is the inverse of engagement rate, that is, it represents the percentage of sessions where users leave a website after viewing only one page and without any further interaction. Therefore, a high bounce rate might suggest that a proportion of visitors are either not finding what they need or are not engaging with the site content.
- As can be seen in Chart 6 below, the bounce rate for the ERN eUROGEN website has remained largely stable over time, with perhaps only a noticeable rise during July and August 2024.

Chart 6: ERN eUROGEN website bounce rate (Nov-22 to Jun-25)



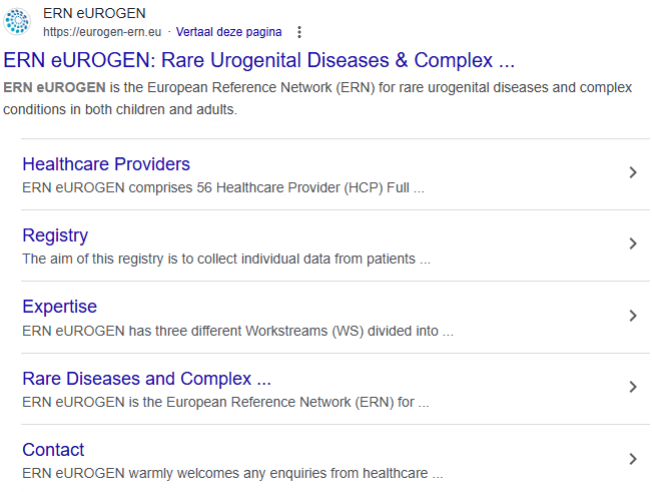
- Whilst we would like to see increased engagement with the website (through higher engaged visits), the overall engagement/bounce rate will be determined to a large extent by the way users are accessing the site and, of course, their purpose for being there.
- Chart 7 below breaks down the engaged and non-engaged visits by channel.

Chart 7: Engaged and non-engaged sessions by channel



- We can see again, as in Chart 2 above, that the largest channel for visits is organic search. Of these 57% are engaged visits, as we might expect if people are arriving at the home page via a search engine and then navigating to the page or information that they want. Of course, users also have the chance to navigate directly to other pages from the search results (shown in Figure 1 below), which could actually reduce the number of engaged sessions we might have otherwise expected if users do not browse for more than 10 seconds.

Figure 1: Google Chrome search results for ERN eUROGEN



- The chart also shows that engaged visits also dominate the smallest three channels of organic social, referral, and email. Whilst these links would take the user directly to the page of interest, presumably it is something specific that they are interested in and thus will spend longer than 10 seconds on that page, which will thus flag it as an engaged

session. Furthermore, these pages might well contain other links for users to interact with, e.g. registering for a webinar on the Upcoming webinars page.

- The main reason that the bounce rate is pushed up toward 50% is due to the second largest channel, direct, being dominated by non-engaged visits. This category will predominantly include users visiting via a bookmark to the home page or a particular page of interest that they check frequently. If the former, one would expect them to then navigate to their destination of choice. If the latter, one might expect them to stay on the page for more than 10 seconds. Either of these cases would produce an engaged session. It could be that users are checking quickly for an update but, not finding anything immediately, end their session before 10 seconds has elapsed.
- Within the grant, we have said that we are aiming to lower the bounce rate, albeit modestly. However, the fact remains that the bounce rate will not change significantly unless:
    - The balance *between* the channels shifts away from direct to the other categories. This is not really within ERN eUROGEN's gift to influence, other than ensuring that the content at the end of the link is engaging and relevant. We already include the appropriate links to our website in all of our social media posts (organic social) and newsletters (email). We also do not want to make our communications less user-friendly by simply putting the homepage url in our communications and then hoping that users navigate to the appropriate page, thus producing an engaged session.
    - Alternatively, the balance of engaged and non-engaged visits must shift *within* the larger channels. This will be difficult to influence as we cannot influence users' habits in terms of what they bookmark for direct visits, nor what they choose to click once there. They have their own motivations for using the link at that time, rather than being a response to something that we have issued.
    - On other interesting thing to note regarding the organic social channel, the split shown in the graph relates only to Nov-24 to Jun-25 as this is the period in which the numbers became significant and thus are more reflective of the current state of play. In comparison, during the period Nov-22 to Oct, the split was 46% engaged and 54% non-engaged. If we could, therefore grow visits from this channel, we might expect the engaged share to increase further.

4. PAGE VISITS & POSTS

4.1. Most visited pages

- The table below shows the most visited pages since November 2022:

Table 2: Top ten most viewed web pages on the ERN eUROGEN website (Nov-22 to Jun-25)

Rank	Page Title	Number of months
1	Rare Urogenital Diseases & Complex Conditions: ERN eUROGEN	32
2	Upcoming Webinars	32
3	Past Webinars	32
4	Healthcare Providers	32
5	Webinar Programme	32
6	Workstream 1	32
7	Registry	23
8	Coordination Team	32
9	Healthcare & CPMS	23
10	Workstream 2	32

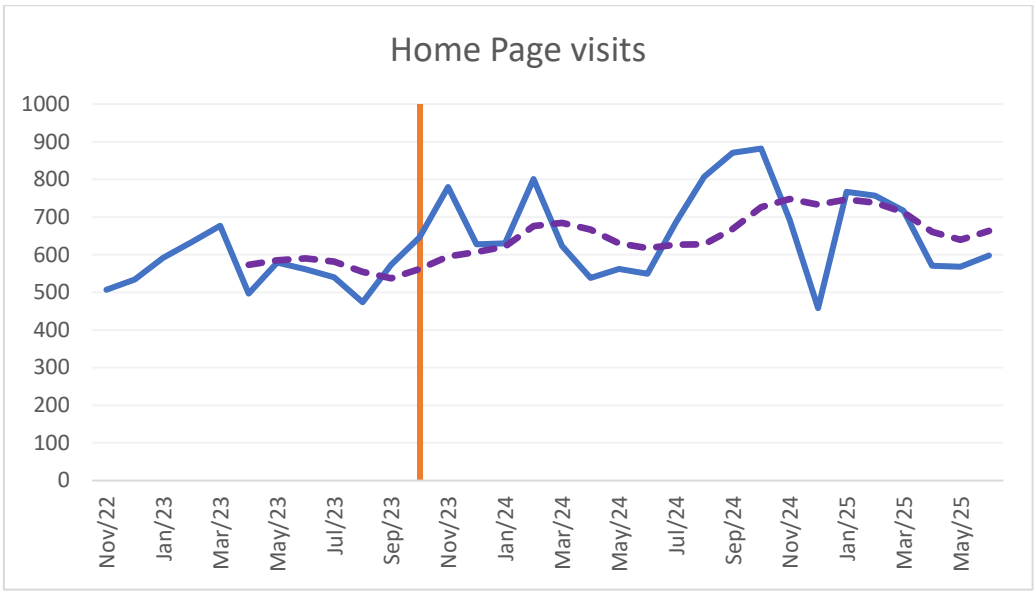
- These results are largely unsurprising. Aside from the home page, we push people to the website to view and register for our upcoming webinars, as well as finding links to our previous webinars, which are all grouped by Expertise Area.
- Furthermore, Workstream 1 (our paediatric workstream) is the largest of the three workstreams in terms of HCPs that cover those areas. Other popular pages cover some of the other main areas of work of the network, namely the registry and CPMS.
- Of course, this methodology is unlikely to show new pages that have been created more recently (as evidenced by the high number of months that have been counted for the pages shown). To look at the data another way, we could also look at the pages using their mean views. These are shown in the table below (for pages that are currently used and that have existed for at least three months):

Table 3: Top ten most viewed web pages based on monthly mean visits (Nov-22 to Jun-25)

Rank	Page Title	Mean	Month Count
1	Rare Urogenital Diseases & Complex Conditions: ERN eUROGEN	634	32
2	Upcoming Webinars	132	32
3	Past Webinars	123	32
4	Healthcare Providers	90	32
5	Registry	75	23
6	Webinar Programme	74	32
7	Workstream 1	72	32
8	Urorectal/Anorectal Malformations	63	12
9	ERN eUROGEN	55	13
10	Healthcare & CPMS	54	23

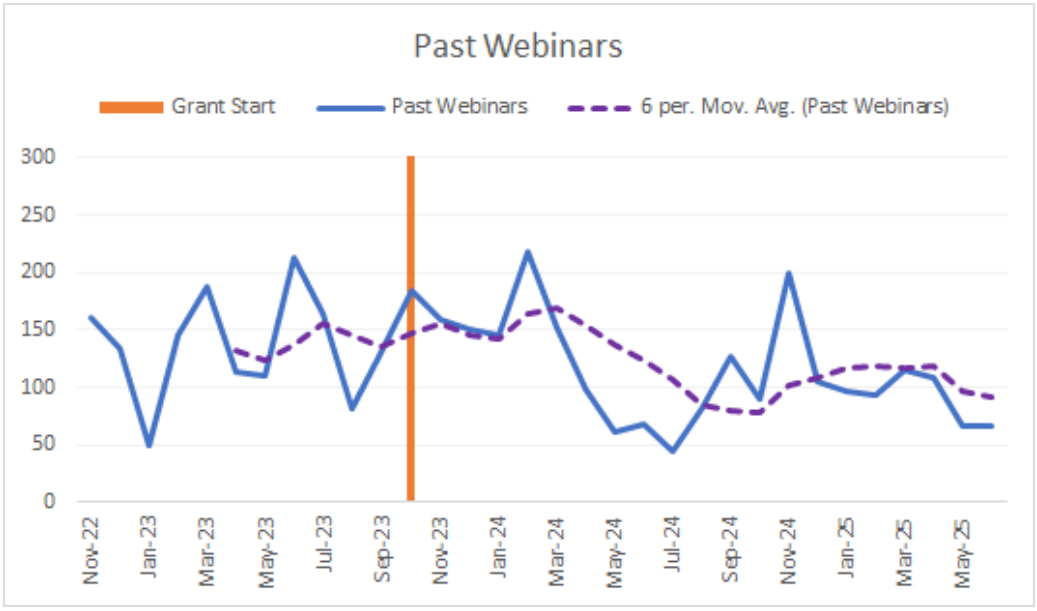
- This shows two pages that were not in the top ten previously. Firstly, the Urorectal/Anorectal Malformations page which was only created 12 months ago, and refers to one of our busiest Expertise Areas. Secondly, the ERN eUROGEN page falls under the About section of the website and provides an overview of the network. It is also notable that the Registry page ranks higher as a result since it was only created in Aug-23.
- The trends for the majority of the top ten pages are quite stable over time. Below are two of the more interesting ones.

Chart 8: Visits to the ERN eUROGEN homepage



- Visits to the homepage have seen a gradual increase of around 15% since 2023. This is to be expected with the overall increase in page views and user visits.

Chart 9: Visits to the Past Webinars page



- There has been a 30-35% decrease in visits to the Past Webinars page since mid-2024. This will be primarily due to ERN eUROGEN posting webinar recordings solely on YouTube from Sep-24, and there not being a version on the new Zoom webinar platform as there was previously with GoToWebinar. As many YouTube viewers will already be subscribed to our YouTube channel, there is therefore no need for them to find the link via the website.

4.2. Posts

- These are usually news posts on the website and thus we would expect to see a high number of page views in month 1 or month 2 (depending on the date of posting in the month) before it reduces significantly. The table below shows the highest viewed posts in their first two months after publication (only for posts that were published after Nov-22).

Table 4: Most viewed posts in first two months after publishing

Post	Visits

ERN eUROGEN Resources Available for Anorectal Malformations	534
Patient Empowerment: A Journey from Isolation to Advocacy	464
Application for 2023-2027 Funding Resubmitted	443
Results: ERN eUROGEN Five-Year Evaluation	405
Horizon Europe Work Programme 2025: Calls Open	386
New ARM Brochure: A Resource for Patients and Families	360
Cross-ERN OR Nurses Meeting: Building Connections, Sharing Knowledge	309
Loes Oomen: PhD Thesis on Pediatric Kidney Transplantation Care	135
Clinical Practice Guideline: Diagnosis and Treatment of ARM	118
Vaginal Replacement in ARM: Consensus Meeting Held	116

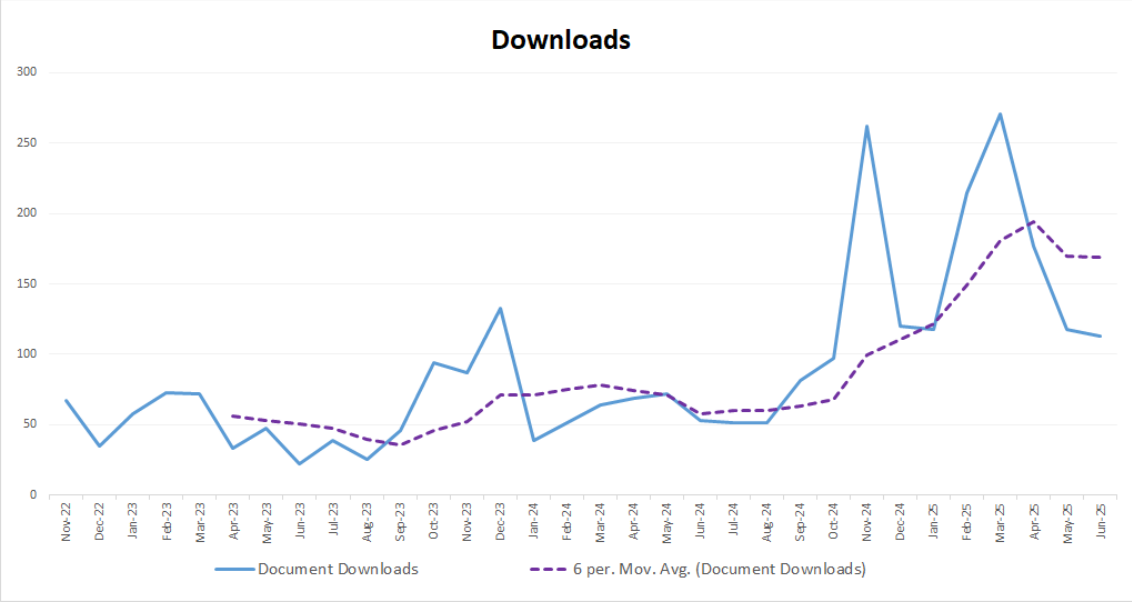
- The top two pages for downloads are probably due to them being patient driven and thus shared with the relevant groups, e.g. ARM-Net, AIMAR, SoMA, EAT, TOFS, VACTERL Association UK, Max's Trust, etc.
- Furthermore, whilst links to most of the documents on the pages are shared via the main ERN eUROGEN newsletter, some are also shared via internal emails, which will increase the download volumes.

5. DOWNLOADS

5.1. Website downloads

- The number of documents downloaded from the website has increased significantly since Nov-24. This is in line with the increase in visits from social media channels.

Chart 10: Document downloads from the ERN eUROGEN website



- Table 5 below shows the pages from which most downloads have occurred (excluding pages that have been either made inactive or no longer contain a download link die to reorganisation).
- **Note:** Where a webpage contains more than one download link, it is not possible differentiate the downloads from each, only the total downloads from that page. Many of the pages below contain more than one link, and some documents are downloadable from a number of different pages.

Table 5: ERN eUROGEN webpages with most downloads (Nov-22 to Jun-25)

Page	Downloads

Urorectal/Anorectal Malformations	269
Registry	262
ERN eUROGEN Resources Available for Anorectal Malformations	227
Guidelines	209
Clinical Practice Guideline: Diagnosis and Treatment of ARM	191
Healthcare & CPMS	188
Patient Information	166
Patient Empowerment: A Journey from Isolation to Advocacy	96
Expertise	90
An Urge To Act: EU Continence Health Summit	86

6. CONCLUSIONS

- Overall, it appears that the ERN eUROGEN website is moving in a positive direction.
- Increases in usage suggest that we are now reaching a wider audience.
- The only points of concern relate to bounce rate and engagement time, which might suggest only cursory uses of the website, although this is not certain.

7. NEXT STEPS & FUTURE IMPROVEMENTS

- Further evaluation of the ERN eUROGEN website will take place at M48.
- We intend to use the annual ERN eUROGEN Network Survey to help gather feedback from our members, to further understand how they utilise the website and thus help us to identify potential updates and improvements to the website to hopefully increase meaningful engagement.
- We shall also continue to identify improvements for the website via the ERN eUROGEN Quality Improvement Group (QIG).

ANNEX D: EVAUATION OF ERN EUROGEN WEBINAR REPORT (T3.11)

1. BACKGROUND

1.1. Evolution of the ERN eUROGEN Webinar Programme

- The ERN eUROGEN Webinar Programme started in June 2019. The first webinar was held in conjunction with the EAU. Having used this as a pilot session, ERN eUROGEN set up its own GoToWebinar account in order to be able to run webinars independently. This began in November 2019.
- The number of webinars were increased during 2020 and 2021. From 2022 onwards, we have aimed to deliver between 30 and 40 webinars per year. These are held mainly on Wednesdays at 18:00 CET, although, for example, we run our series for Ukrainian clinicians on Thursday evenings.
- All of our full members are expected to deliver at least one webinar every 18 months. As of the end of November 2025, we have run a total of 155 webinars (including the webinars for Ukrainian clinicians). The analysis presented below separates out the Ukrainian webinars from the others and is presented independently in Section 6. This is due to these webinars being deliberately aimed at a different audience, and a significant number of people were automatically registered for those events, which would, therefore, skew the results.
- Figure 1 below shows the breakdown of our webinars to date by our so-called Expertise Areas (EAs), also referred to as subthematic areas. Those highlighted are EAs that are still awaiting official approval from the Commission before they are added to the ERN eUROGEN remit. Furthermore, our 18 Ukrainian webinars would fall under EA 1.4, but have not been included in the table. Whilst we aim to deliver sessions that cover all of our expertise areas, there are some areas where we currently have little clinical representation and thus it is difficult to find volunteers for these topics.

Figure 1: Number of webinars related to each ERN eUROGEN Expertise (Subthematic) Area

Workstream 1		Workstream 2		Workstream 3	
1.1	3	2.1	7	3.1	6
1.2	5	2.2	0	3.2	5
1.3	3	2.3	6	3.3	4
1.4	10	2.4	0	3.4	1
1.5	2	2.5	9	3.5	1
1.6	4	2.6	2	3.6	0
1.7	50	2.7	2	3.7	0
1.8	3	2.8	1		

- We have run a number of our webinars in collaboration with other ERNs. More particularly, we have organised three different webinar series via these collaborations. These are:
    - A joint series on spinal dysraphisms with OMNI-NET Ukraine, & the International Federation for Spina Bifida and Hydrocephalus (IFSBH). This also involved cross ERN-collaboration with ERN ITHACA and ERKNet. The series aims to deliver a virtual webinar training program specifically aimed at Ukrainian clinicians dealing with rare or complex uro-recto-genital diseases, thereby helping to address current Ukrainian needs for clinical support. The first series of nine webinars ran from November 2023 to April 2024, and a second series of nine sessions from November 2024 to June 2025. Another series covering more areas within WS1 is planned for 2026. Please note that the analysis of these webinars is included here in Section 5 (and also Section 3) rather than in D8.2.
    - A colorectal series (EA 1.7) organized jointly with ERN ERNICA (the ERN for rare Inherited and Congenital (digestive and gastrointestinal) Anomalies). These are supported by two of our Supporting Partners: ARM-Net and EUPSA (European Paediatric Surgeon's Association). These webinars cover all aspects of paediatric colorectal surgery, in particular (congenital) anorectal malformations. This series has been running since 2020, and will continue to do so into 2026 and hopefully beyond. As of early November 2025, 50 of these sessions have been run.
    - We ran an interstitial cystitis/bladder pain syndrome (IC/BPS) webinar series through the latter half of 2023. These were joint webinars with our Supporting Partner, the International Society for the Study of Bladder Pain Syndrome (ESSIC), a non-profit organisation for professionals. Its members are scientists and/or medical

practitioners from all over the world with an interest in research into and/or treatment of BPS. We are planning to organise further webinars with them in 2026.

- With a few exceptions, all of our webinar recordings are published on our YouTube channel. An overview of all the webinars organised so far can be found in Annex 1 and more information about YouTube performance can be found in Section 3.

1.2. Notable Changes

- ERN eUROGEN applied for accreditation for its webinars from September 2023 onwards. The vast majority of sessions have been accredited since that time. A few webinars miss out of accreditation due to us not having the time to go through the necessary process (that takes 6 tom8 weeks). This happens mostly because we accredit our webinars in blocks of 10 where possible to optimise cost savings. The cost of accrediting individual webinars is prohibitve.
- In October 2024, ERN eUROGEN made the decision to move from using GoToWebinar to run our webinars and instead switch to Zoom. This allowed us to utilise live captioning for our Ukraine webinars, as well as offering greater control in terms of the organisation of the sessions and the functionality utilised to run them.

1.3. Evaluation & Feedback

- In order to facilitate a regular and robust evaluation of our webinar programme, we gather information from different sources:
    - Registration and Attendee reports for each webinar (see Section 2). These enable us to track the number of registrations per session, their location, and their job title. These are derived from the questions that each person must complete when registering for an event. Post-event, we can then also see who attended, how long they spent in the webinar etc.
    - As we publish almost al, of our webinars on YouTube, we can also monitor the extent to whichh these are viewed month by month (see Section 3)
    - Webinar Survey reports for each webinar (see Section 4). These ask the individual attendees a series of questions, some of which are required for us to report to the European Accreditation Council for Continuing Medical Education (EACCME), whilst others allow us to assess how people felt about the webinar environment and the presentation style.
    - Finally, we issue an annual webinar survey each year, around September (see Section 5). This is sent to all previous registrants of our webinars. The aim is to gather a more global view of our webinar programme.
- The analysis below builds on a report that was done at M12 as stipulated for T3.11 in the Grant Agreement.

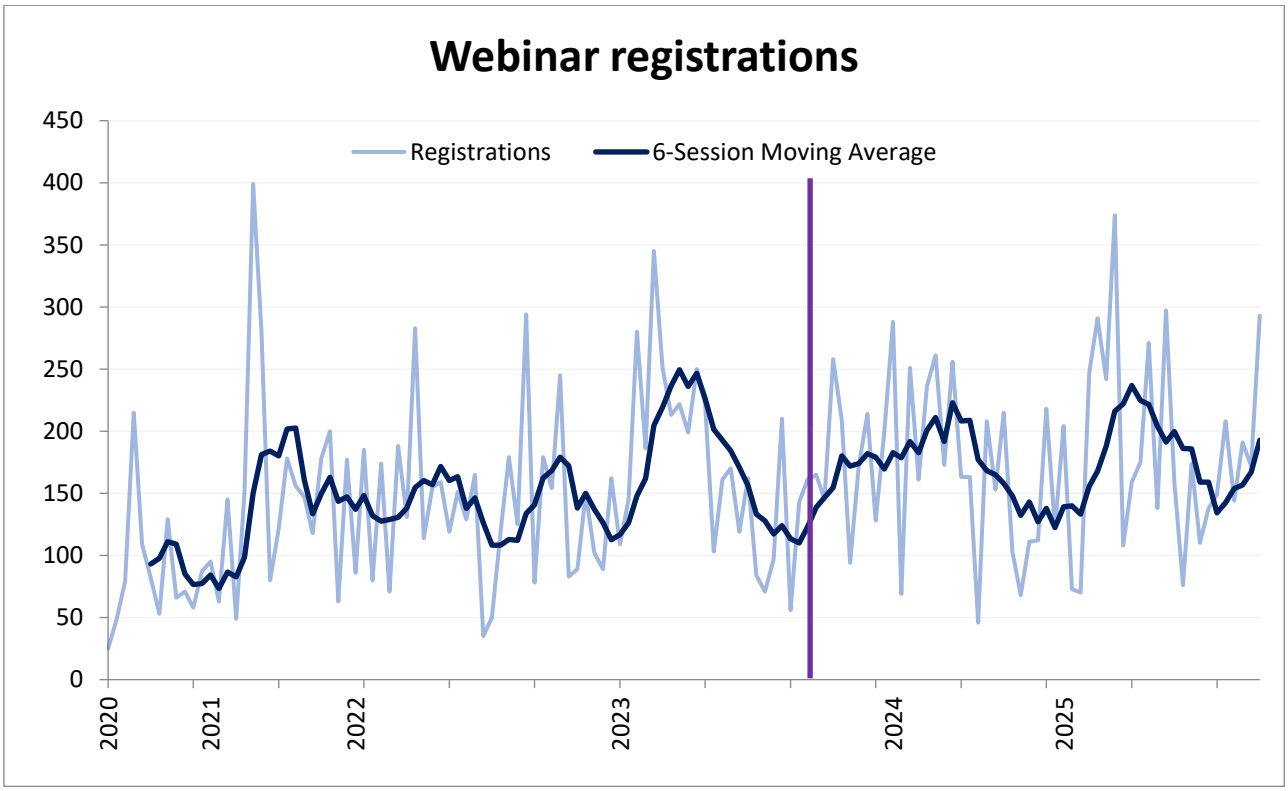
2. REGISTRANTS & ATTENDEES

2.1. Registration Volumes

- To date, we have organised 137 webinars (excluding our Ukraine series), and there have been a total of almost 21,000 registrations for these sessions. This figure comprises approximately 5,350 individuals.[1]
- Fig. 3 below shows that registrations per session are highly variable as they will depend on the topic being presented, in terms of both the Workstream within which it falls and, within that, the area of particular expertise within that Workstream.
- Adding a 6-session moving average to smooth the variance helps to show that registrations have increased from 2023 onwards. However, over this period, the registration level has still been very up and down, with no obvious increase in the volume of registrations. The vertical line shows the start of the current grant period.

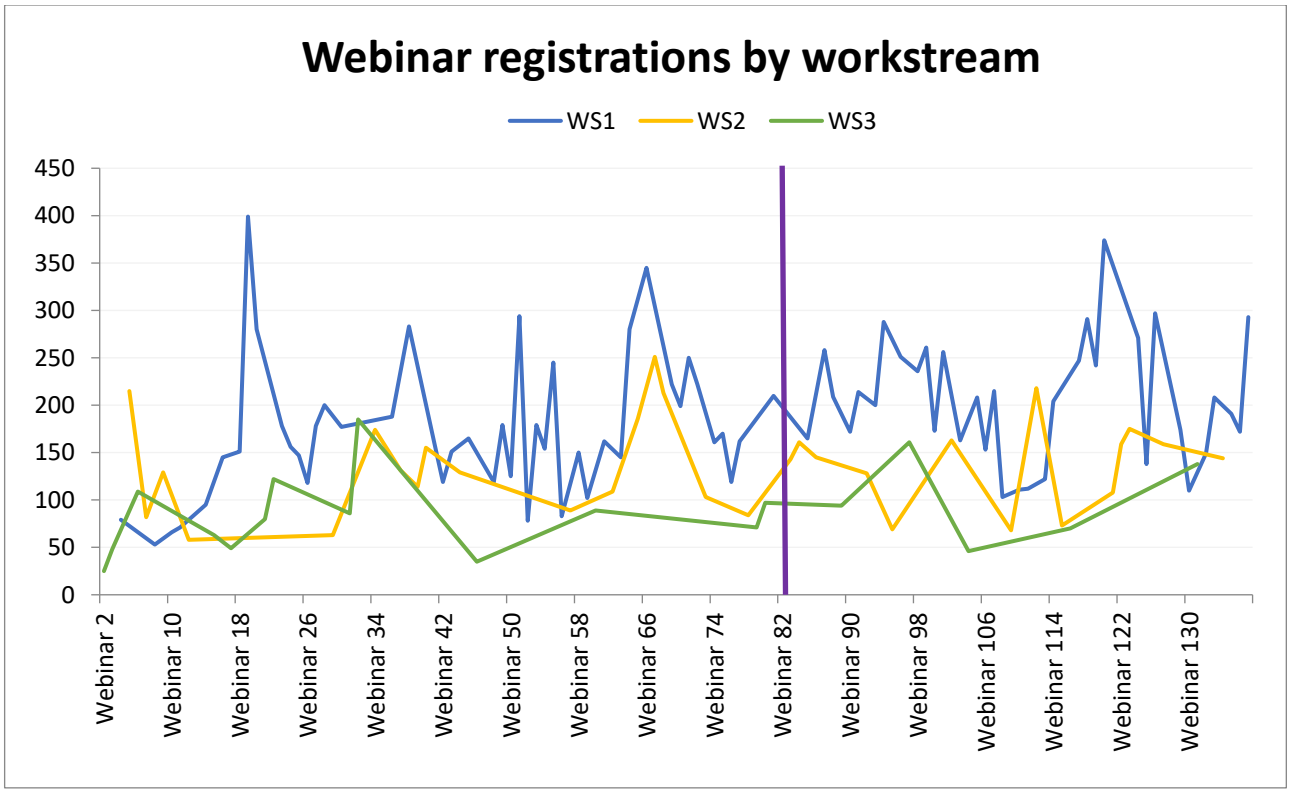
Figure 3: Registrations to the ERN eUROGEN Webinar Programme (November 2019 to November 2025)

[1] This is based on individual email addresses, and thus may double-count people who have registered with different email addresses.



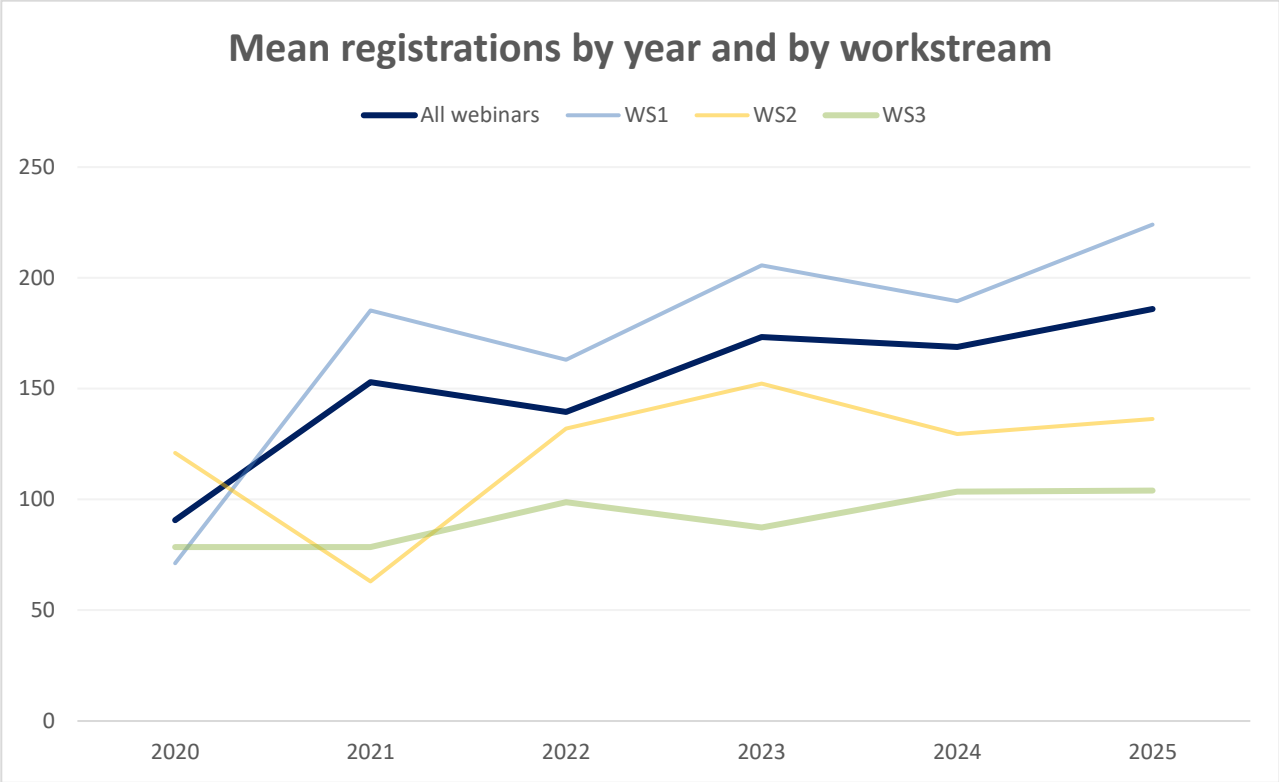
- Figure 4 below helps explain the variability seen in Figure 3. Whilst each Workstream shows variation, it can clearly be seen that each Workstream typically operates at a different level of registrations. These trends also appear relatively flat.

Figure 4: Registrations to the ERN eUROGEN Webinar Programme by Workstream (November 2019 to November 2025)



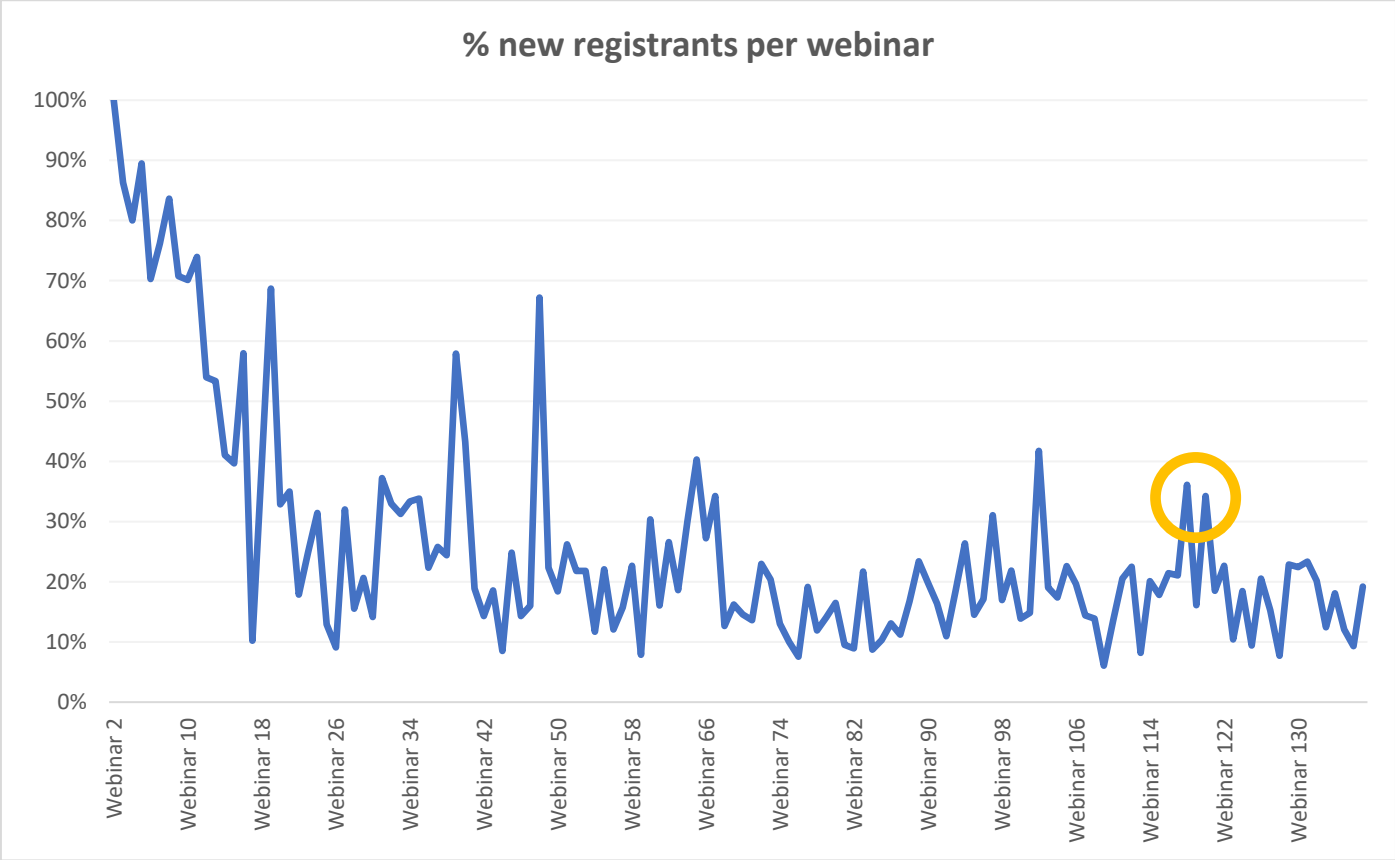
- Figure 5 below tries to provide a better view of what is happening year by year. This shows that there has been an overall increase in mean registrations in 2025 to their highest level, following a slight fall from 2023 to 2024.

Figure 5: Mean Registrations to the ERN eUROGEN Webinar Programme by Workstream and year (November 2019 to November 2025)



- Figure 6 below shows the percentage of first-time registrants for each webinar. As expected, the percentage falls sharply during the first year, and has now settled now typically to between 10% and 30%, with the odd exception. Focusing on the two spikes for recent webinars (circled), Webinar 118 related to paediatric kidney transplantation (EA 1.8), an area that has only been covered three times in total (see Figure 1 above), whilst Webinar 120 was part of our colorectal series and focused on a topic within the remit of ERN ERNICA. Therefore, it ius unsurprising that both attracted a slightly different audience compared to other webinars in that period.

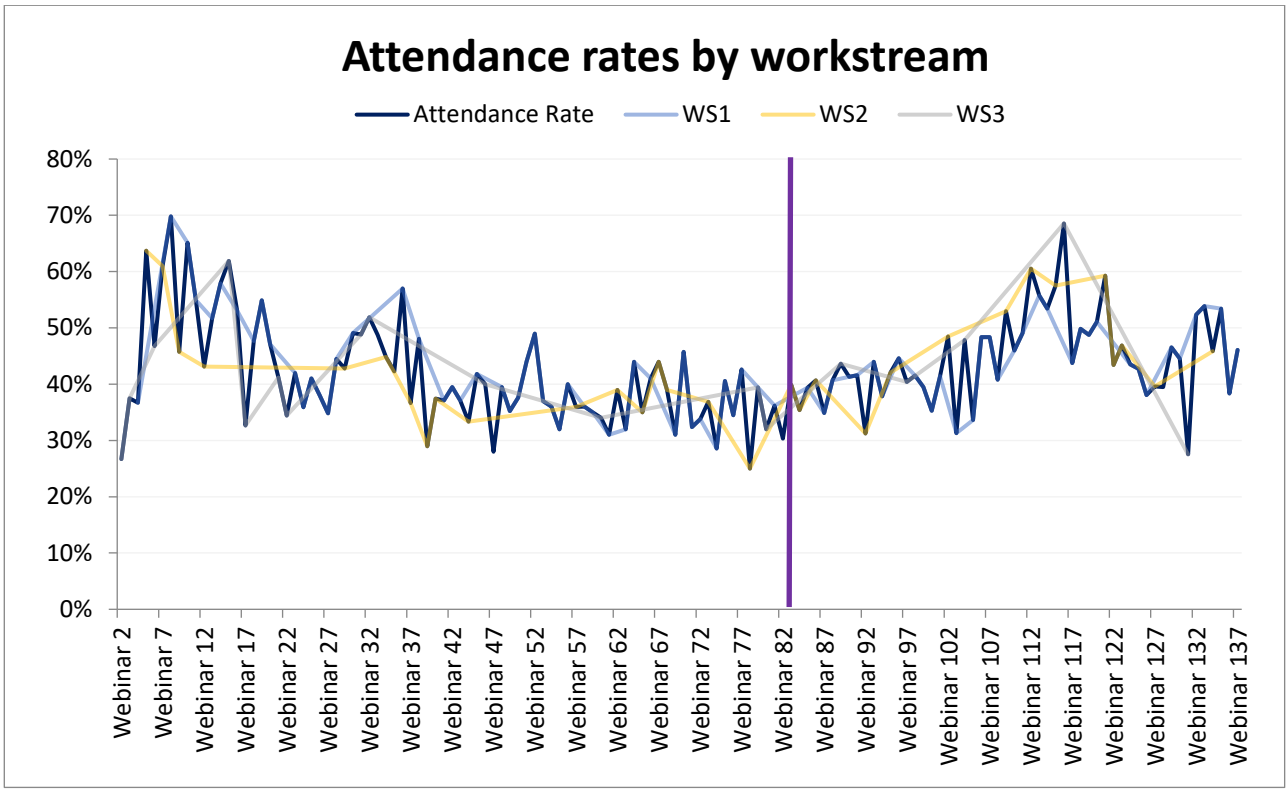
Figure 6: The Percentage of First-Time Registrants for each ERN eUROGEN Webinar (November 2019 to November 2025)



2.2. Attendance Rates

- Figure 7 below shows that attendance rates fell steadily up until the start of the grant period, after which they began to increase once again. Whilst this level has fallen back once more, the current levels are often above 50%. It is difficult to determine the reasons for this. The graph also shows that this trend is followed by all three workstreams.
- The decline shown from 2019 to 2023 may well have been a result of registrants becoming familiar with the fact that the recordings would be available the next working day, and that, if they had registered, they would receive a direct email with the YouTube link from the ERN eUROGEN Webinar Team. Of course, if they had subscribed to our YouTube channel, this would be unnecessary for them, and thus the suggested cause is purely speculative.
- In terms of the increase, this does not start at the beginning of the grant period (designated by the vertical line), but slightly later - around June 2024. ERN eUROGEN started to accredit its webinars September 2023, and thus this may not explain the later rise in live attendees (as this is the only way to receive a credit), though it is possible that it took time for registrants to become of the change. Another possibility, driving the higher rates from October 2024 is the switch from GoToWebinar to Zoom. As shown in Section 1.2 above, the change has been a positive one in the eyes of our registrants.

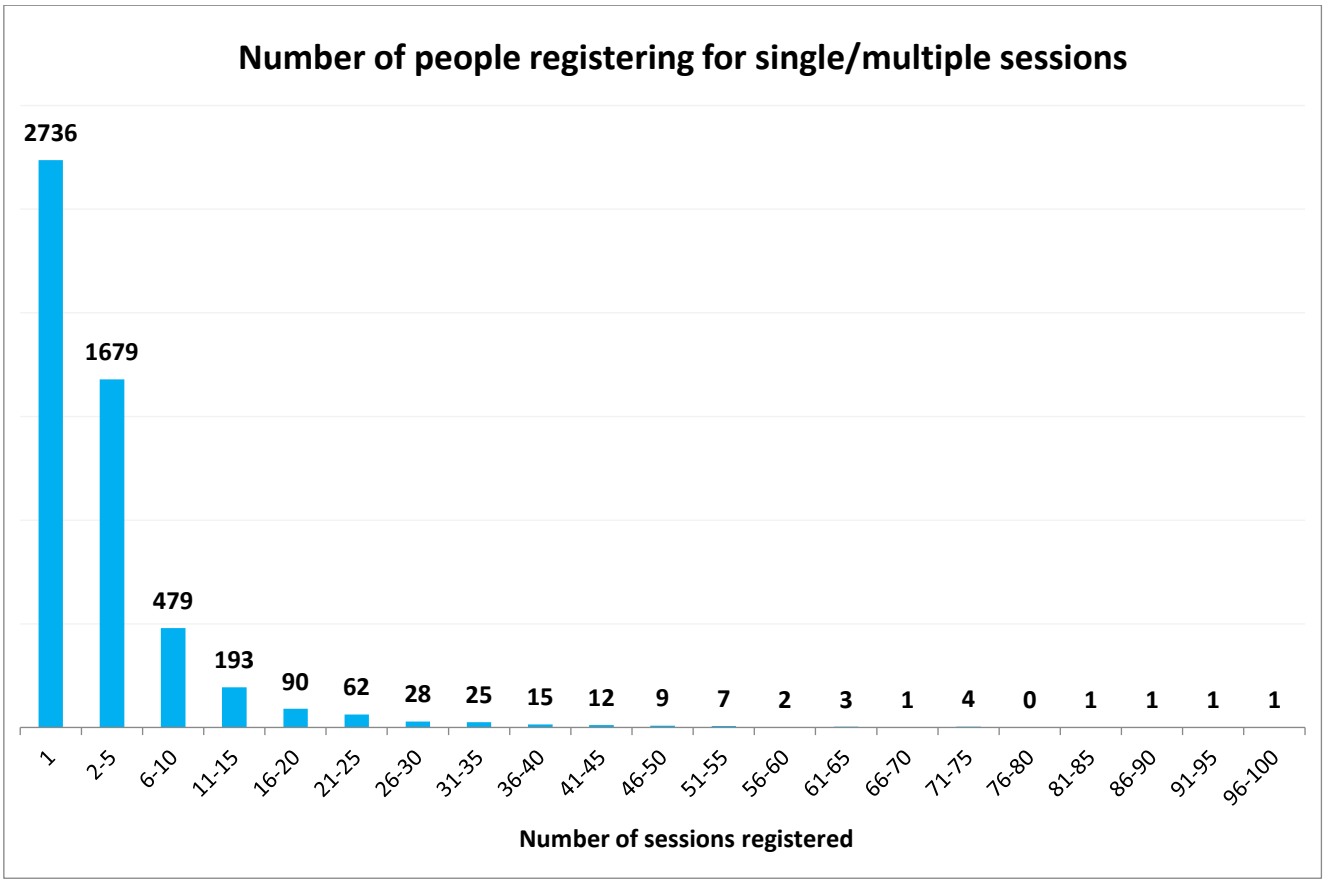
Figure 7: ERN eUROGEN Webinar Programme Attendance Rates (November 2019 to November 2025)



2.3. Repeat registrations and attendances

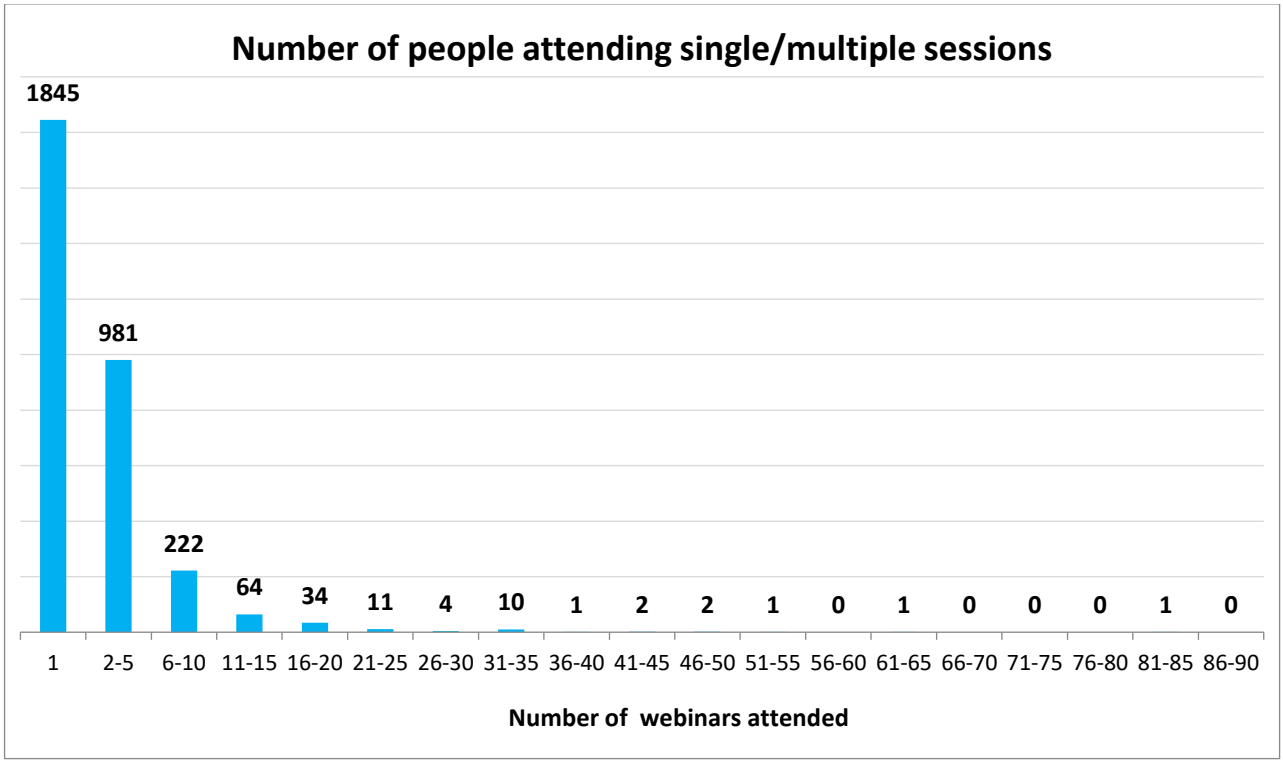
- One measure of our success is the number of people that register for and attend multiple webinar sessions. Figure 8 shows the number of individuals by the number of sessions for which they have registered (whether they attended live or not).
- Out of a total of 5,349 registrants, over 2,700 of them (51%) have only registered for one session. However, of the remaining half, over 450 (9%) of people have registered for 11 webinars or more, and twenty have even registered for more than 50 of our 137 sessions.

Figure 8: Number of Individuals by number of sessions for which they registered



- In terms of repeat attendance, Figure 9 shows a similar breakdown. Out of a total of 3,179 attendances, over 1,800 of them (58%) have only attended one session. However, of the remaining 42%, over 130 people have attended 11 webinars or more, with one individual attending more than 80 sessions!

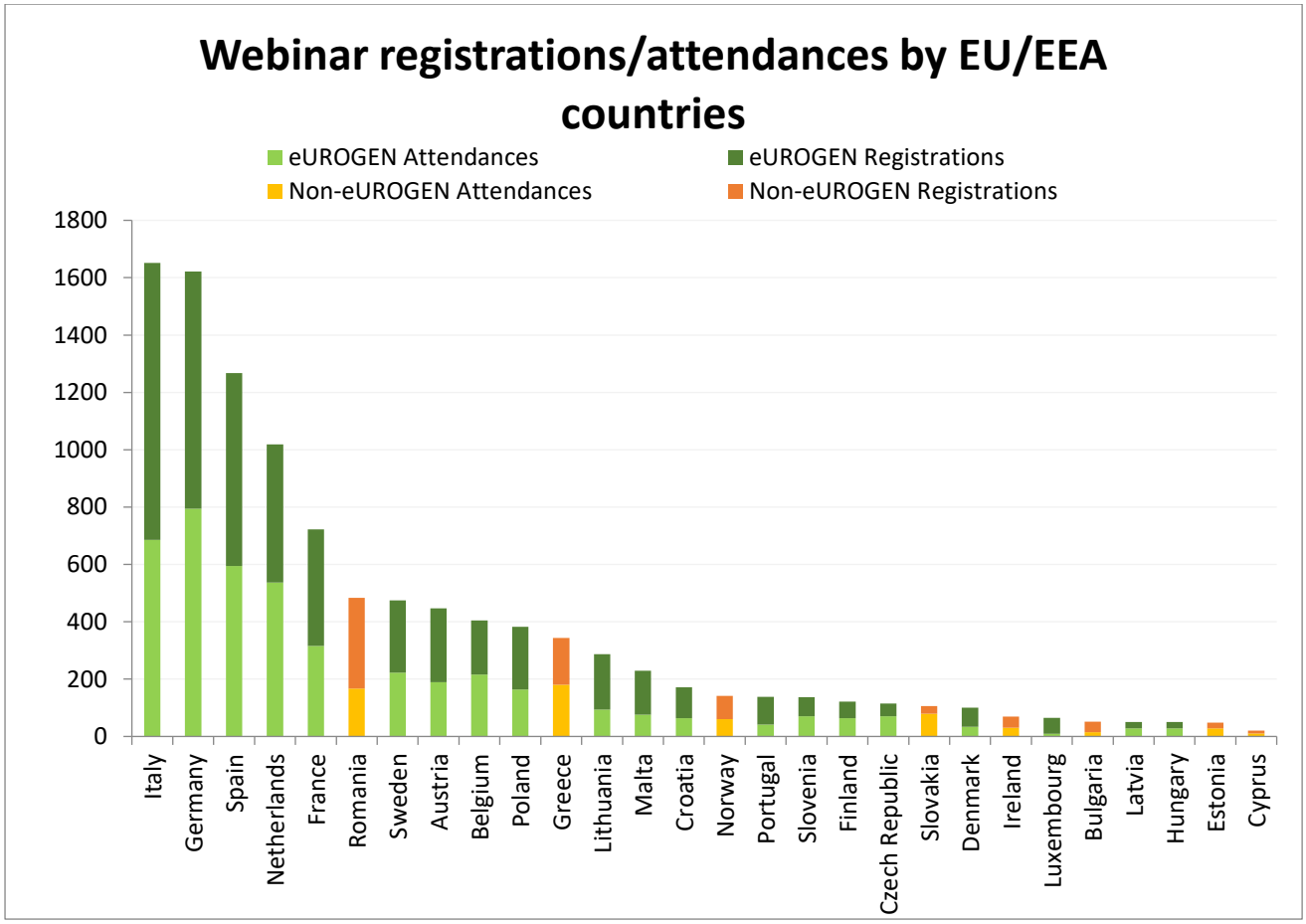
Figure 9: Number of Individuals by number of sessions they attended



2.4. Geography of registrants and attendees

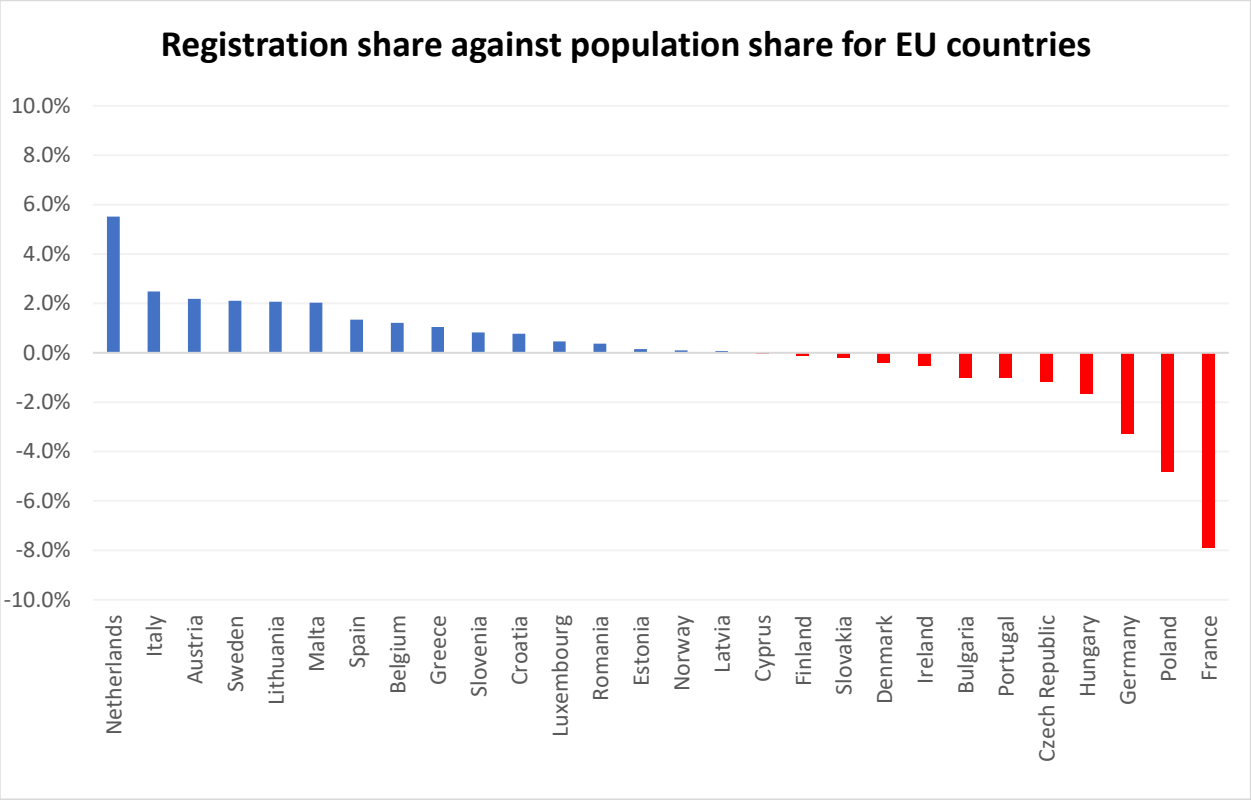
- Figure 10 shows the volume of registrations and attendees by EU country, differentiated by whether there is a current ERN eUROGEN member from that member state.

Figure 10: Registrations, Attendances, & Attendance Rates by Country (November 2019 to November 2025)



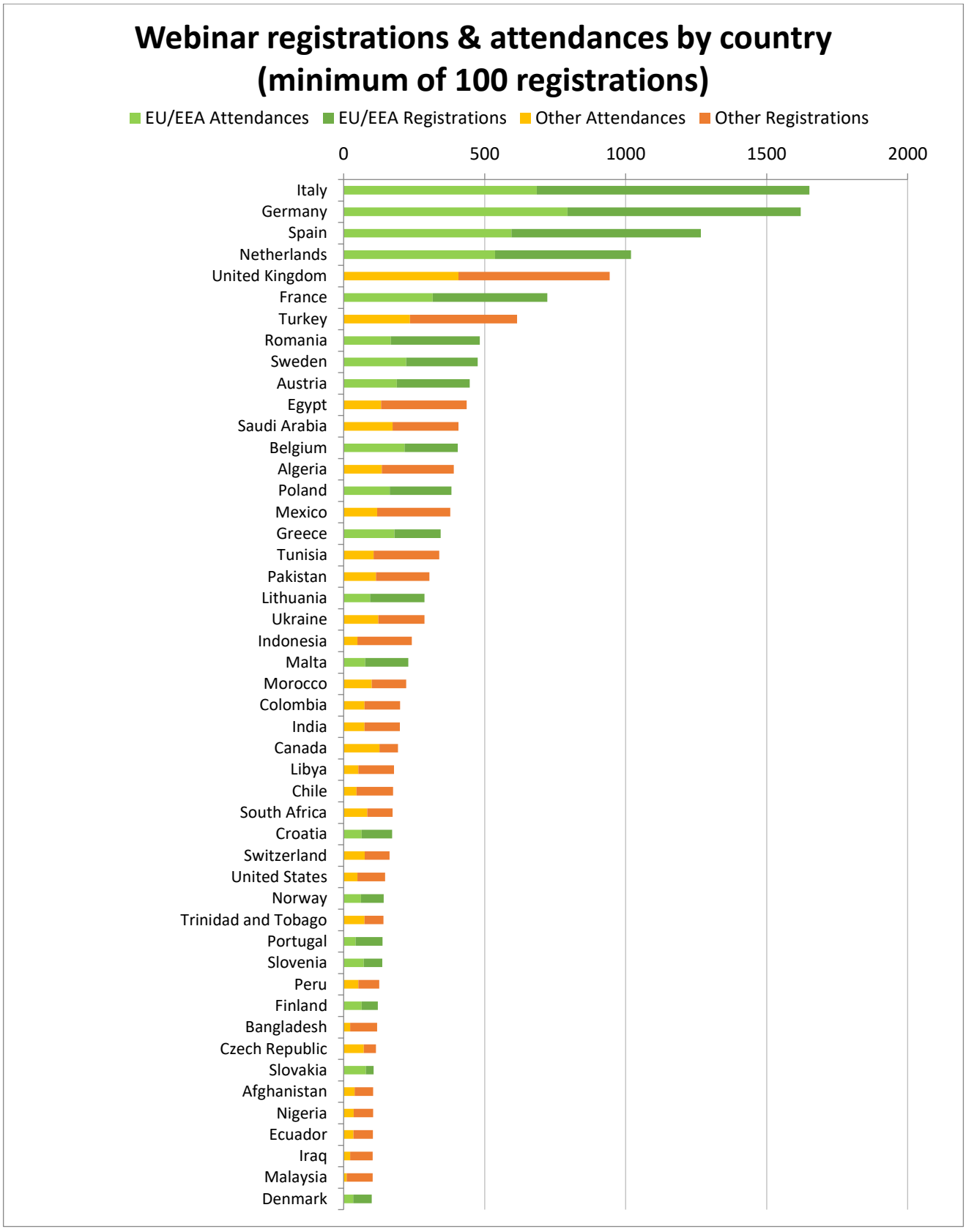
- However, Figure 11 below compares the share of registrations amongst EU countries against the share of their population. This shows, for example, that Germany has actually had fewer registrations than one might expect, and that France has even greater disparity, which is likely to be the result of a language barrier. Conversely, the Netherlands have had far more registrations compared to their population.
- This could help us to decide where we need to work more through particular national societies to make them more aware of the webinar series.

Figure 11: Share of registrations between EU countries compared to their population share (November 2019 to November 2025)



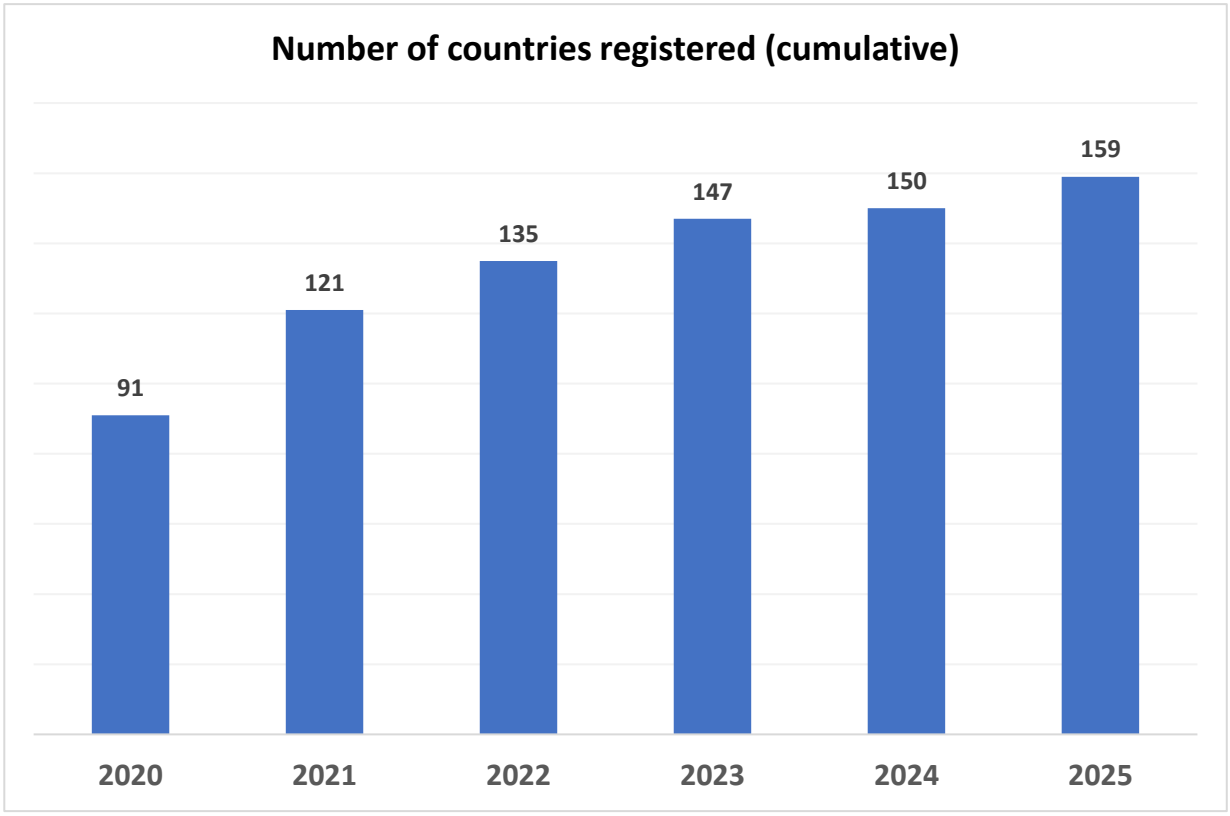
- Figure 12 below shows the registrations and attendances for all countries that have recorded at least 100 registrations. As expected, the highest registrations come from the major EU countries, plus the UK and Turkey.
- Outside of Europe, there are a high number of registrations from Egypt, Saudi Arabia, Algeria, and Mexico.

Figure 12: Registrations, Attendances, & Attendance Rates by Country (November 2019 to November 2025)



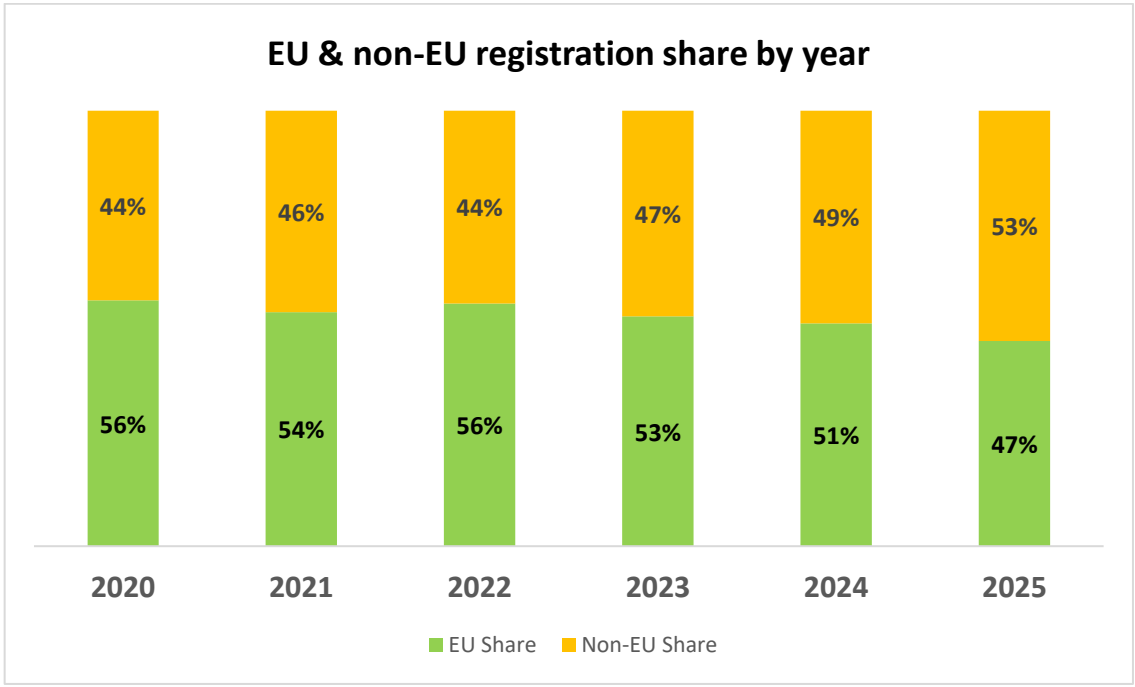
- Figure 13 shows that, as of the end of November 2025, there have been registrations from 159 countries over the life of the programme, although, technically, some of the options available, for example French Polynesia and Mayotte, are not officially countries.

Figure 13: Number of countries with at least one registration by year (2020 to 2025, cumulative)



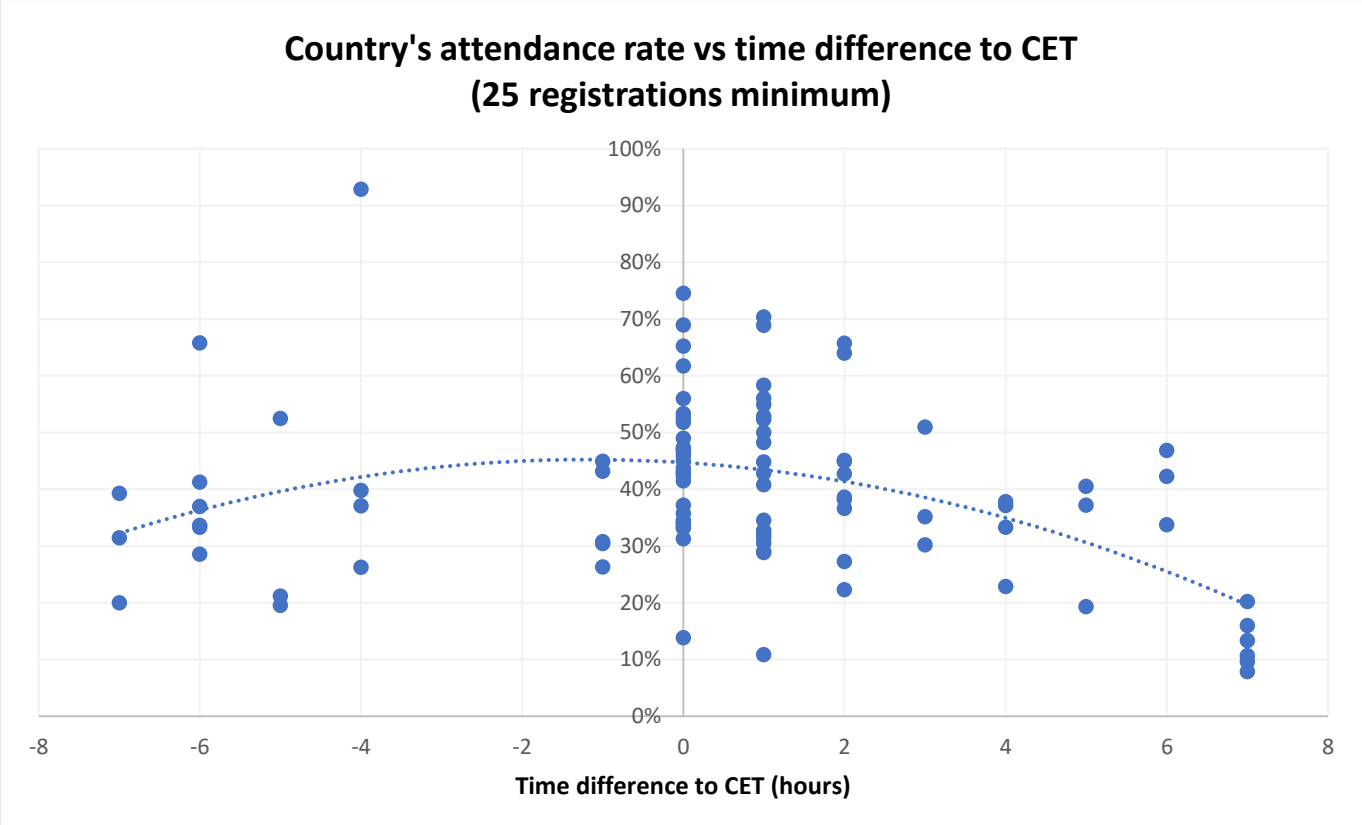
- Figure 14 looks at the share of registrations between EU and non-EU countries. The graph clearly shows that non-EU registrations have increased in share for the last three years, and notably accounted for 53% of all registrations in 2025. It is certainly true that registrations have been made from more and more countries each year.

Figure 14: Share of registrations between EU and non-EU countries (2020 to 2025)



- Figure 15 looks at the attendance rates for each country with at least 25 registrations and compares this to their time zone difference in hours from Central European Time (CET). As one would expect, countries that are 7 hours ahead of CET all have a relatively low rate of attendance. However, two countries also have a very low rate even though one is on CET (Luxembourg) and the other is only one hour ahead (Zambia). Again, it may be useful for us to work push the webinar series with the former, as well as the Affiliated Partner HCP-member of ERN eUROGEN from that country.

Figure 15: The attendance rate of each county with at least 25 registrations vs its time zone difference to CET (November 2019 to November 2025)



3. YOUTUBE CHANNEL

3.1. Background

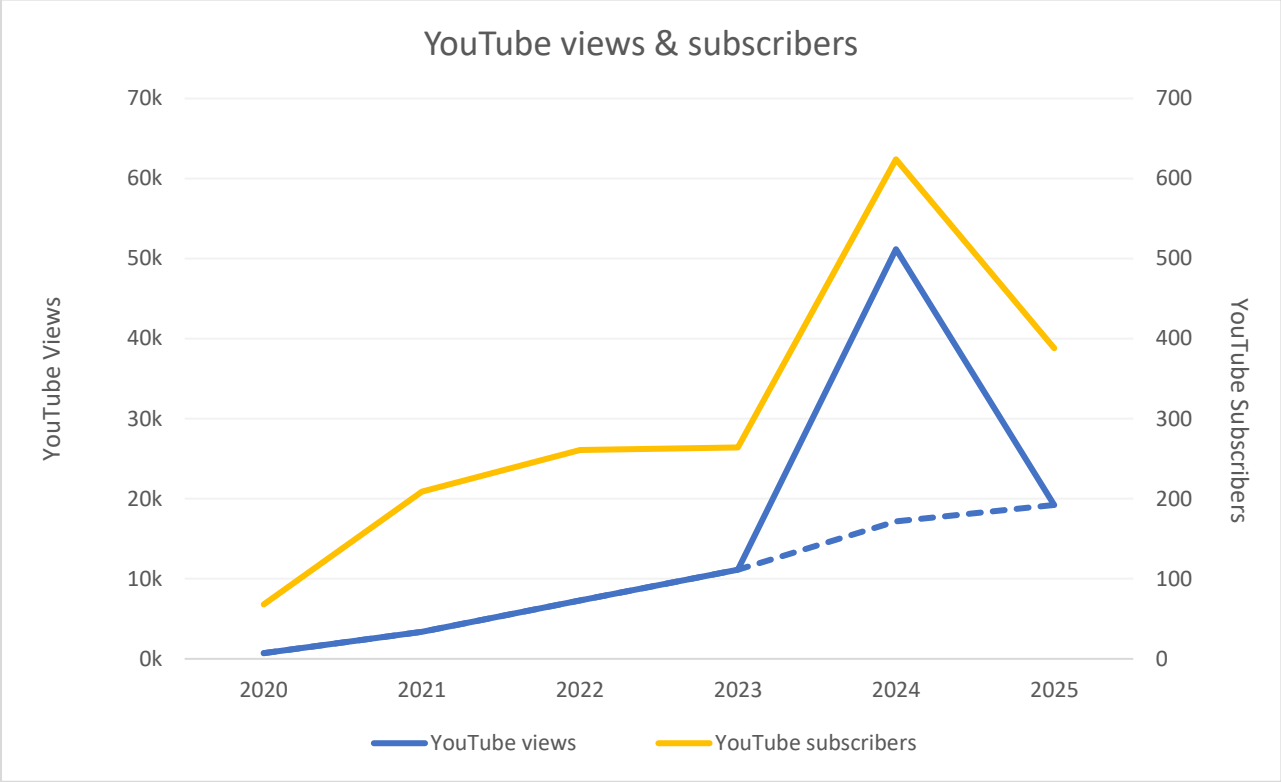
- The ERN eUROGEN YouTube channel was started in June 2020, with earlier webinars being retrospectively uploaded. As mentioned earlier, almost all of our webinars are published on the channel, with only 5 sessions not having been uploaded to the site (due to the clinicians involved not wishing to allow unrestricted access to the material). A few other non-webinar videos are also available, but, for ease, these have been included in the data below, as are views etc. for the Ukraine webinar series, which is otherwise examined in Section 5.

3.2. Views & Subscribers

- Figure 16 shows the volume of views of and subscribers to our YouTube channel. To date, we have about 95,000 total views and over 1,800 subscribers.
- The large increase in 2024 was due to video receiving very high views for 3 months. Currently, it has around 34,000 views in excess of what we might expect it to have. Therefore, the dotted line represents what the views trend would look like removing those additional views. This also drove a rapid increase in subscribers.

- Taking this into account, views have continued to grow in recent years, despite the fact that we are not increasing the number of webinars per year. However, views should naturally rise as there is an ever-growing library of content that new and existing subscribers can watch retrospectively.

Figure 16: YouTube views and subscribers (June 2020 to October 2025)



4. FEEDBACK – SESSION SURVEYS

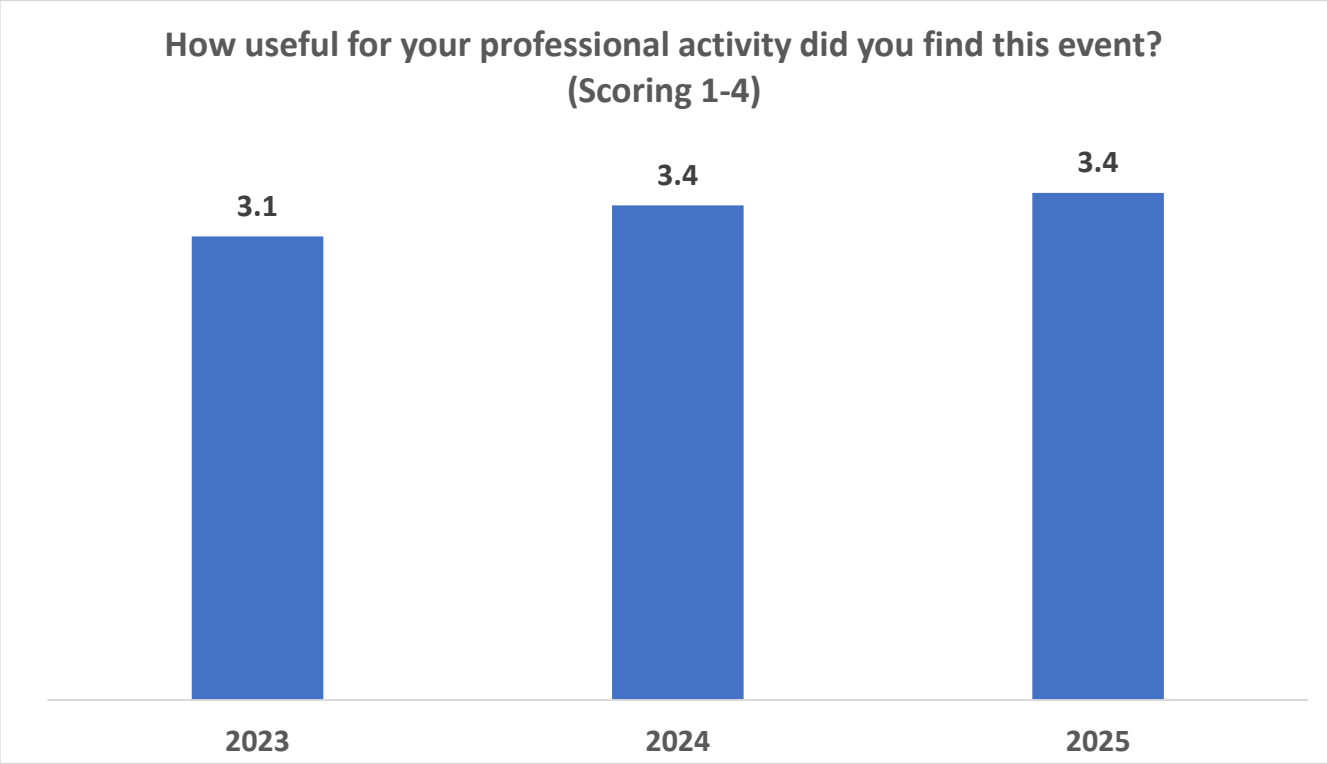
4.1. Introduction

- After each webinar, those who attended live receive a survey asking for their feedback. This is optional to complete, but must be done in order to receive one's accreditation certificate for that event.
- The questions have been changed over the course of the programme, particularly after we began to accredit the webinars as certain questions were required in order for us to feedback to EACCME.
- The sections below go through the results for the most relevant questions in the current survey for the most recent year and, where applicable, previous years.

4.2. Usefulness for professional activity

- This question was reformulated after the start of accreditation, and changed from a 1-5 score to a 1-4 score. Therefore, ratings for 2023 only start from mid-September 2023.
- It shows that we are maintaining the provision of useful support to attending clinicians.

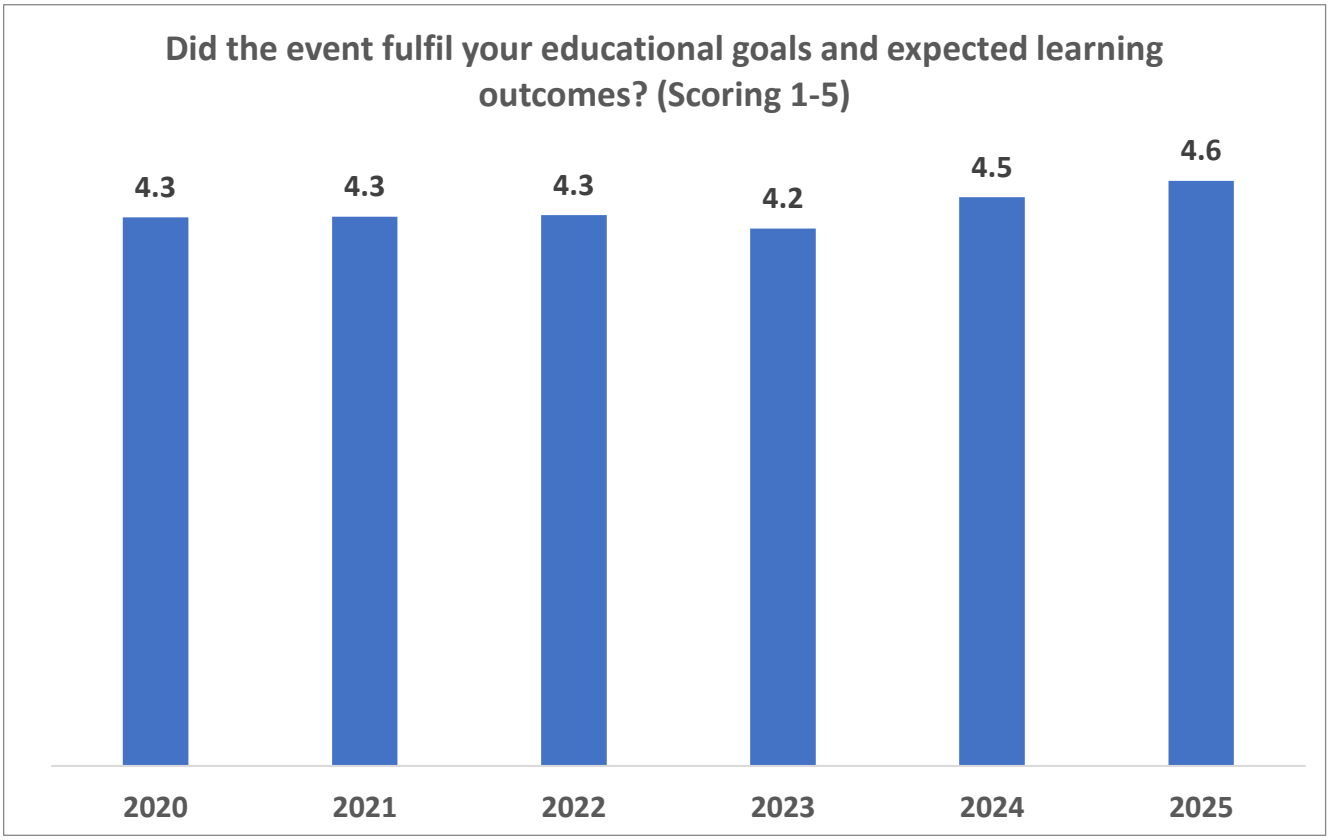
Figure 17: Webinar Survey Question 1: How useful for your professional activity did you find this event?



4.3. Fulfilling educational goals and expected learning outcomes

- We have seen an increase in the score for this question in the last two years.

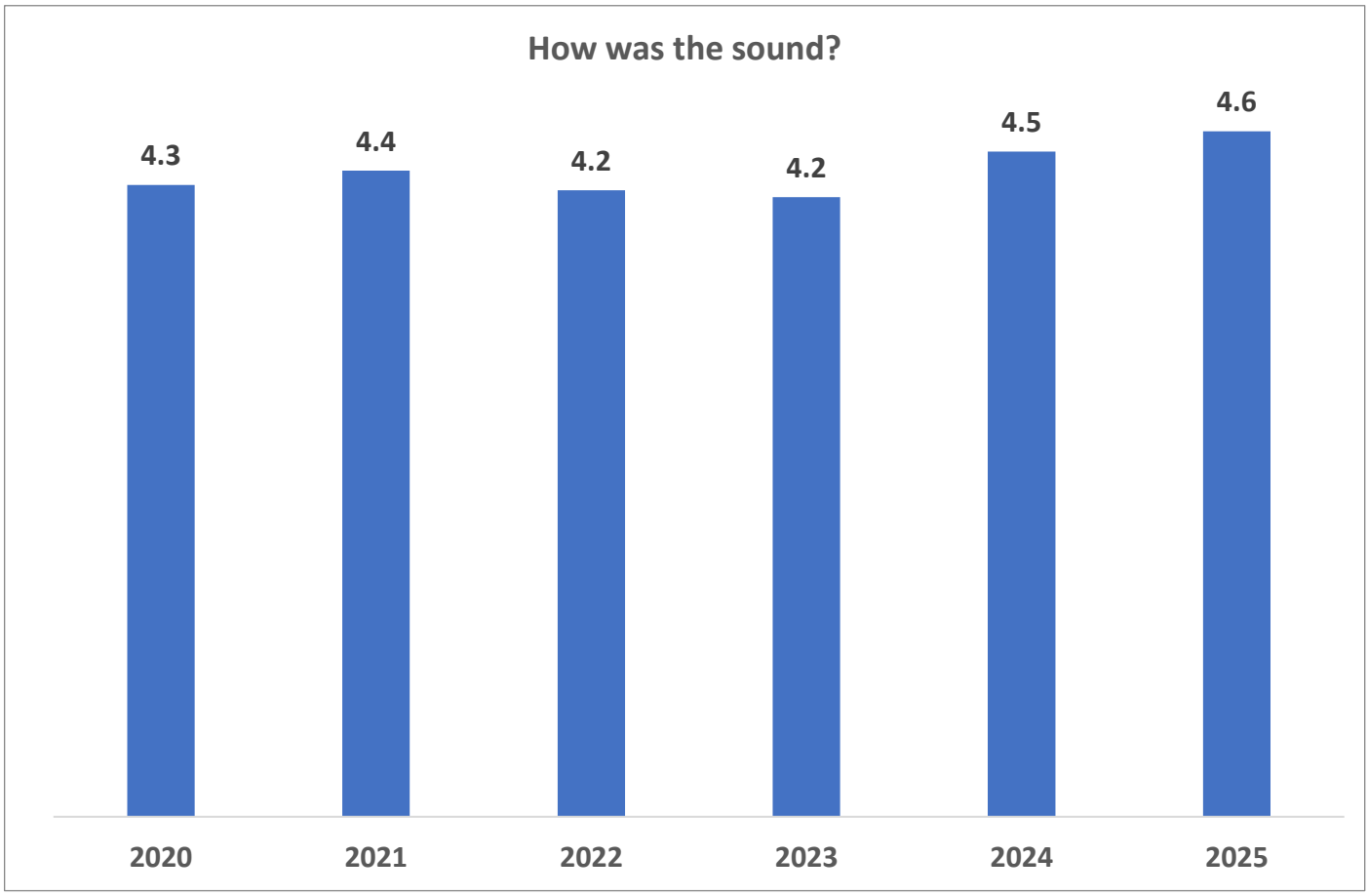
Figure 18: Webinar Survey Question 2: Did the event fulfil your educational goals and expected learning outcomes?



4.4. Quality of the sound

- Again, we have seen an increase in the score for this question in the last two years. It is coincident with the switch to using Zoom.

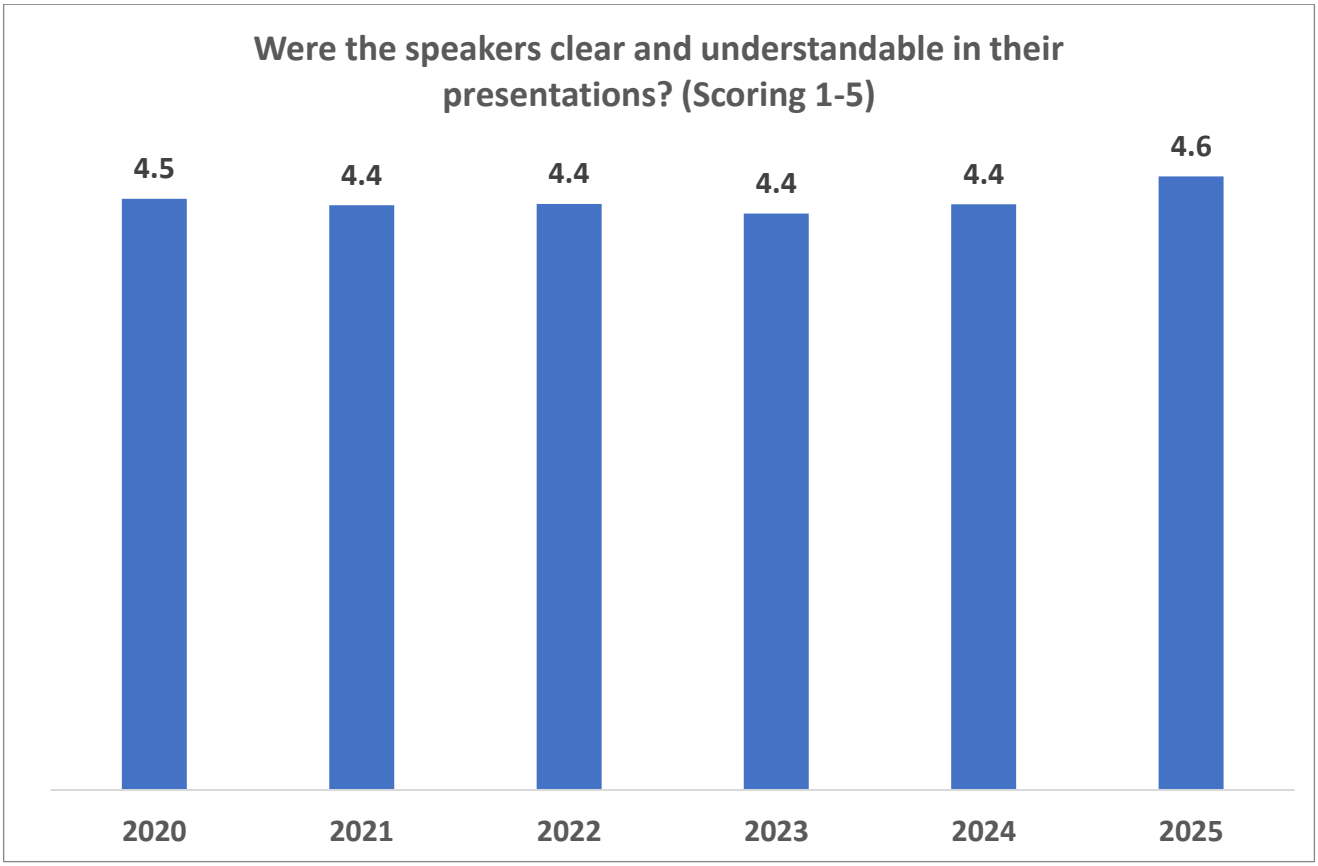
Figure 19: Webinar Survey Question 3: How was the sound?



4.5. Clear and understandable presentations

- As with the previous measures, 2025 has seen an increase to the highest rating so far. Again, this may be due to moving to a more stable platform, building on the improved audio.

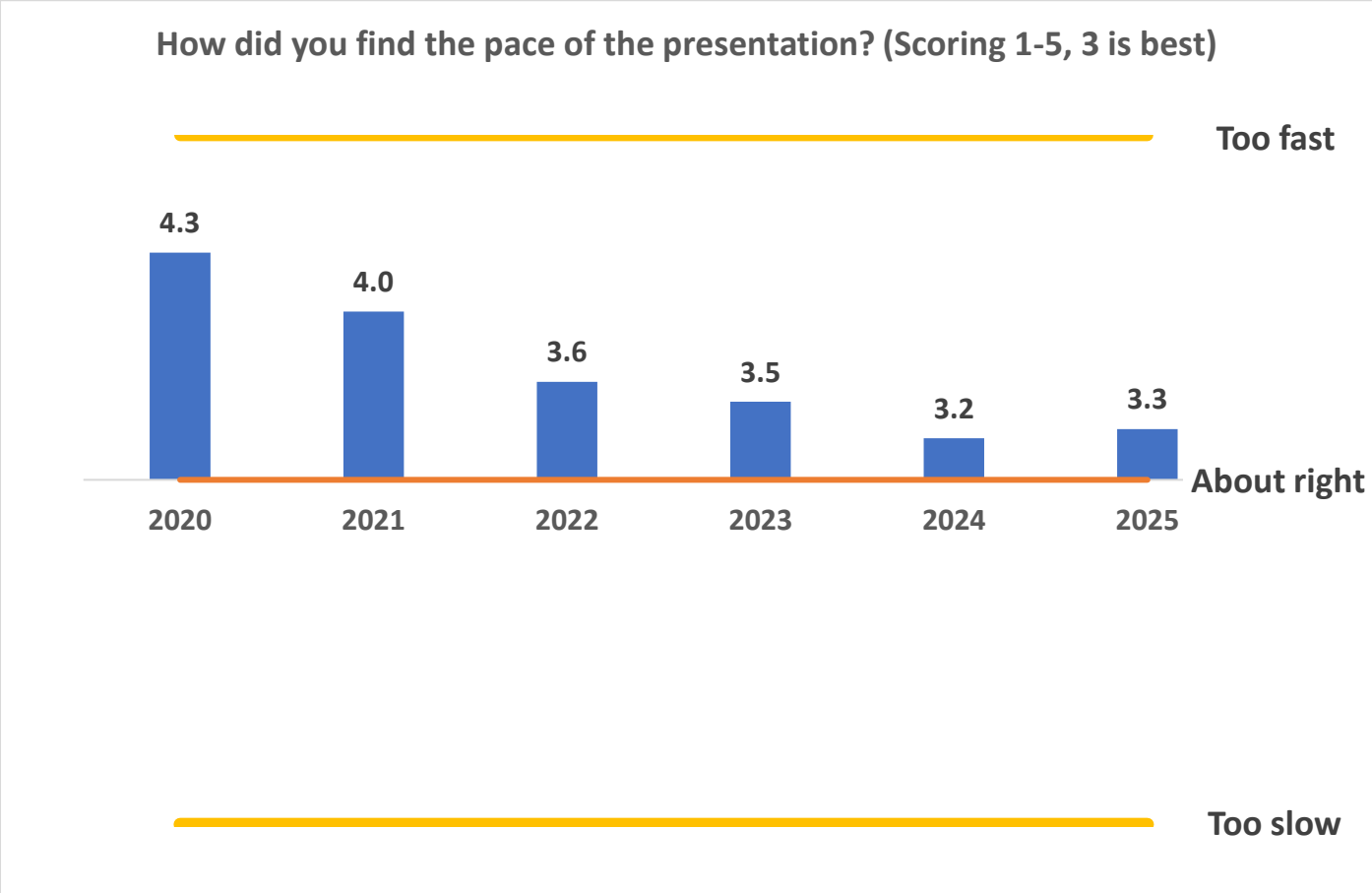
Figure 20: Webinar Survey Question 4: Were the speakers clear and understandable in their presentations?



4.6. Pace of the presentation

- The attendees' view of the pace of the webinar presentations has improved significantly over the years.

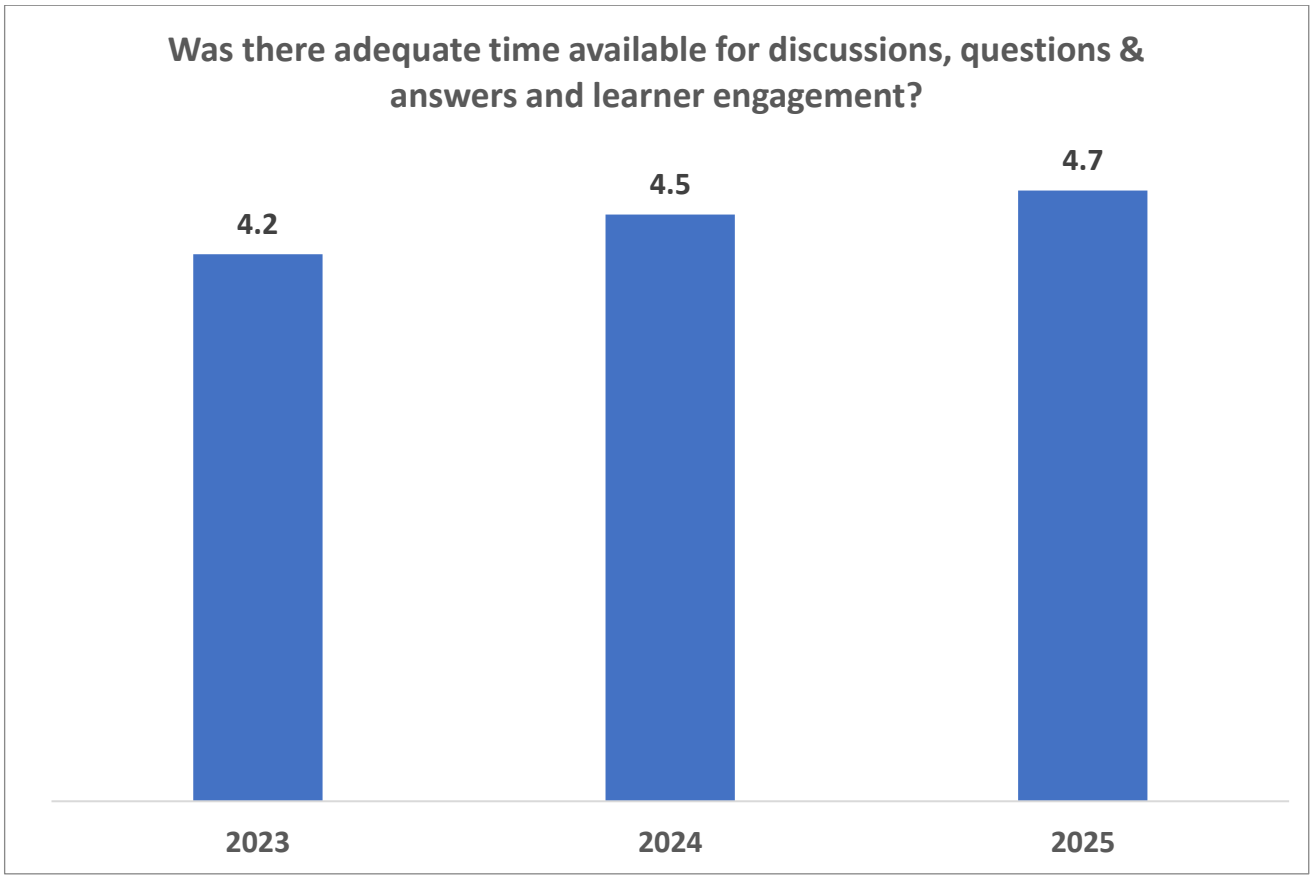
Figure 21: Webinar Survey Question 5: How did you find the pace of the presentation?



4.7. Time available for discussions, questions & answers, and learner engagement

- Once more, we have seen an improvement in the last year for the provision of time in the sessions for Q&A sessions.

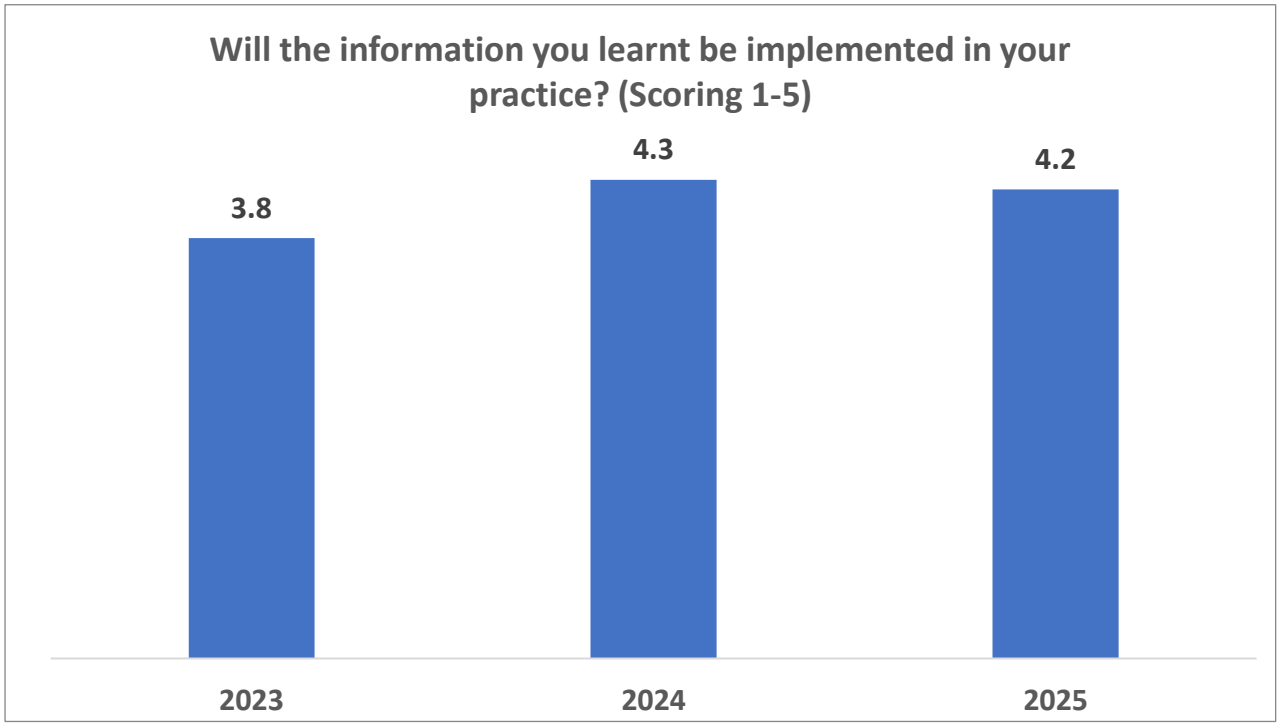
Figure 22: Webinar Survey Question 6: Was there adequate time available for discussions, questions & answers and learner engagement?



4.8. Information learned being implemented in practice

- This score is a little lower than most of the others, though it still shows an improvement from 2023 and is close to the score for 2024.

Figure 23: Webinar Survey Question 7: Will the information you learnt be implemented in your practice?

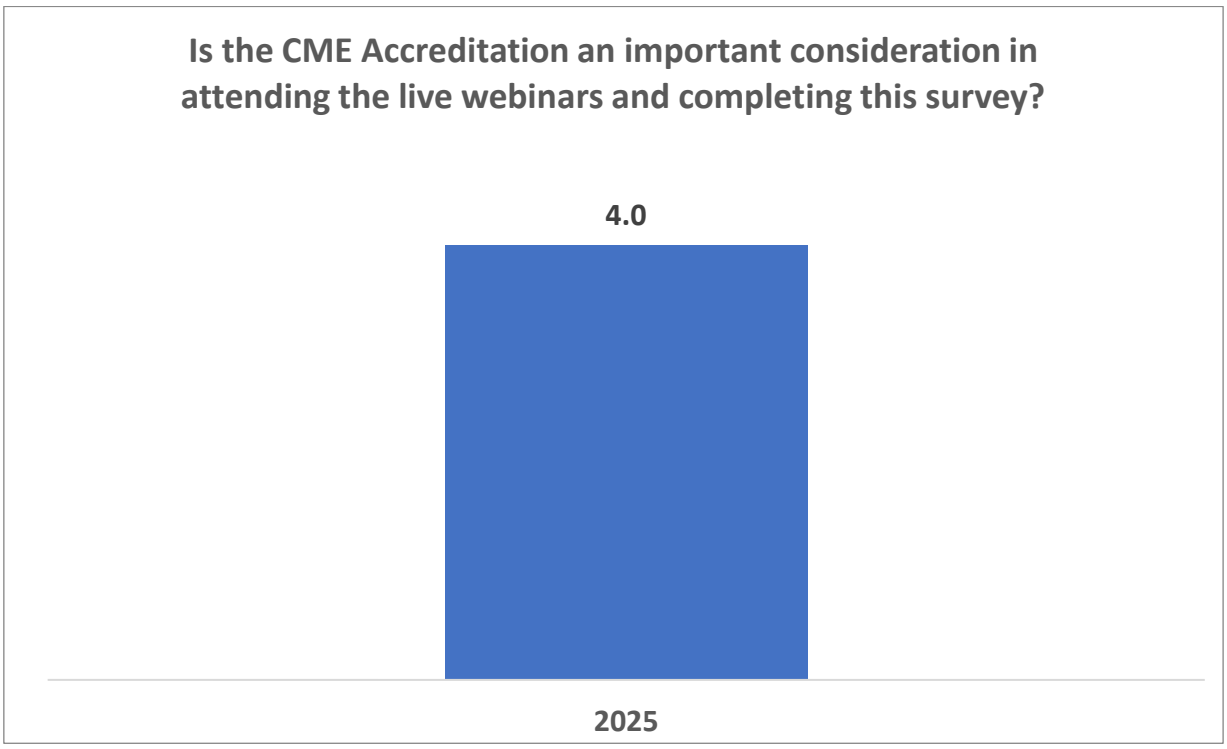


European Reference Networks
Funded by the European Union
European Reference Network for rare or low prevalence complex diseases
Network Urogenital Diseases (ERN eUROGEN)

4.9. Importance of accreditation

- We recently included this question in the survey. It should be noted that we also included this question in the annual survey (see Section 5.6) as the session survey is likely to be biased in favour of accreditation. This is because receiving the survey is dependent upon live attendance, which is also a stipulation for receiving the EACCME credit.

Figure 24: ERN eUROGEN Webinar Survey Question 10: Is the CME Accreditation an important consideration in attending the live webinars and completing this survey?



5. FEEDBACK – ANNUAL SURVEY

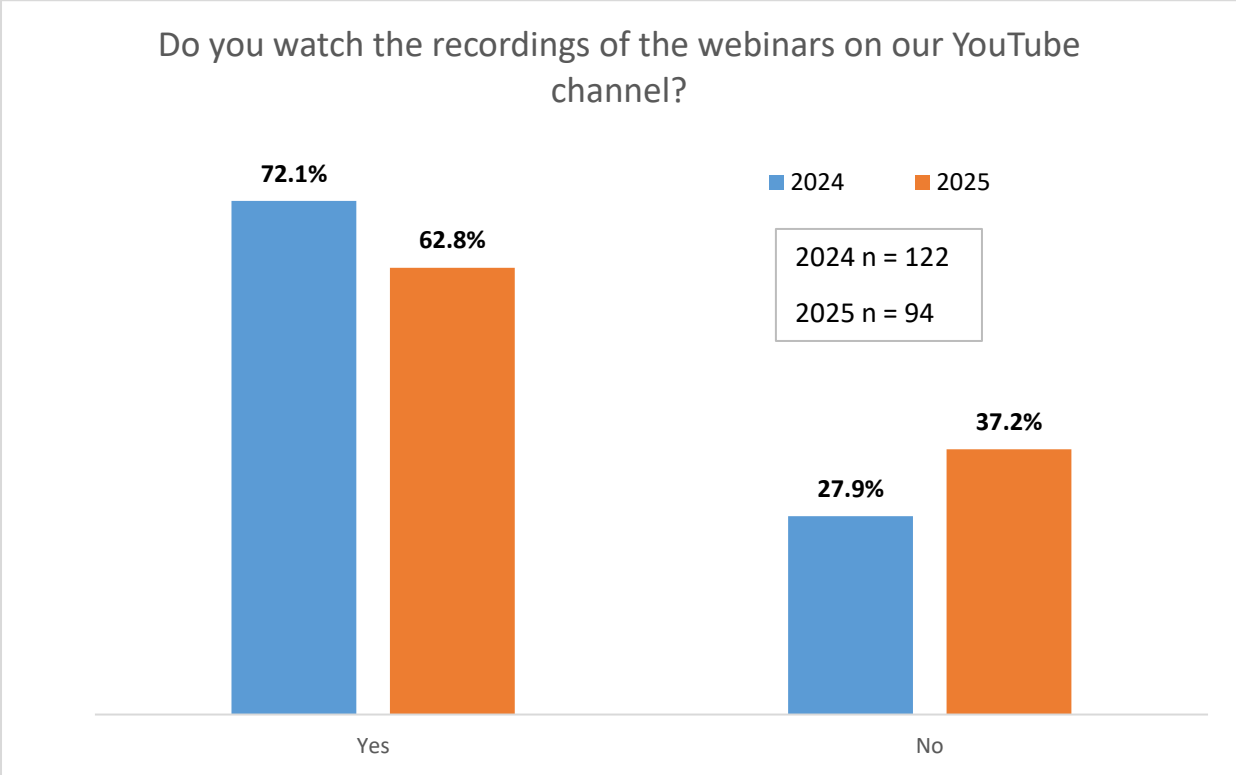
5.1. Introduction

- The annual webinar survey was first issued in 2024 when we received 122 responses. In 2025, we received 95 responses.
- The survey is sent to all previous registrants.
- The results below compare 2024 and 2025 where possible. Additional questions were added for 2025, and others removed.

5.2. Webinar recordings

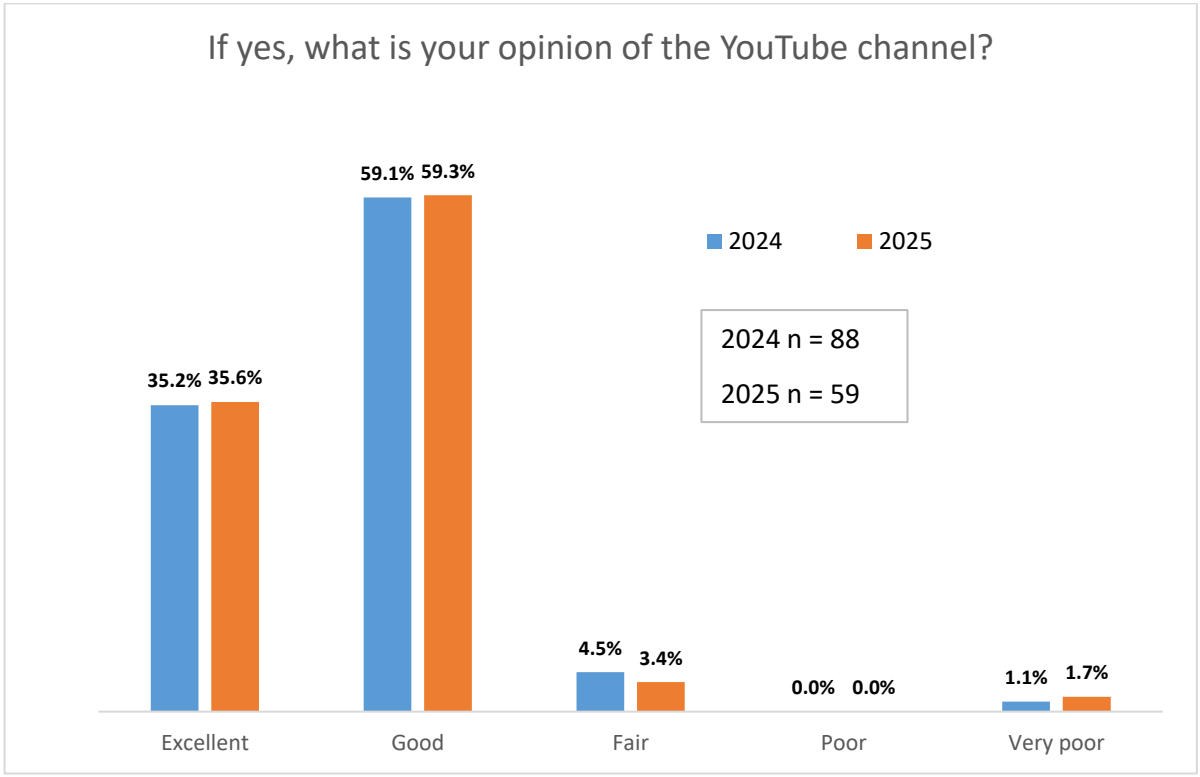
- Figure 25 shows that around two-thirds of our respondents do watch the webinar recordings through our YouTube channel, although there is a percentage fall in 2025. It will be interesting to see if this falls again in 2026 or it is just natural variation.

Figure 25: Webinar Annual Survey Question 2: Do you watch the recordings of the webinars on our YouTube channel?



- Figure 26 clearly demonstrates that 95% of respondents rate the YouTube channel as Good or Excellent. This suggests that we do not need to look for an alternative platform or indeed make any major changes to the current set-up.

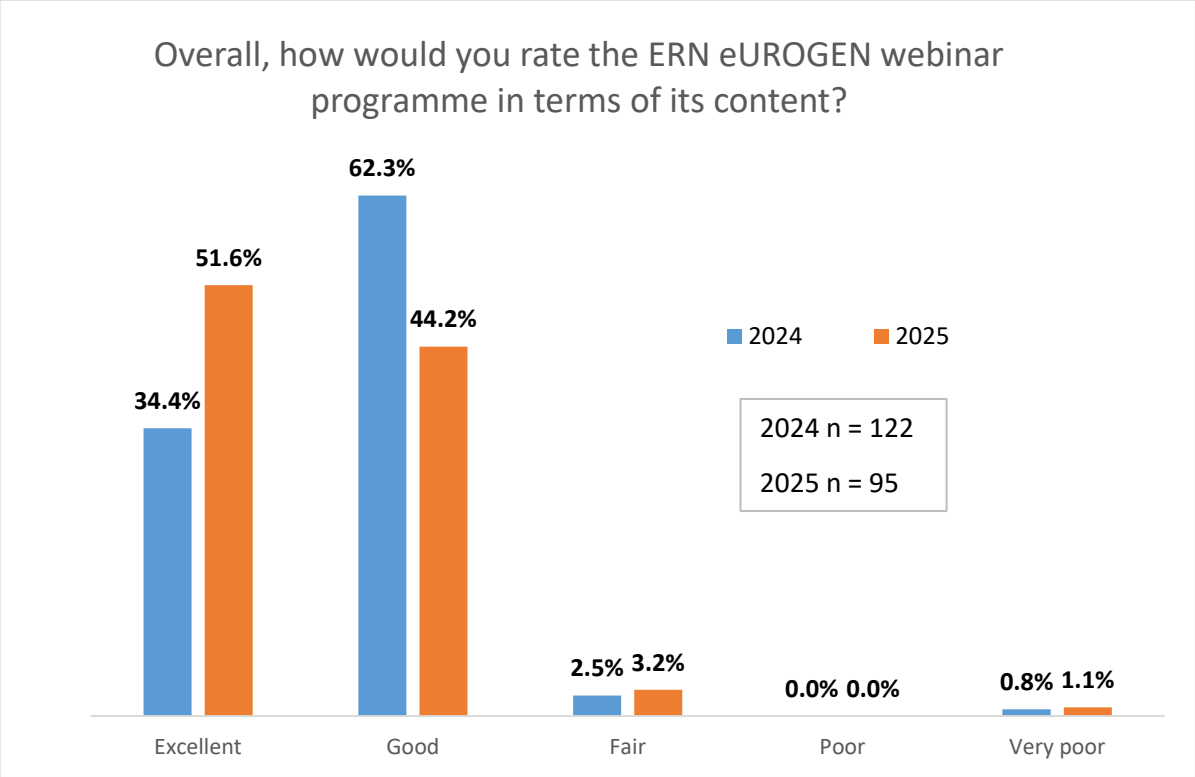
Figure 26: Webinar Annual Survey Question 2b: If yes, what is your opinion of the YouTube channel?



5.3. Overall view of the webinar programme

- Figure 27 shows that more than 95% of respondents rate the webinar programme as Good or Excellent. It is positive to see that there has been a large increase in the Excellent rating from 2024 to 2025.

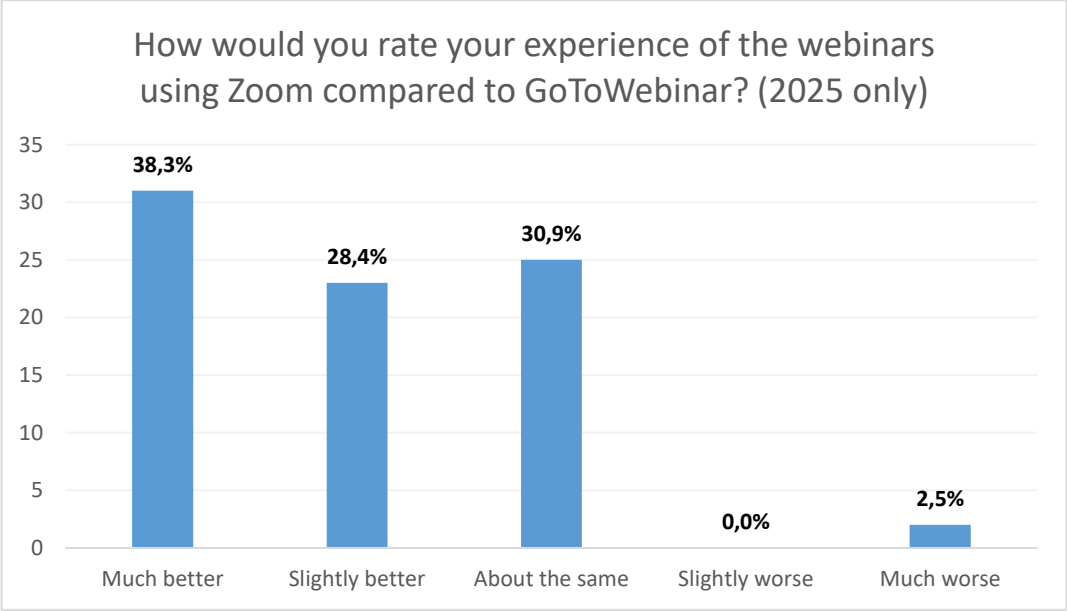
Figure 27: Webinar Annual Survey Question 3: Overall, how would you rate the ERN eUROGEN webinar programme in terms of its content?



5.4. Change of software

- Figure 28 suggests that this was a positive change, with the majority of respondents noting an improvement, and almost 40% of respondents rating the new platform as "much better". Only 2.5% of respondents viewed it as a negative step.

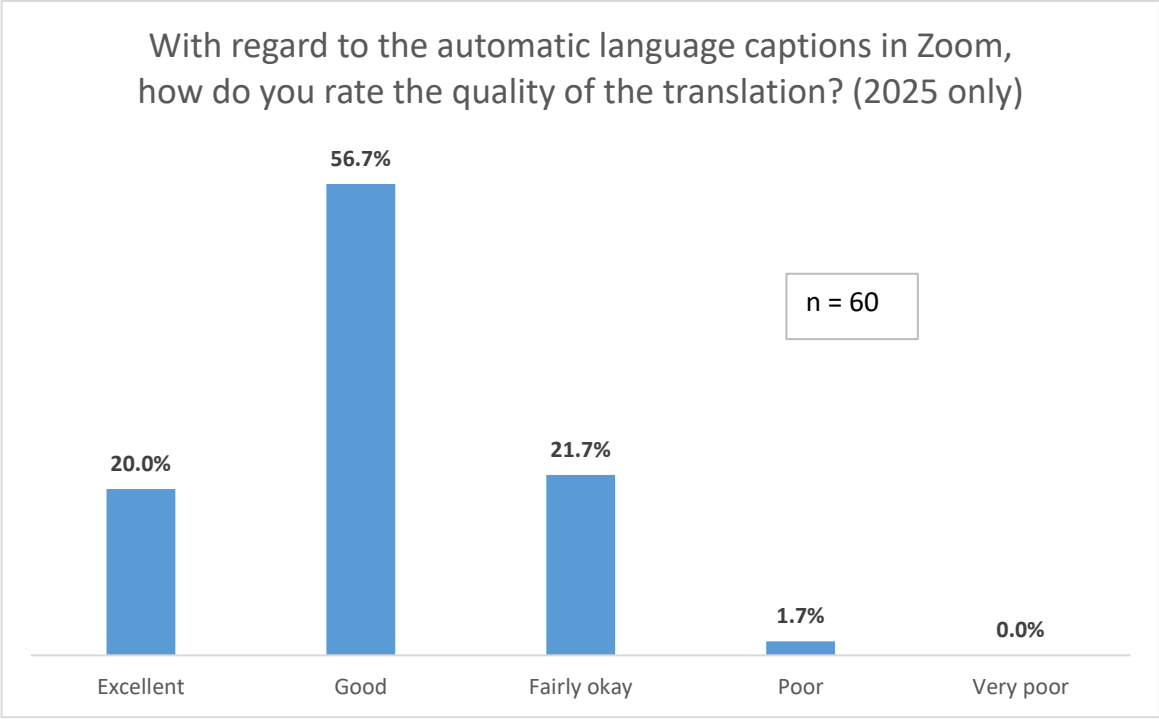
Figure 28: Webinar Annual Survey Question 3: Overall, how would you rate the ERN eUROGEN webinar programme in terms of its content?



5.5. Automatic captions

- One of the major reasons for swapping to Zoom as our webinar platform was the inclusion of automatic captions. Whilst these were ostensibly of use for our Ukrainian-focused sessions, they can be used by everyone else too.
- Figure 29 indicates that a clear majority of respondents (77%) rate the quality and accuracy of the captions as Good or Excellent, with less than 2% suggesting they are below par. 32 respondents indicated that they did not use automatic captions.

Figure 29: Webinar Annual Survey Question 5: How do you rate the quality of the translation via automatic captions?

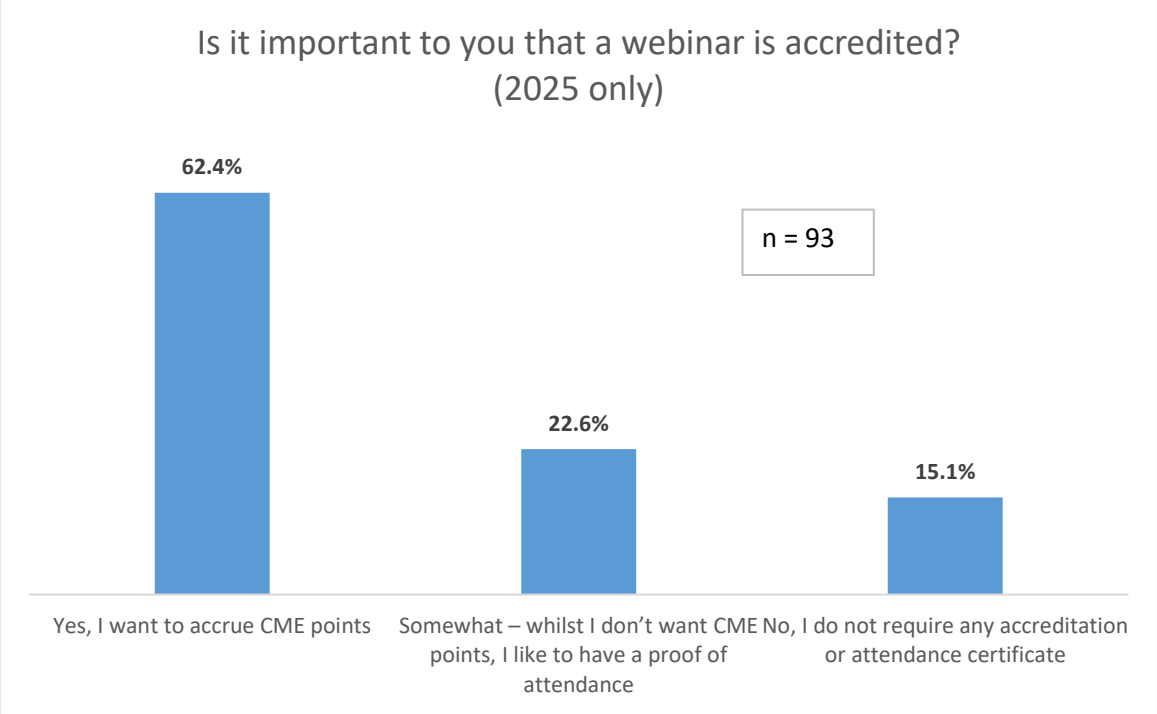


5.6. Importance of accreditation

- ERN eUROGEN began to accredit its webinars in September 2023.

- Figure 30 indicates tat accreditation is an important consideration for registrations and thus helps support live attendance. This also supports the rating given for this question in the session survey (see Section 4.9 above).

Figure 30: Webinar Annual Survey Question 9: Is it important to you that a webinar is accredited?



6. MISCELLANEOUS

6.1. Webinar advertising

- Figures 31 & 32 show how registrants say that they found out about our webinars. We reworked the categories at the end of September 2025 due to possible confusion over the categories, hence the two different graphs.
- For each session, we send out a dedicated mailshot to all previous registrants (eUROGEN registration email). We also include forthcoming sessions in the monthly ERN eUROGEN newsletter, as well as also having the registration links available on our website. Furthermore, all sessions are also advertised via our social media channels.
- Figure 31 seems to show that the monthly newsletter was the predominant way that people registered for sessions, and the dedicated mailshot was the next most popular. However, this seems a little surprising. And indeed, once we recast the labels for the options, the dedicated registration email becomes the most popular method, as shown in Figure 32, albeit from a much smaller sample size.
- Other notable takeaways are that the email and newsletter channels, along with the website, are all above the social media channels. In terms of the particular social media channels, Facebook appears to be the most used, followed by Instagram, and then LinkedIn. It is noticeable that social media channels have increased their share more recently.

Figure 31: How registrants found out about the webinar (June 2024 to September 2025)

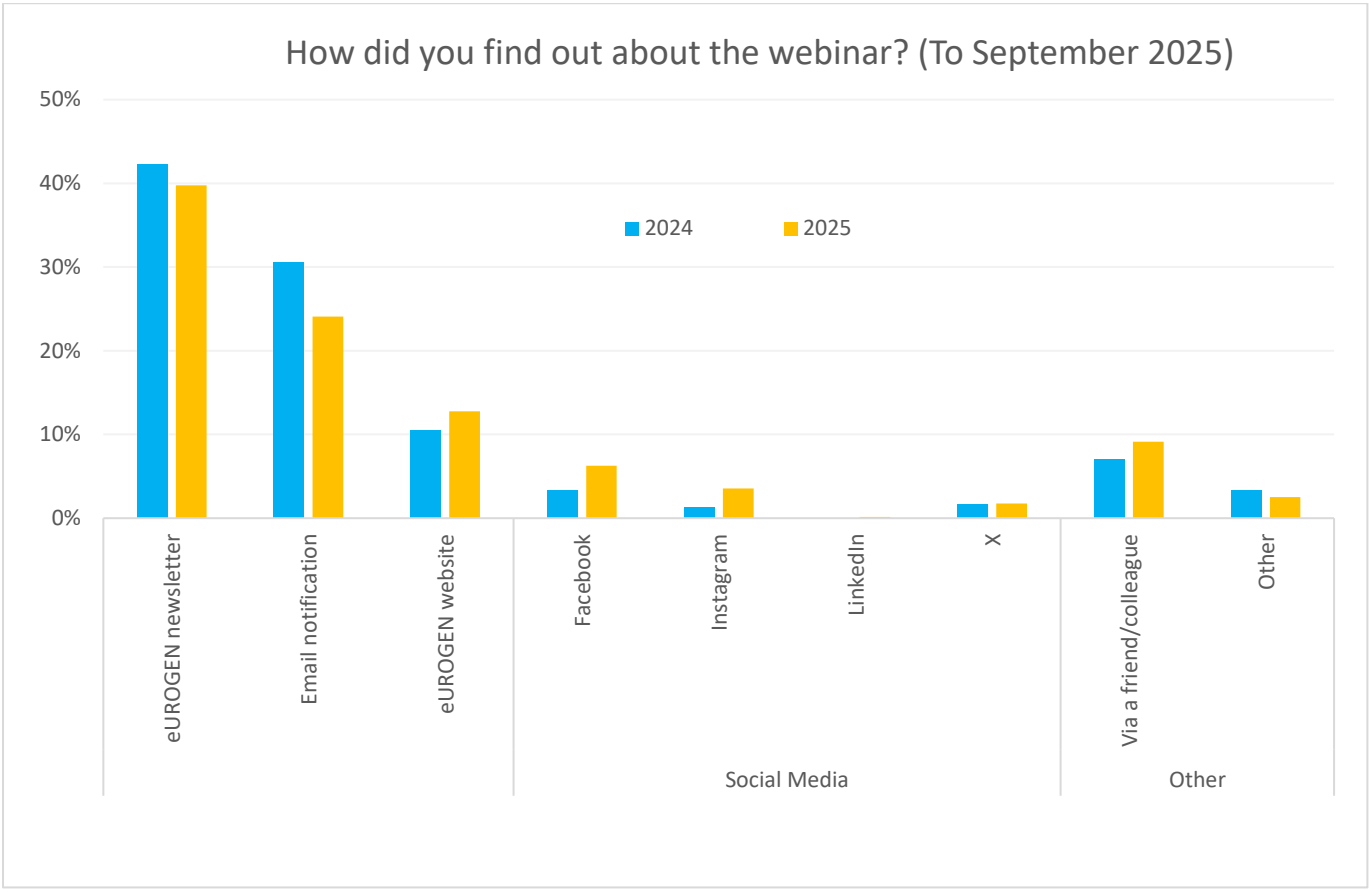
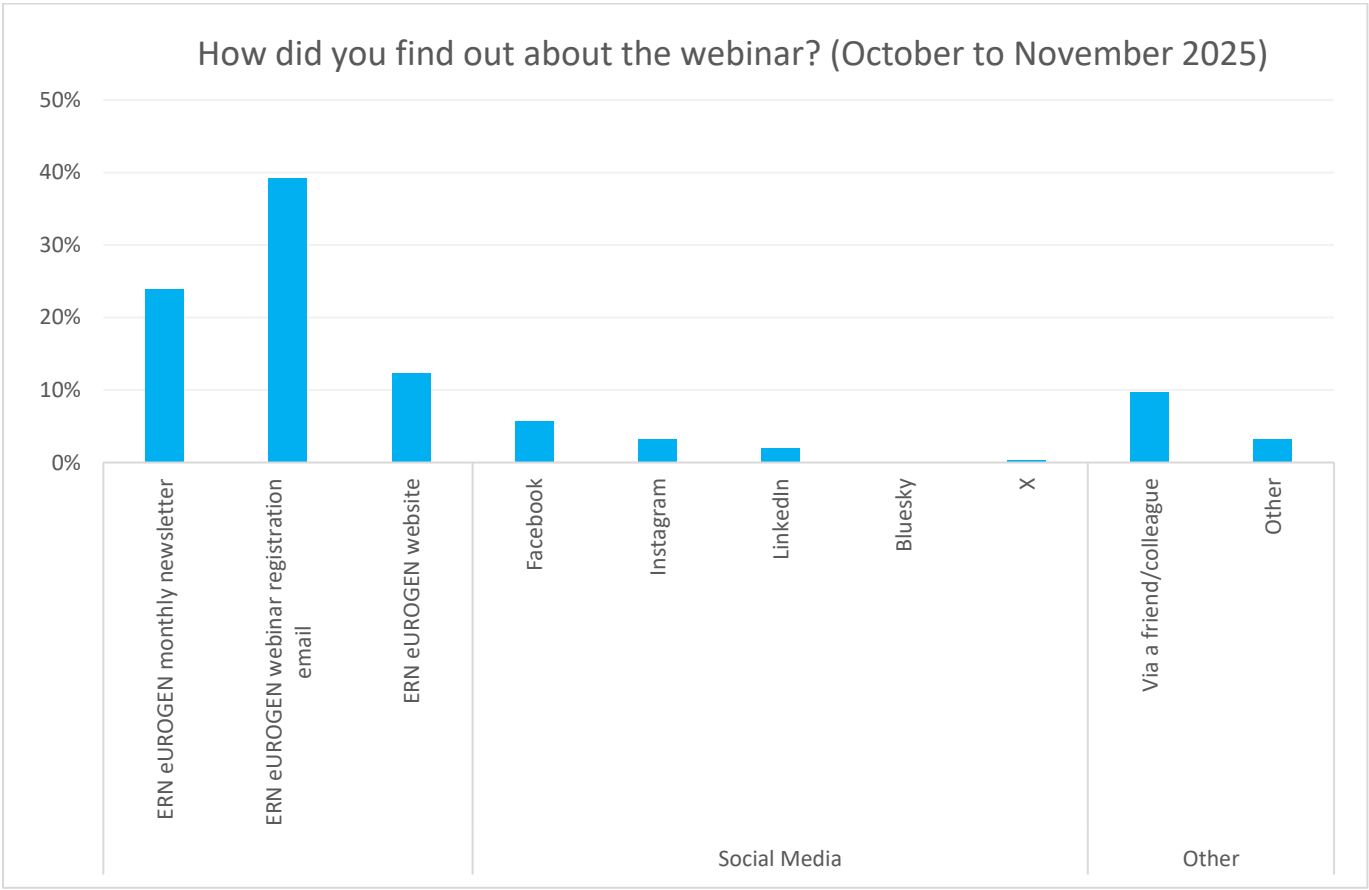


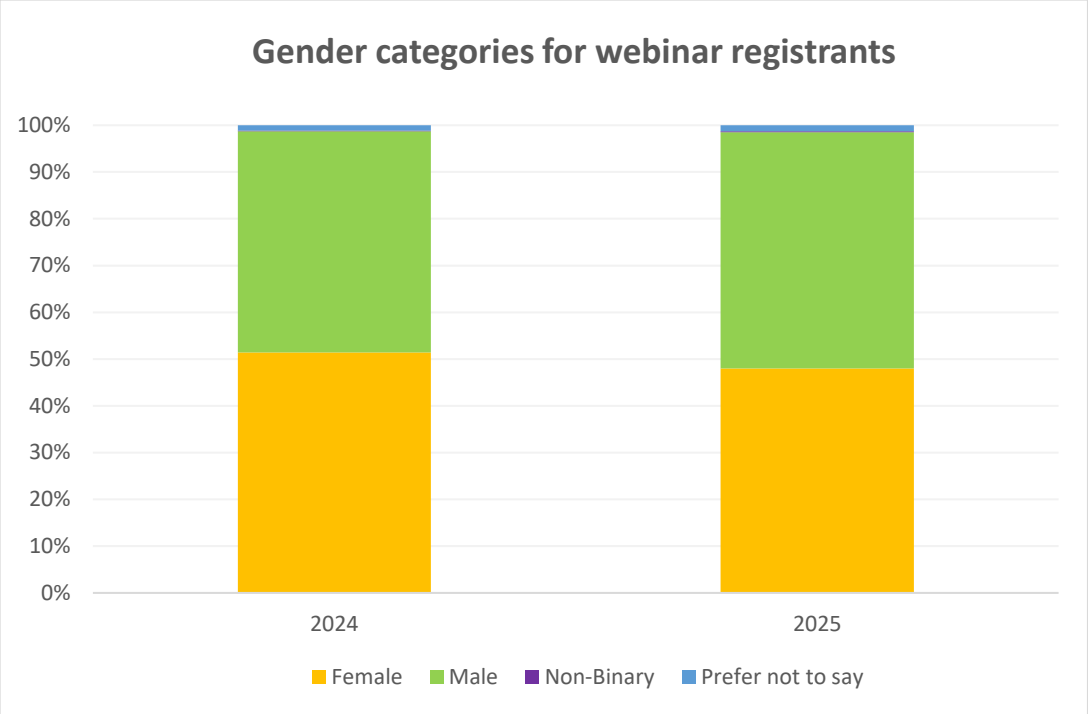
Figure 32: How registrants found out about the webinar (October 2025 to November 2025)



6.2. Gender of registrants

- Figures 33 shows that we have a very even split between male and female registrants.

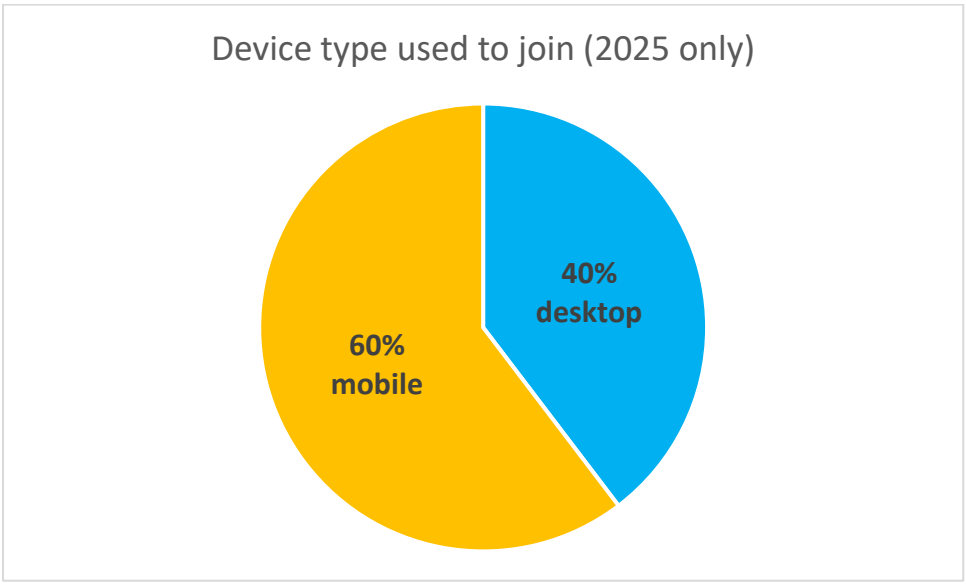
Figure 32: Reported gender of registrants (June 2024 to November 2025)



6.3. Gender of registrants

- Figures 34 shows that most registrants join our sessions via mobile, which is something we need to keep in mind regarding the design and set-up. Zoom allows us to see how the registration and lobby pages are seen in mobile applications.

Figure 34: Primary device used by registrants to join webinar (September 2025 to November 2025)

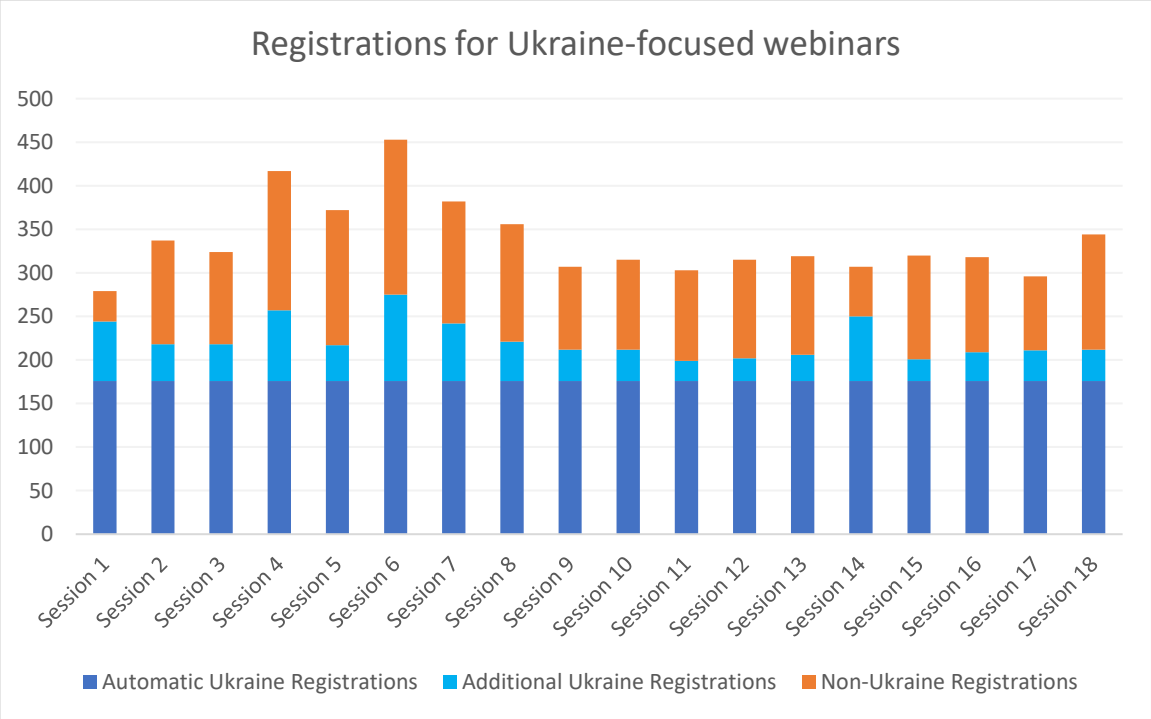


7. UKRAINE WEBINARS

7.1. Regsistrations and attendance rates

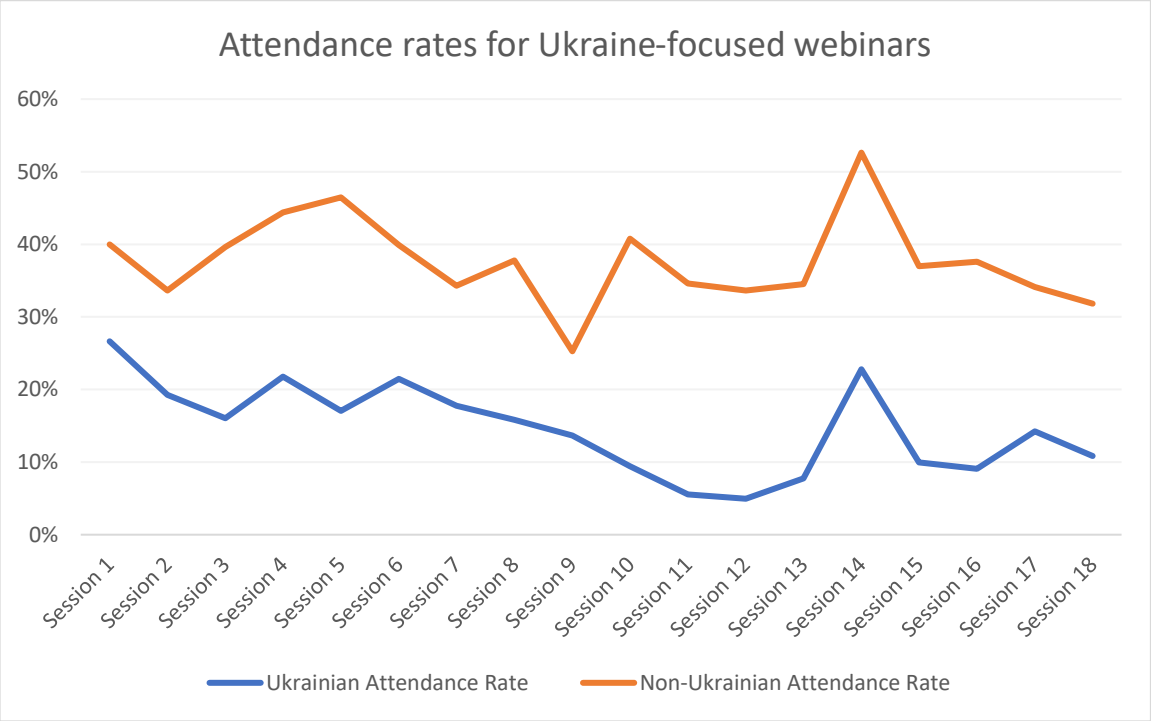
- Figure 31 shows the number of registrations for each of the 18 Ukraine-focused webinars that we have run so far, and how these are broken down between Ukrainian and non-Ukrainian registrants. In terms of the Ukrainian registrants, we received a list of 176 individuals from OMNI-Net Ukraine at the beginning of the series whom they wished us to automatically register for each session.
- It can be seen that the first 9 webinars (Series 1) which ran from Nov-23 to Apr-24, received higher registrations, with an average of 359 overall and 234 for Ukrainian registrants, than webinars 10 to 18 (Series 2) which ran from Nov-24 to Jun-25 and received an average of 315 overall and 211 Ukrainian registrants.

Figure 31: Registrations for joint Ukraine-focused webinars (November 2023 to June 2025)



- Figure 32 shows that the attendance rate for Ukrainian registrants was much lower than for non-Ukrainian registrants. One reason for this is probably the difficulty for many Ukrainian clinicians to join the live webinars due to the ongoing conflict. These webinars did gain substantial views on YouTube but, unfortunately, the daily numbers are not high enough to generate a geographical breakdown of those views (YouTube requires at least 10 views in a single day from a country in order to show those numbers for that day. Secondly, it seems probable that many non-Ukrainian clinicians found the sessions helpful as well.

Figure 32: Attendance rates for joint Ukraine-focused webinars (November 2023 to June 2025)



- Although the highest-registering countries are still predominantly the major EU players, where one would expect these educational sessions would not be so required.

Figure 33: Highest number of registrations to Ukrainian-focused webinars by country

Country	Registrations	Attendances
Ukraine	4004*	608
Italy	163	55
Germany	148	48
United Kingdom	106	46
Spain	94	51
France	75	23
Poland	67	32
Egypt	56	18
Unknown	52	24
Croatia	50	23
Mexico	49	6

- Figure 34 shows the average scores for the most relevant questions from Ukrainian attendees split by series. The scores from the comparable questions from the non-Ukrainian webinars for 2025 (see Section 4) are given as comparators. As can be seen, there is a high level of consistency between series 1 and series 2, as well as with the other webinars.

Figure 34: Average survey scores for Ukrainian respondents for series and series 2 compared to other webinars

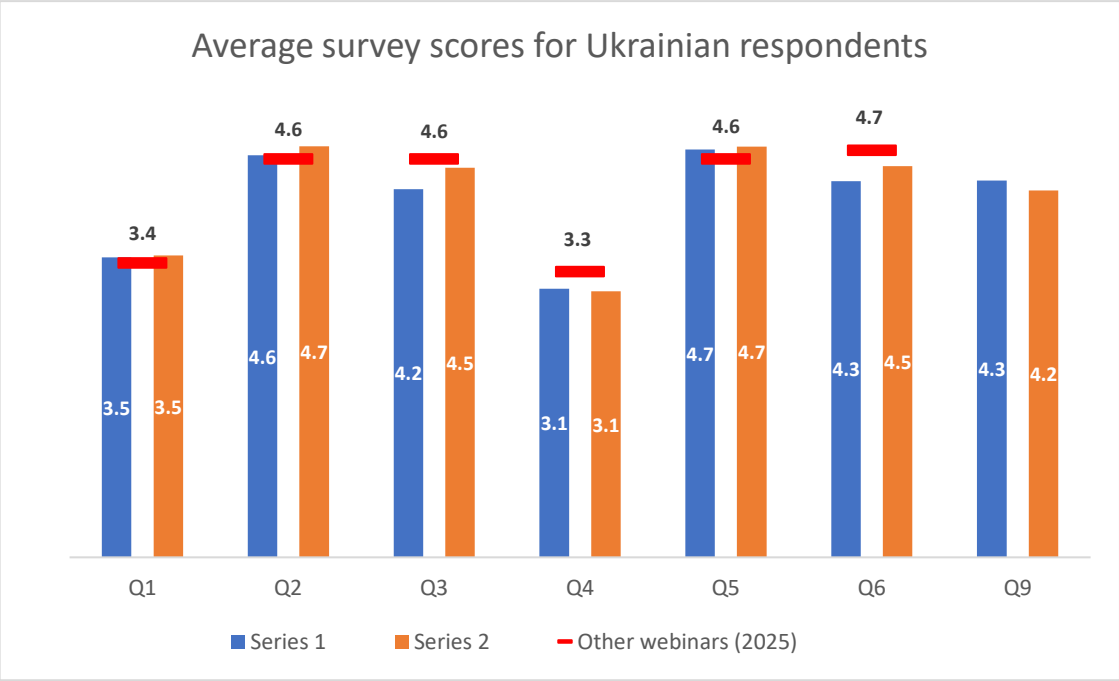


Figure 35: Key for the questions shown in Figure 34

Questions key	
Q1	How useful for your professional activity did you find this event? (Scored 1-4)
Q2	Did the event fulfil your educational goals and expected learning outcomes?
Q3	How was the sound?
Q4	How did you find the pace of the presentation? (3 is the optimal score)
Q5	Was there adequate time available for discussions, questions & answers, and learner engagement?
Q6	Will the information you learnt be implemented in your practice?
Q9	For Ukrainian attendees, how do you rate the quality of the translations for the presentations?

8. CONCLUSIONS

- The ERN eUROGEN webinar programme has remained a popular and well thought of activity, with growing registrations and improved feedback.

9. NEXT STEPS & FUTURE IMPROVEMENTS

- Further evaluation will continue in the next two years of the grant.
- We are aiming for greater collaboration with other ERNs (for example, we are scheduled to jointly run a webinar with Endo-ERN in February 26 for Ukrainian clinicians regarding CPMS), as well as our supporting partners - another series of

Ukraine webinars will run in 2026, and we are also planning a new series of webinars with ESSIC on interstitial cystitis/bladder pain syndrome.

- We are also always looking to improve the presentation of the webinar programme and the effectiveness of our dissemination in terms of advertising the individual sessions.