

Survey Analysis:

1st EULAR Online Course for Patient Research Partners

Total number of learners: 49

Survey format: Participants are asked to rate on how much they agree with the statement on a scale of 1 to 10; 10 being the best score.

Quicklinks:

Geographical Report

Module 1 – Principles of collaborative research

Module 2 – Basic epidemiology

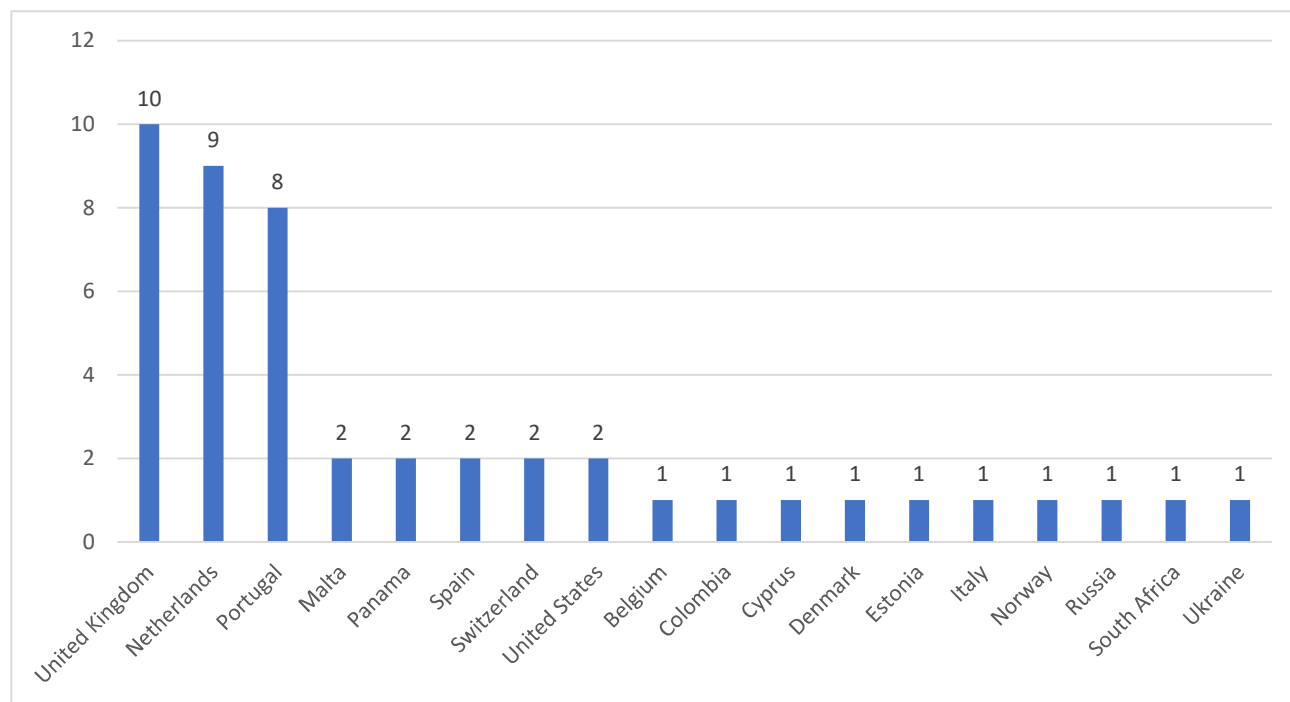
Module 3 – Outcome measures in rheumatology and the role of PRPs

Module 4 – Critical appraisal of scientific publications

Module 5 – Development of recommendations

Module 6 – Researcher-PRP communication

Geographical Report



Top 10 Countries

United Kingdom	10
Netherlands	9
Portugal	8
Malta	2
Panama	2
Spain	2
Switzerland	2
United States	2
Belgium	1
Colombia	1

Module 1 - Principles of collaborative research

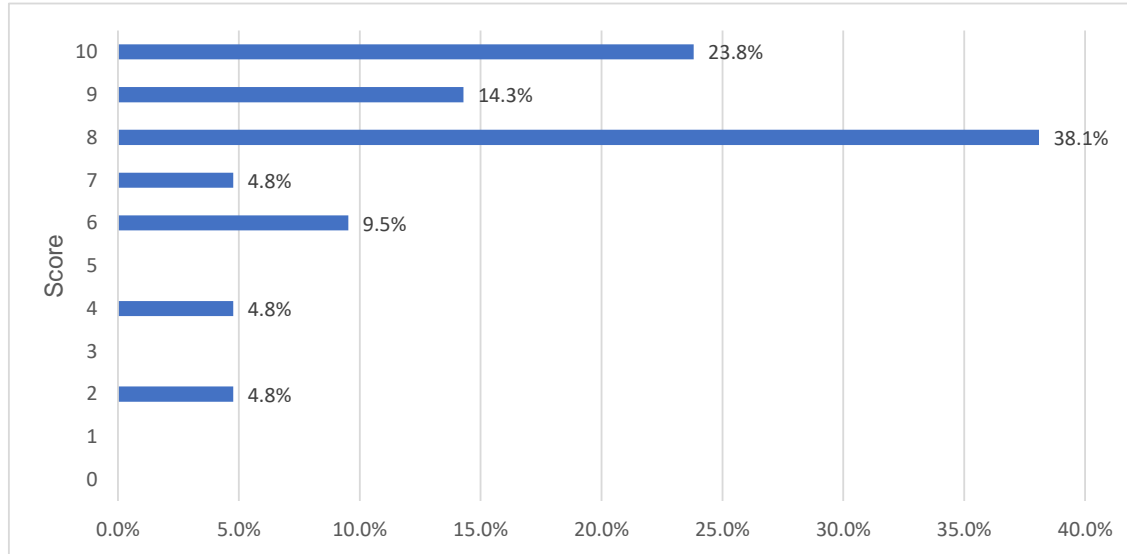
Number of survey participants: 21

Survey participants were asked to give a score between 0 to 10.

0 being very poor.

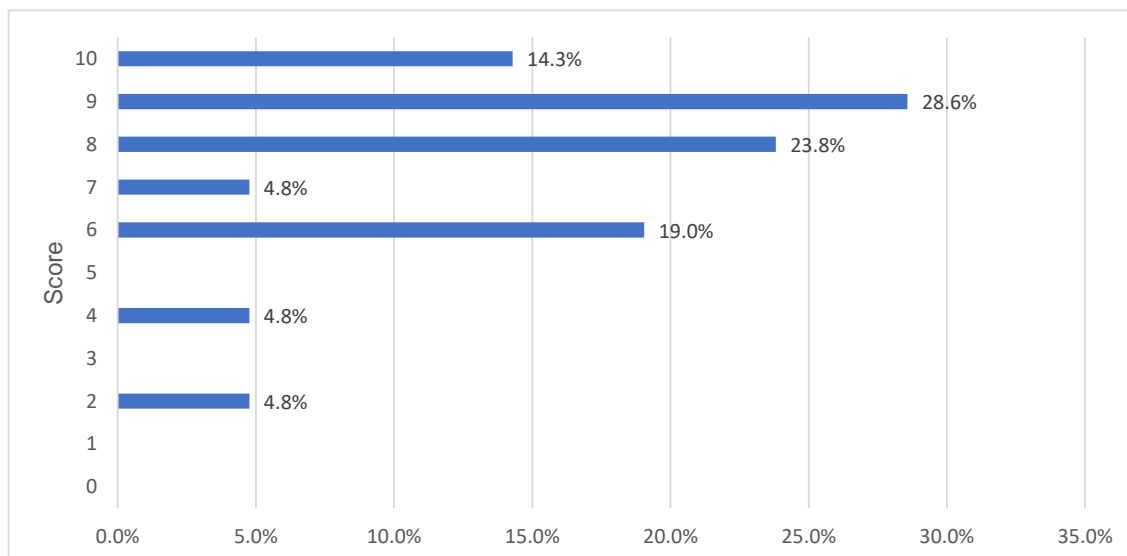
10 being excellent.

Q1: The module was very well organised



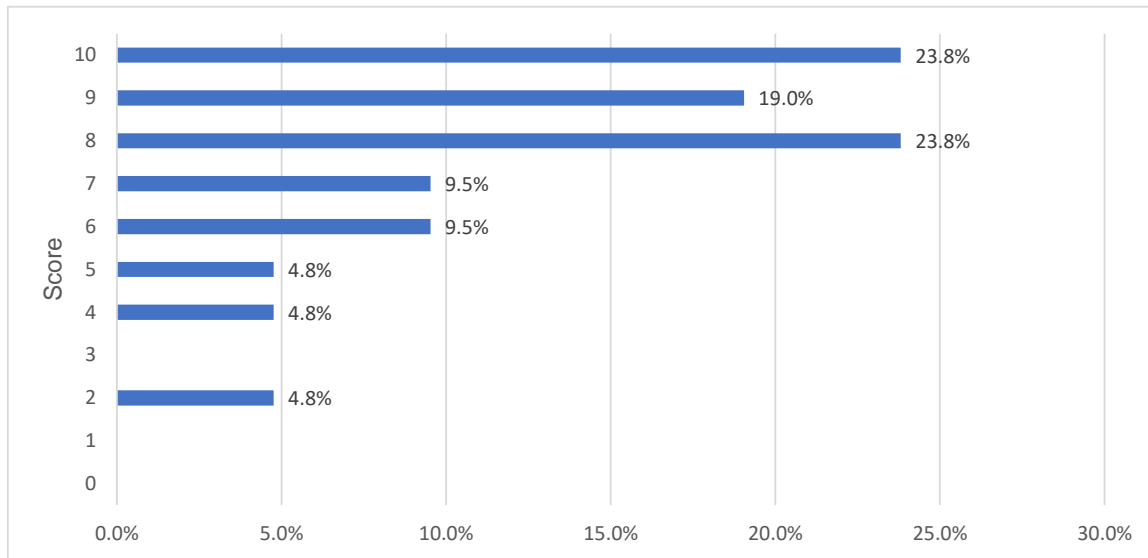
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	0	1	0	1	0	2	1	8	3	5

Q2: The learning objectives and actual teaching content matched well



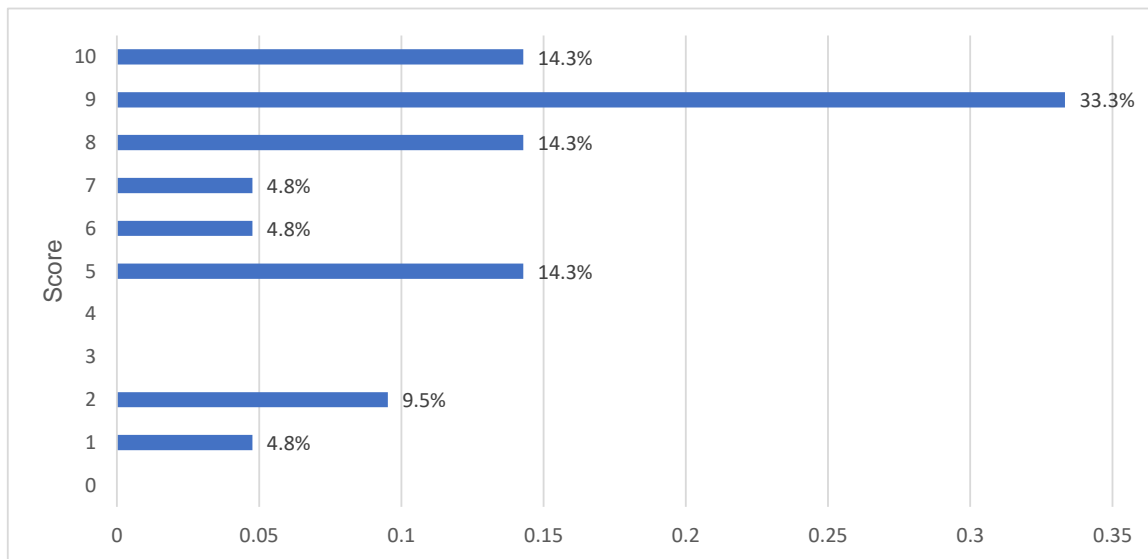
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	0	1	0	1	0	4	1	5	6	3

Q3: Overall the learning material was well presented and clear



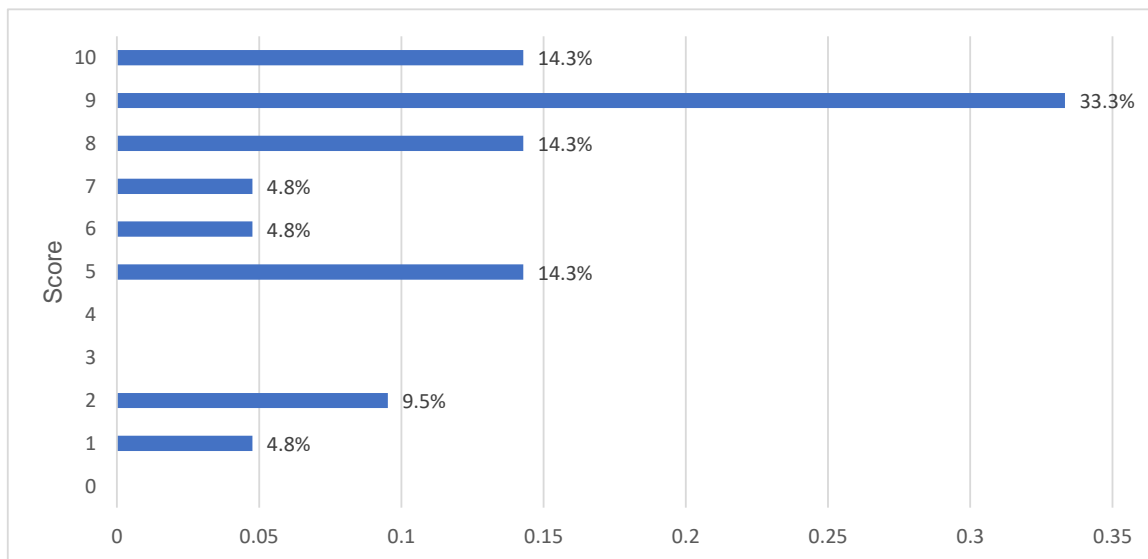
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	0	1	0	1	1	2	2	5	4	5

Q4: The assignments and questions for reflection were very helpful to better master the topic



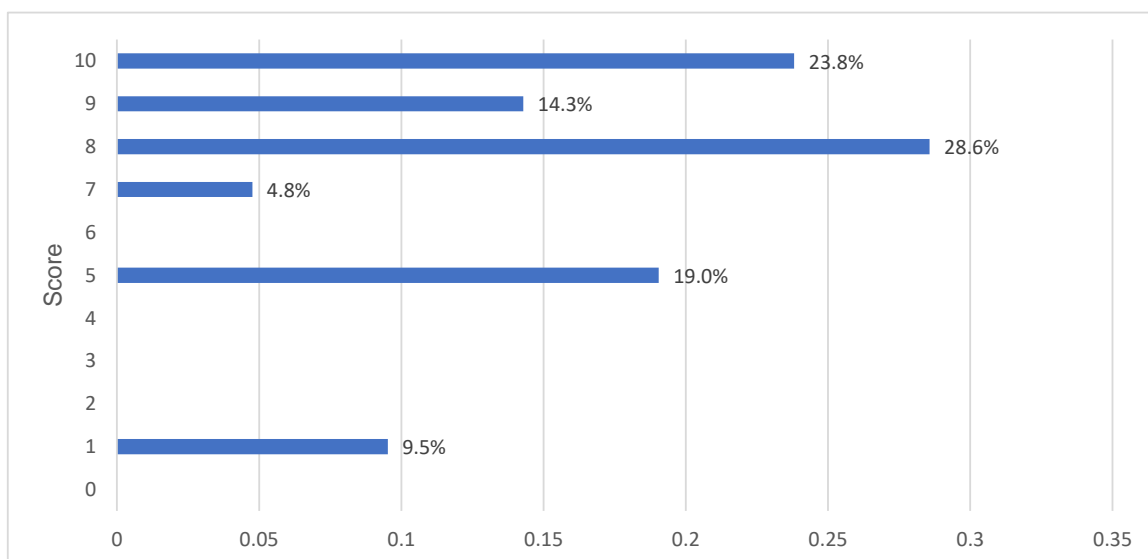
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	1	2	0	0	3	1	1	3	7	3

Q5: The self-assessment questions at the end really helped me to test my knowledge about the topic



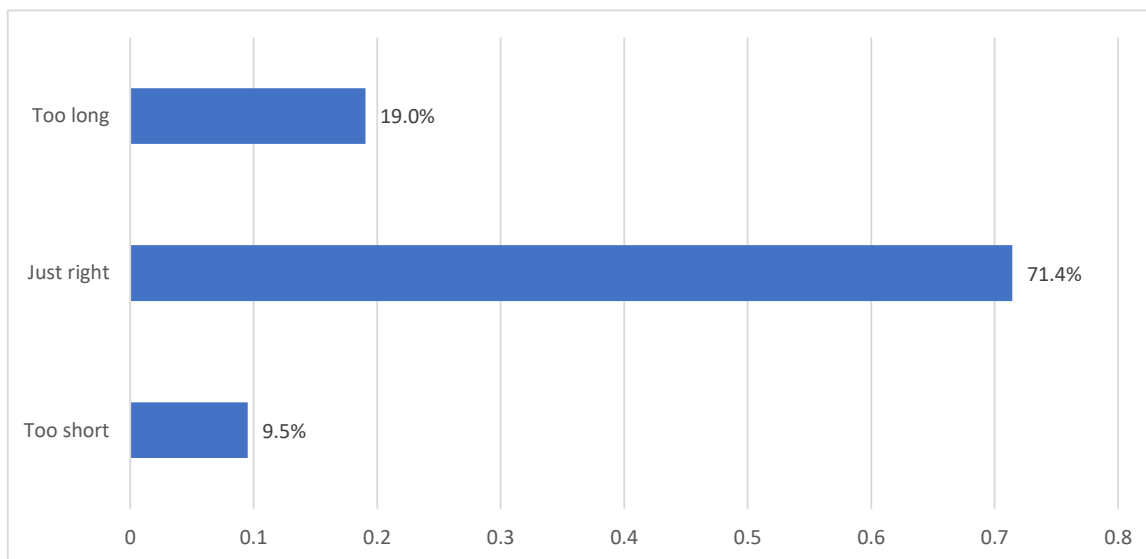
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	0	1	0	2	3	1	2	4	5	3

Q6: The overall quality of the images/graphs/videos/PowerPoints imbedded in the content was excellent



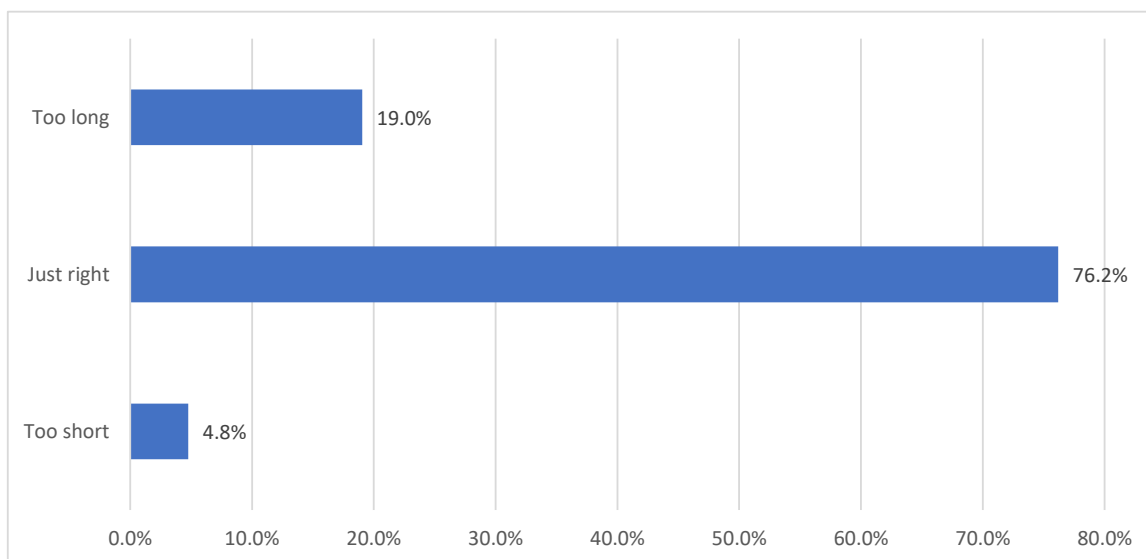
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	2	0	0	0	4	0	1	6	3	5

Q7: The amount of text for this module was:



Response	Too short	Just right	Too long
Count	2	15	4

Q8: The study time estimated for this module was:



Response	Too short	Just right	Too long
Count	1	16	4

What are the three best features of this module for you?

The way the recommendations were summarised, the easy way the roles were explained and the questions that made me reflect.
It was clearly explained, the videos made it easier to follow, and the companion material was extremely helpful
1. The "Patient Roles in Scientific Research" image 2. The "Empirical Research Cycle" image 3. The "Participation Matrix" image. These pictures are the stepping stone for the information given
1. The subtitles in the form of text helped me to secure better course notes for future reference. 2. The visual and audio components in the course videos helped me very much to remember important points of the course content in this module. 3. The ability to save my reflections and have them exported to pdf format for future reference throughout the entire course.
I liked the way Maarten explained each topic, simple, direct and with the perfect rhythm :). Visually appealing and easy to read. A very complete introduction
1- clear, concise, organized review of all aspects. 2- assessment questions make you think, yet interpretation of correct answers may differ based on prior experience with definitions/cultural context/terminology . 3- good, applied learning
Mix of text and video, short videos, hard questions at the end. It was very good with questions that captured the essence in what we are supposed to learn, but not every question felt important.
The 2011 recommendations, the 2x2 matrix and the self assessment questions were most helpful in this module.

Please give any suggestions or comments here

In my humble opinion, advisor may be perceived as a higher level if researchers are listening to patients/PRPs' advice as authentic advisors rather than just asking them to review a protocol as a reviewed without considering the PRPs' input- could be confusing in the assessment and perhaps clarification is required to ensure participant/PRP tester understands that "advisor" is viewed more as a consultant here in this specific assessment rather than an actual advisor during which advice is acknowledged and appreciated often at a higher level with researchers than a PRP reviewing a protocol to complete a checklist. PRP perspectives may also differ with involvement categories depending on experience with inclusion, exclusion, segregation and tokenism depictions.
The voice on the videos are not of very good quality.
The explanations in the videos and text are very long. My first language is English and I have a background in healthcare research and I struggled a bit. Some of the quiz questions are difficult to understand and the quiz at the end did not only test your ability to remember what you had learned, but expected some of the knowledge to be interpreted and / or transferred into a different context.
I would say that holding presentations is dissemination, but in the video you say that presentations are a part of the implementation phase. That's why I marked it as false, but that was wrong. To test us on details like this is such a waste. The questions in the test should be questions that we need to know to do a good job as patient partners. English is not my first language as you probably understand, and I had to google tokenism to understand the question. I guess that I'm not the only one, so it would be good with a little explanation of new terms. Also the mobile interface is not super great for reading and I always get error messages when I try to go back to the menu.

Module 2 - Basic epidemiology

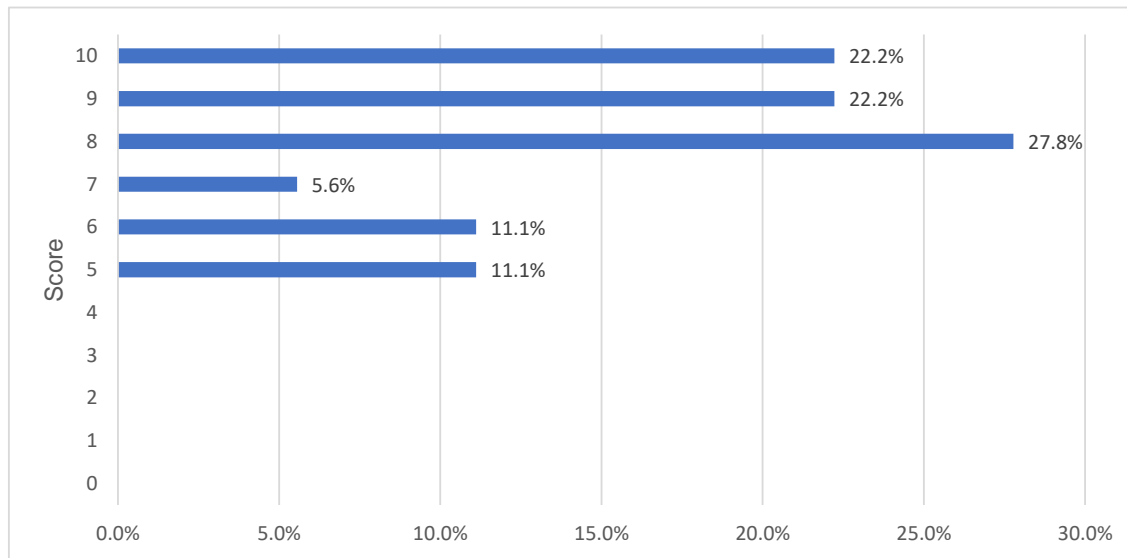
Number of survey participants: 18

Survey participants were asked to give a score between 0 to 10.

0 being very poor.

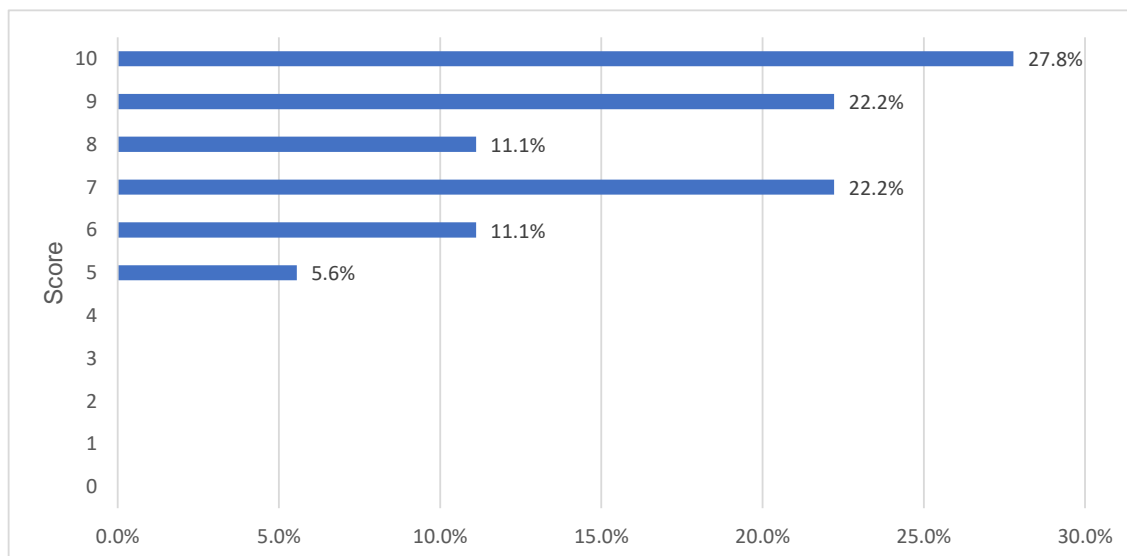
10 being excellent.

Q1: The module was very well organised



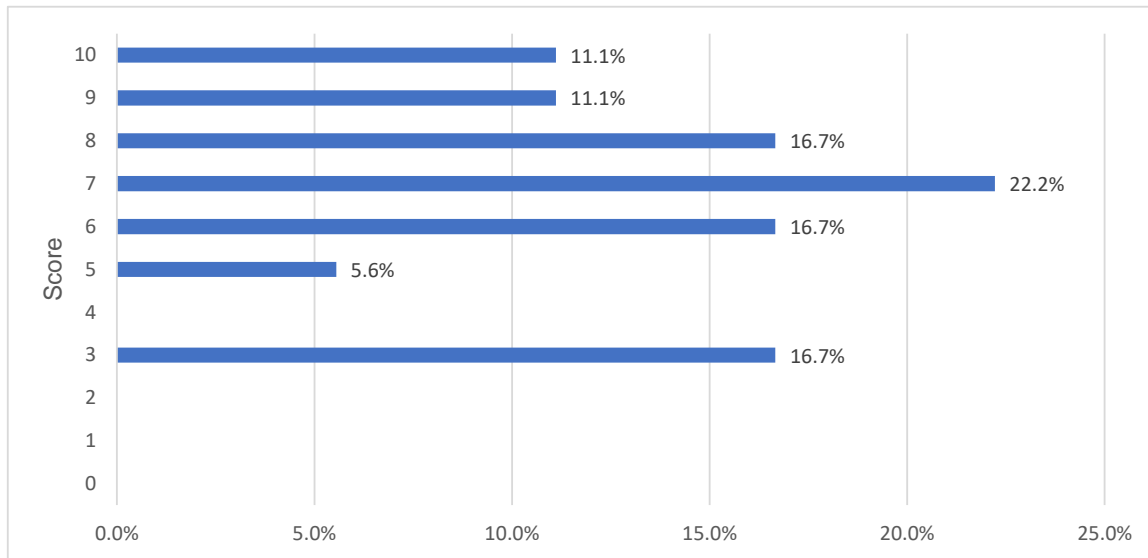
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	0	0	0	0	2	2	1	5	4	4

Q2: The learning objectives and actual teaching content matched well



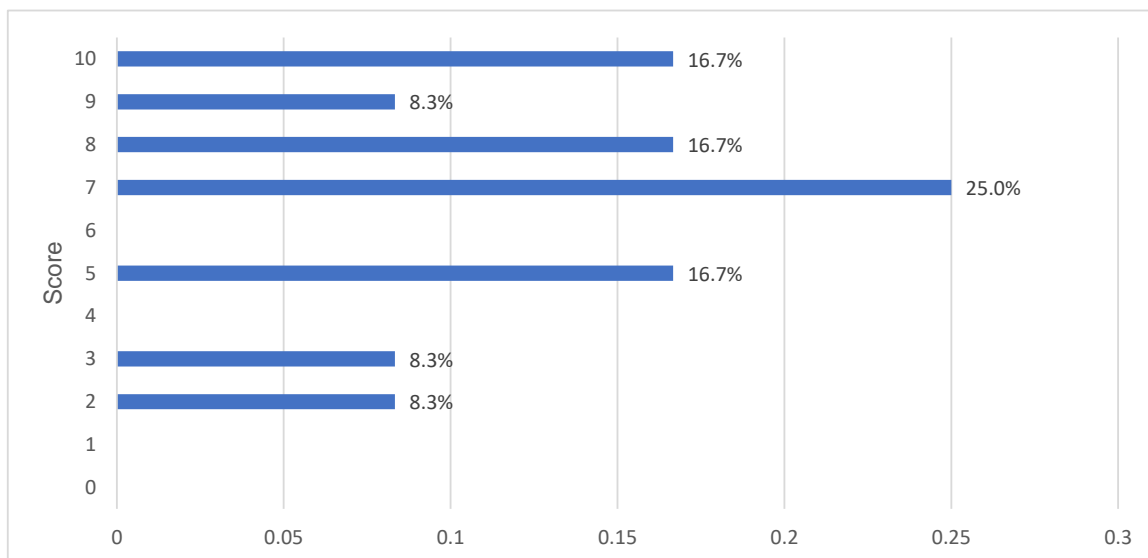
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	0	0	0	0	1	2	4	2	4	5

Q3: Overall the learning material was well presented and clear



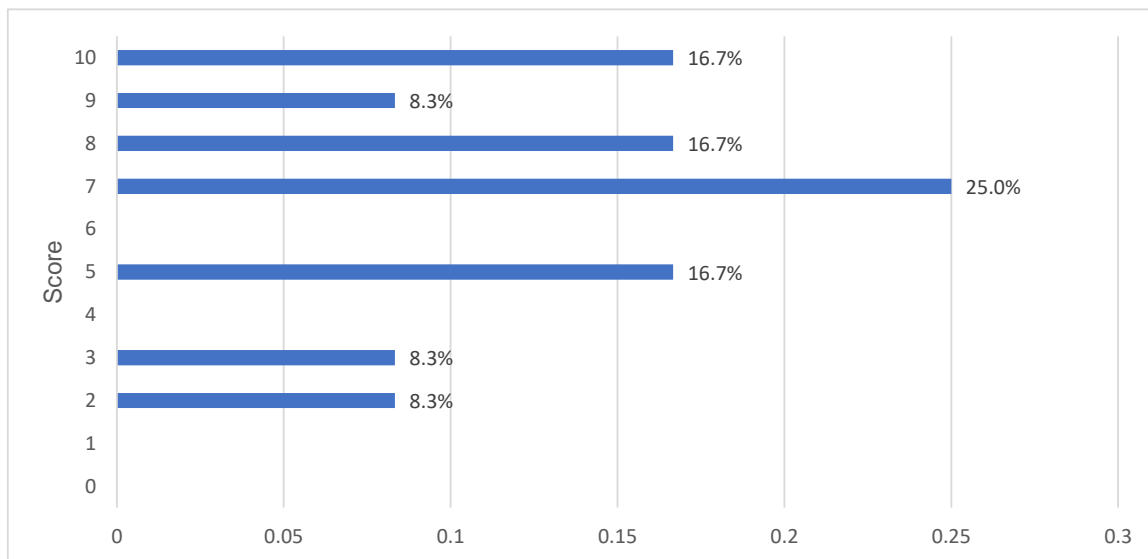
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	0	0	3	0	1	3	4	3	2	2

Q4: The assignments and questions for reflection were very helpful to better master the topic



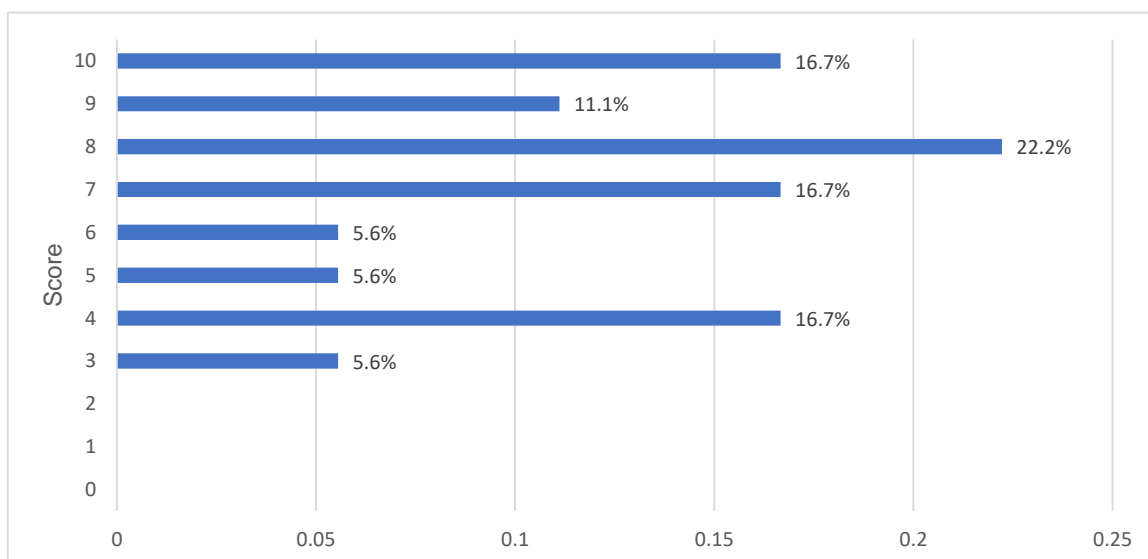
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	0	1	1	0	2	0	3	2	1	2

Q5: The self-assessment questions at the end really helped me to test my knowledge about the topic



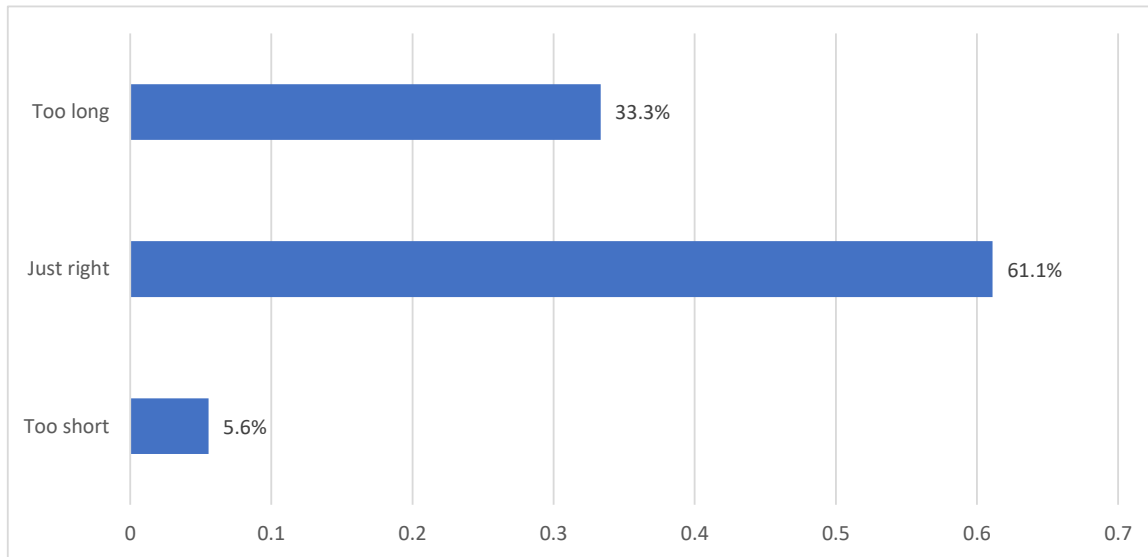
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	0	1	0	1	0	2	1	4	6	3

Q6: The overall quality of the images/graphs/videos/PowerPoints imbedded in the content was excellent



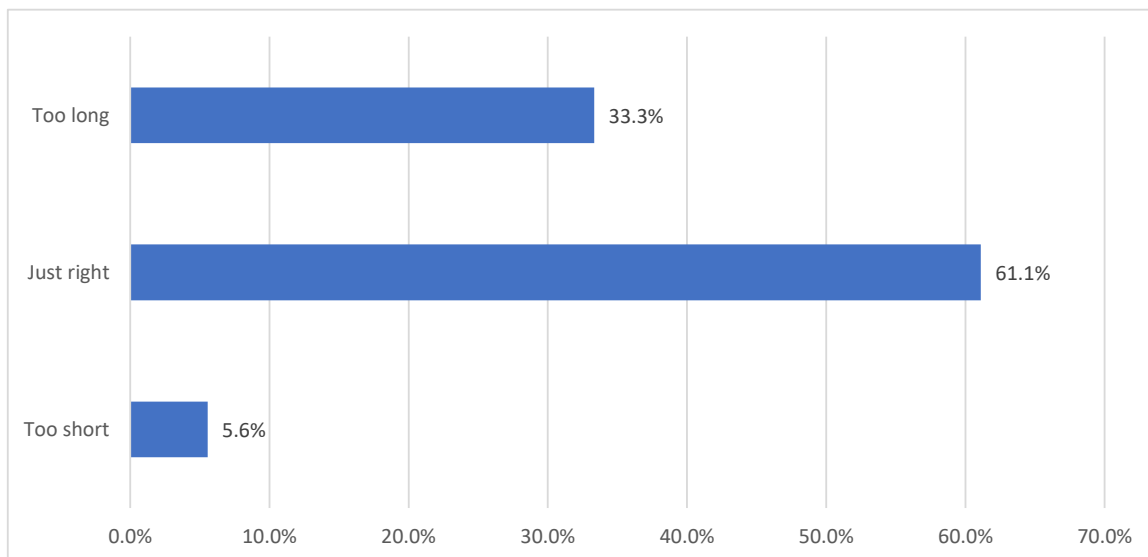
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	0	0	1	3	1	1	3	4	2	3

Q7: The amount of text for this module was:



Response	Too short	Just right	Too long
Count	1	11	6

Q8: The study time estimated for this module was:



Response	Too short	Just right	Too long
Count	1	11	6

What are the three best features of this module for you?

The explanations of the simpler analysis concepts.
The videos was helpful. The self-assessment were important to know what level I am at. The well organised
1- example questions within the module are helpful. 2- module is a bit long for one sitting, yet the content length is great- i think adding the estimated duration will help for planning completion uninterrupted.3- it's nice to be able to save & export notes
Everything is truly very interesting and most thorough. The content of the course material is very rich and informative, and I find I need to read and re-read the content. The subject of epidemiology is of great interest and very intrinsic value to research. I must say that the reference cards are most helpful and I really thank you all for making them available all throughout this course. I have to be honest it is not a very easy online course for me, maybe because I do not have the hands on experience yet. But this is a challenge I hope I will manage to achieve. Thank you so much for your dedication and commitment.
Explanation of different research methods. Assignments are useful. Note export feature
How we find the incidence and the prevalence. The Pyramid of Evidence-Based Medicine. The role of PRPs in Epidemiology
I needed repeating prevalence, incident, sensitivity and specificity and how to calculate it. I also learned some new words like Pharmaco-vigilance.
I learned a lot about applying formulas to studies, this was always foreign to me

Please give any suggestions or comments here

great module! just a couple suggestions to consider: I haven't found where the estimated time is listed to plan in advance for completion duration- please add the estimated time to completion for each module at the beginning of each module, or place it where it is obvious if it is already there- I don't know why I cannot find it for each module??? The length was ok, yet I was unable to complete the course without repeated interruptions as I did not realize it would take more than one hour. It would be helpful to know how long the tests should take as well if you could consider adding that estimated time for completion as well when the test/assessment pops up. for the patient involvement test question, patient help with info leaflets and ICF co-creation could be considered in the development and planning phase, prior to data collection- that question could be confusing as many researchers co-creating with patients involve them in this step during the planning stage for form readability, content/text length, etc. and prior to data collection. Perhaps consider omitting that first paragraph from the answers for the data collection as it could also fall under the planning answer. The graph re: obesity and remission did not have the asterisk symbol b/w obese and non-obese patients to denote a statistically significant difference when answering the questions; thus, it wasn't clear if it was a trick question bc the statistically significant difference was not denoted with an asterisk next to the p-value on the graph- please add the asterisk on the graph to clarify for test question, or the actual p-values to the graph to discern if statistically significant difference did exist- it looks like it from the graph, yet you don't know if it is a tricky question without seeing the actual p-values and/or asterisk denoting a significant difference.
I found the figure in question 8 of the test not very clear. To me it was not obvious what was meant with the P value in this figure. To which data pertained this value?
The self-assessment questions about calculating A and B, good and bad was way too easy when the question stated what values to use.

Module 3 - Outcome measures in rheumatology and the role of PRPs

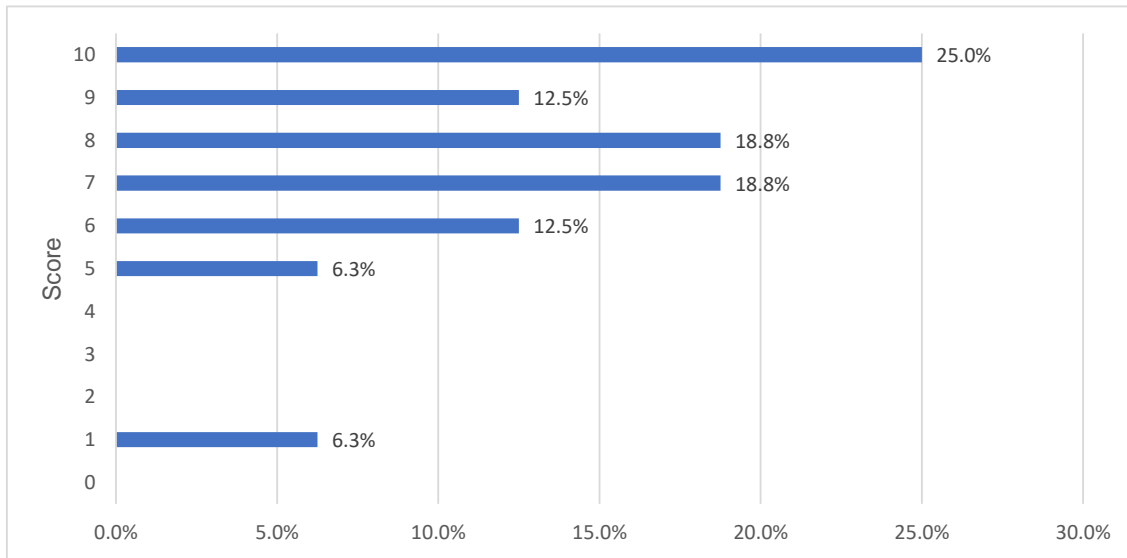
Number of survey participants: 16

Survey participants were asked to give a score between 0 to 10.

0 being very poor.

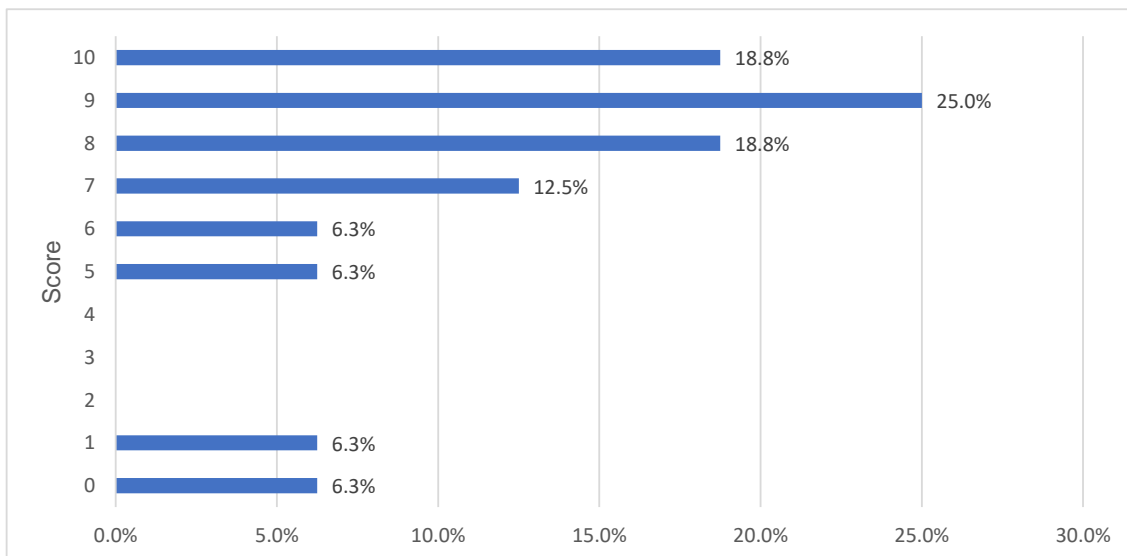
10 being excellent.

Q1: The module was very well organised



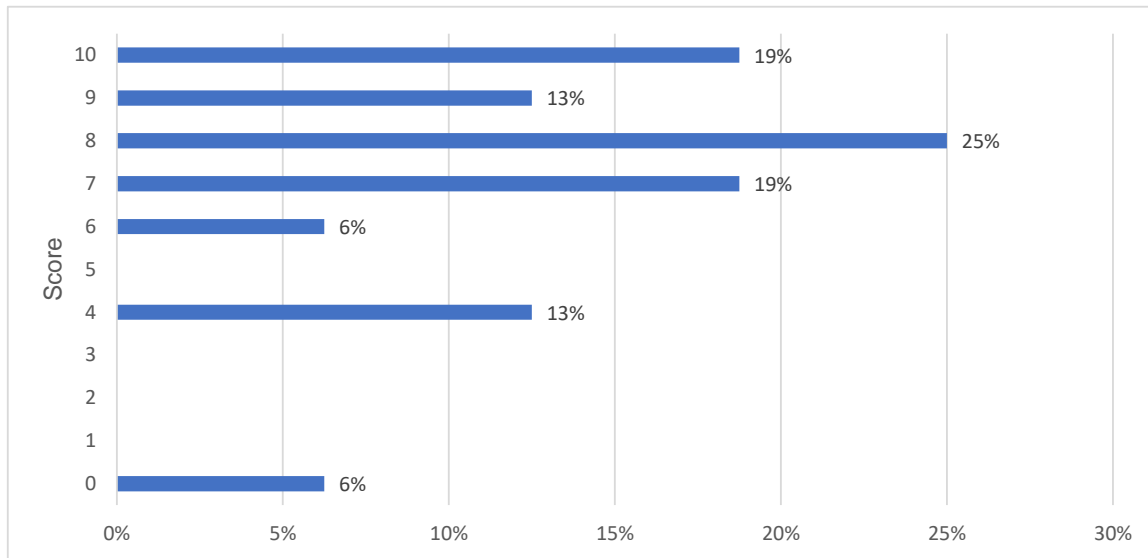
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	1	0	0	0	1	2	3	3	2	4

Q2: The learning objectives and actual teaching content matched well



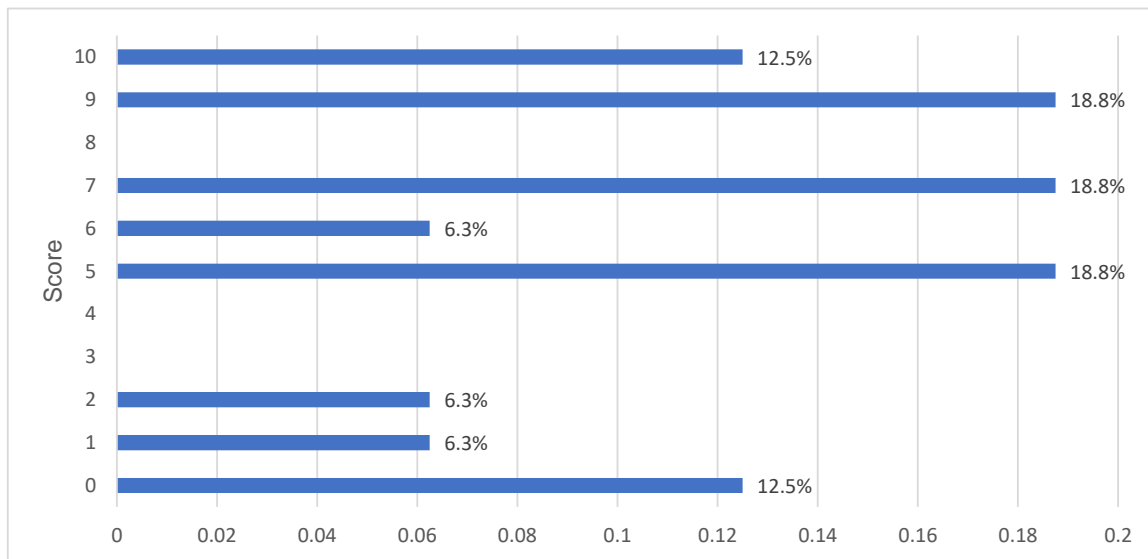
Score	0	1	2	3	4	5	6	7	8	9	10
Count	1	1	0	0	0	1	1	2	3	4	3

Q3: Overall the learning material was well presented and clear



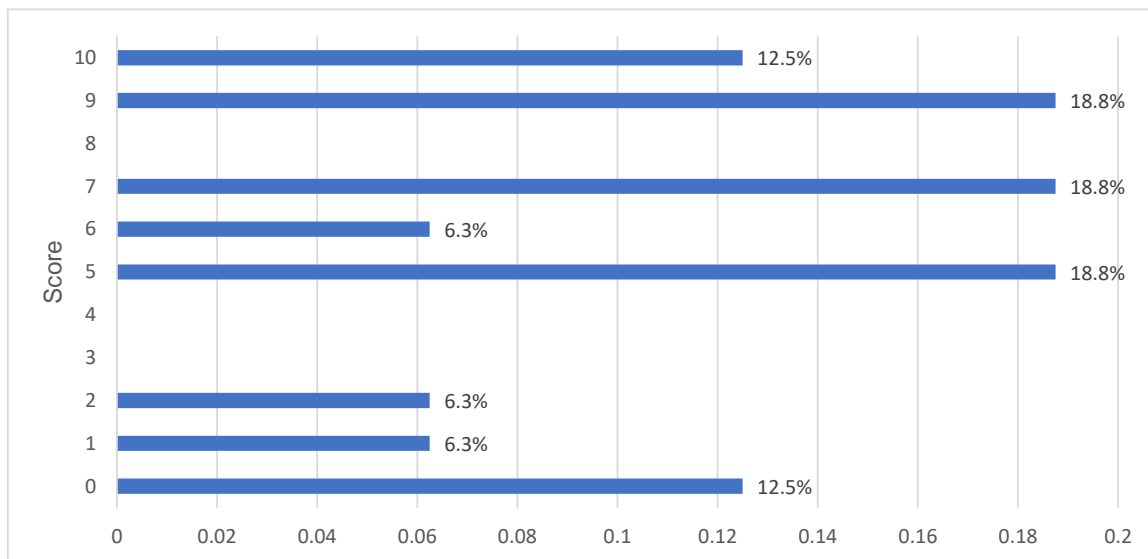
Score	0	1	2	3	4	5	6	7	8	9	10
Count	1	0	0	0	2	0	1	3	4	2	3

Q4: The assignments and questions for reflection were very helpful to better master the topic



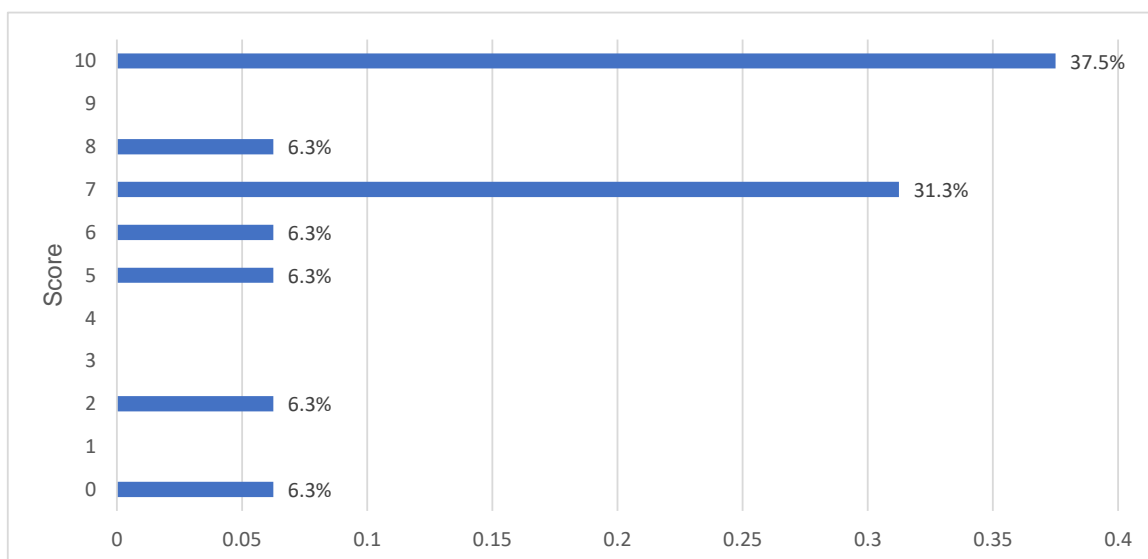
Score	0	1	2	3	4	5	6	7	8	9	10
Count	2	1	1	0	0	3	1	3	0	3	2

Q5: The self-assessment questions at the end really helped me to test my knowledge about the topic



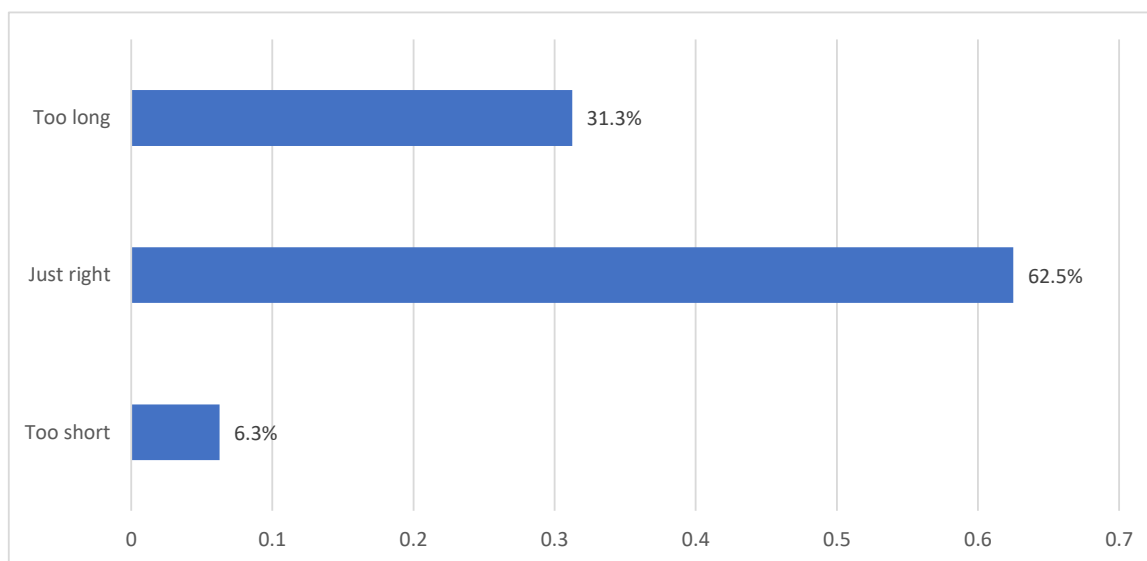
Score	0	1	2	3	4	5	6	7	8	9	10
Count	1	0	1	0	0	1	2	2	4	1	4

Q6: The overall quality of the images/graphs/videos/PowerPoints imbedded in the content was excellent



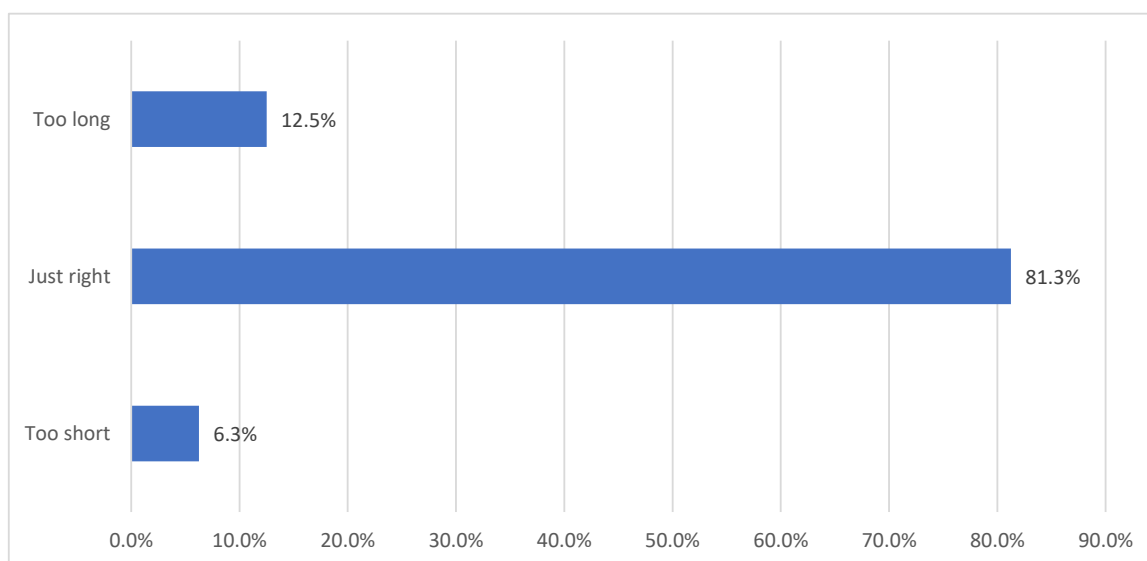
Score	0	1	2	3	4	5	6	7	8	9	10
Count	1	0	1	0	0	1	1	5	1	0	6

Q7: The amount of text for this module was:



Response	Too short	Just right	Too long
Count	1	10	5

Q8: The study time estimated for this module was:



Response	Too short	Just right	Too long
Count	1	13	2

What are the three best features of this module for you?

That I have learned a lot . All the knowledge will help me as been a better PRP. My participation in research will be much better in future.
This module has definitely helped me to understand the important role that a patient has in patient research partnership. This module taught me the many different aspects and dimensions to PRO's. I will definitely need to refer to my course notes from time to time as a point of reference.
Understanding the difference between PROs and physician reported / objective outcomes The information on how PROs are validated The concept of disease specific or outcomes that can be generally applied
The importance of patient participation in defining outcomes. The different outcomes as defined by researchers/physicians on the one hand and patients on the other hand is something that is important and has to be adressed by patients. The relevance of more subjective variables has to be pointed out by patients. The framework to assess psychometric qualities of a PROM .
Everything was interesting, in particular, patient-reported outcome, outcome measures and measuring quality of life.
Getting to know the different outcome measures, how to know if an instrument is valid or not and the importance of having PRPs in the process of developing outcome measures.
I loved the interview with the 3 Rheumies and PRP A load of new information learned The videos were very imformative

Please give any suggestions or comments here

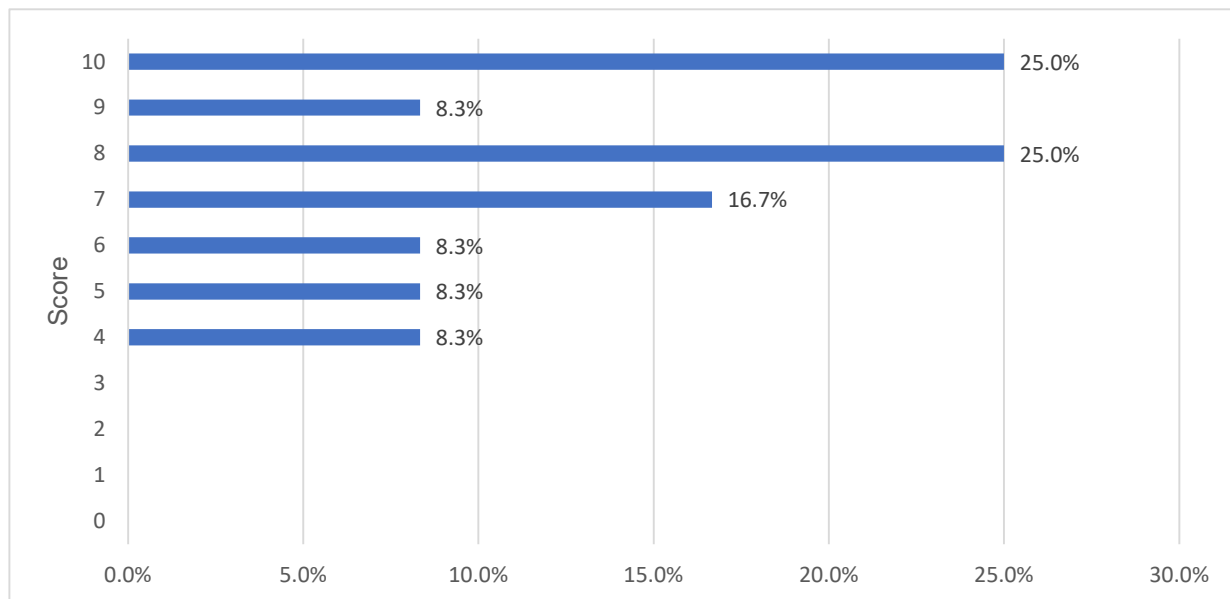
The group discussion was very helpful. Maybe this form of clarification can me used more often.
In the assessment at the end of the module I would like to be able to see the question and all the options for answers in a question at the same time, without the need to keep scrolling up and down, as I find that makes it harder to compare them clearly and make decisions on which to pick. I also find having to often pick ones that are false rather than true harder to keep in mind, odd and maybe just the way I am.
An estimated study time for each module would be helpful Again, big difference between content in basic and advanced study. The Basic was much longer that the advanced, which was just a few pages.
The test questions are a little too spesific. I can't use the knowledge I have obtained, I must find the exact text and check line for line if the words are right
Would be nice to see some practical use for all this theory

Module 4 - Critical appraisal of scientific publications

Number of survey participants: 12

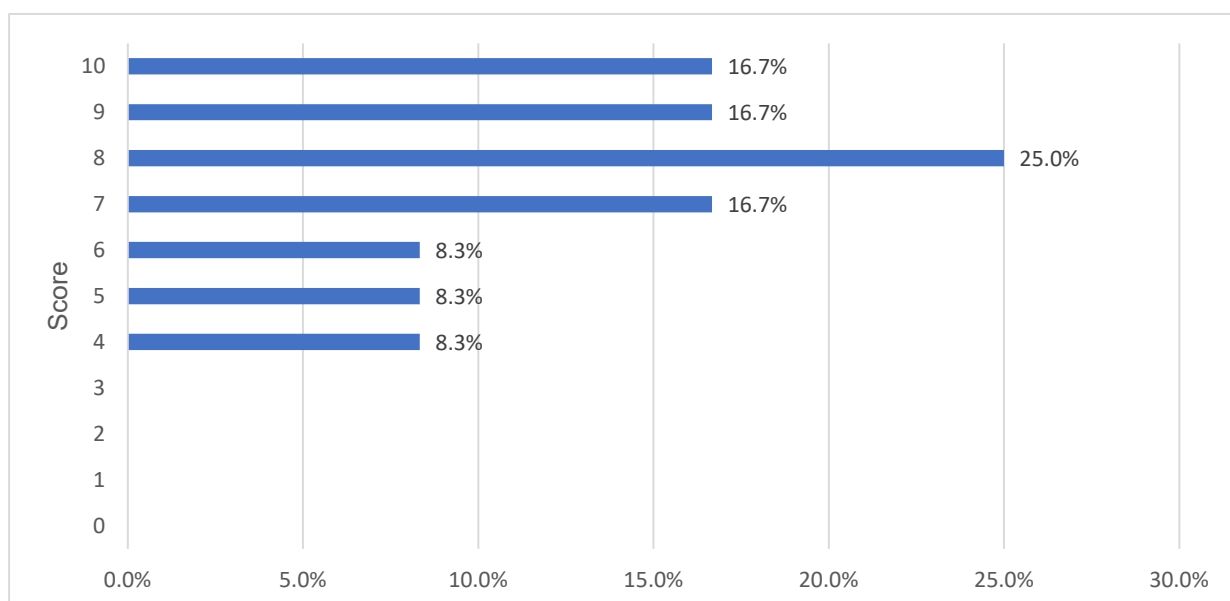
Survey participants were asked to give a score between 0 to 10.
0 being very poor.
10 being excellent.

Q1: The module was very well organised



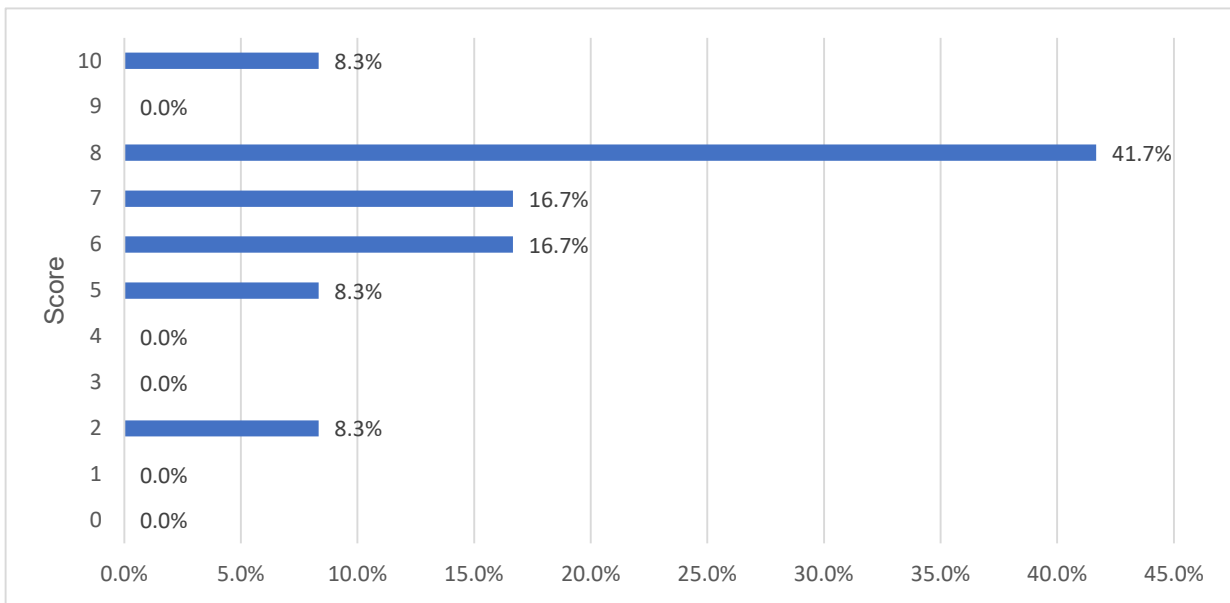
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	0	0	0	1	1	1	2	3	1	3

Q2: The learning objectives and actual teaching content matched well



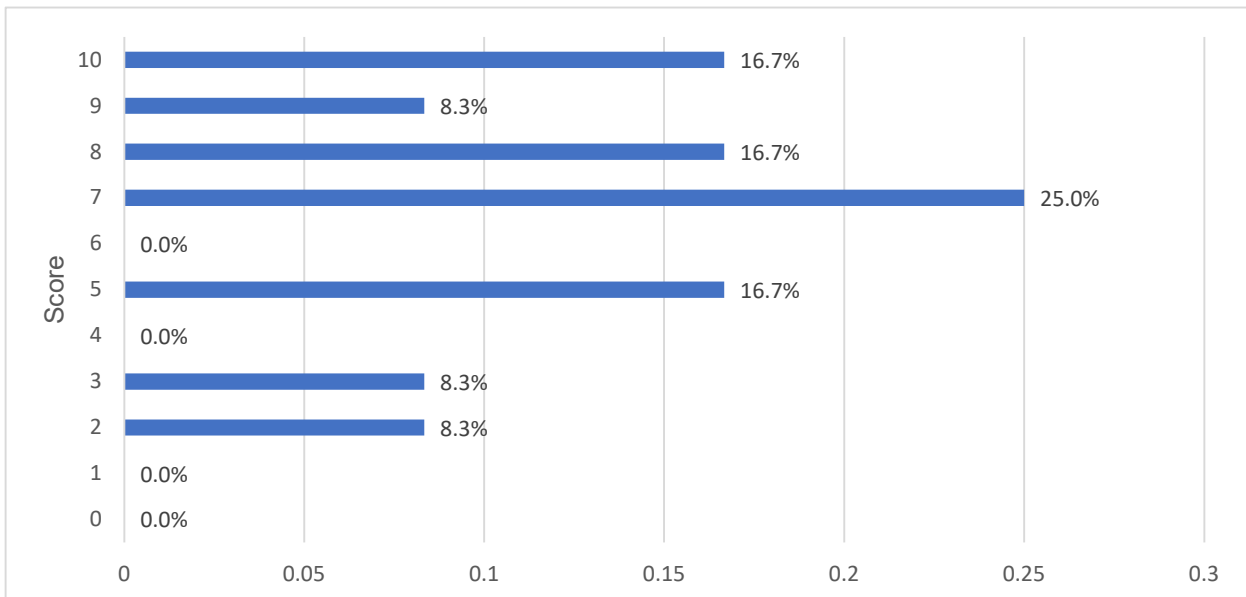
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	0	0	0	1	1	1	2	3	2	2

Q3: Overall the learning material was well presented and clear



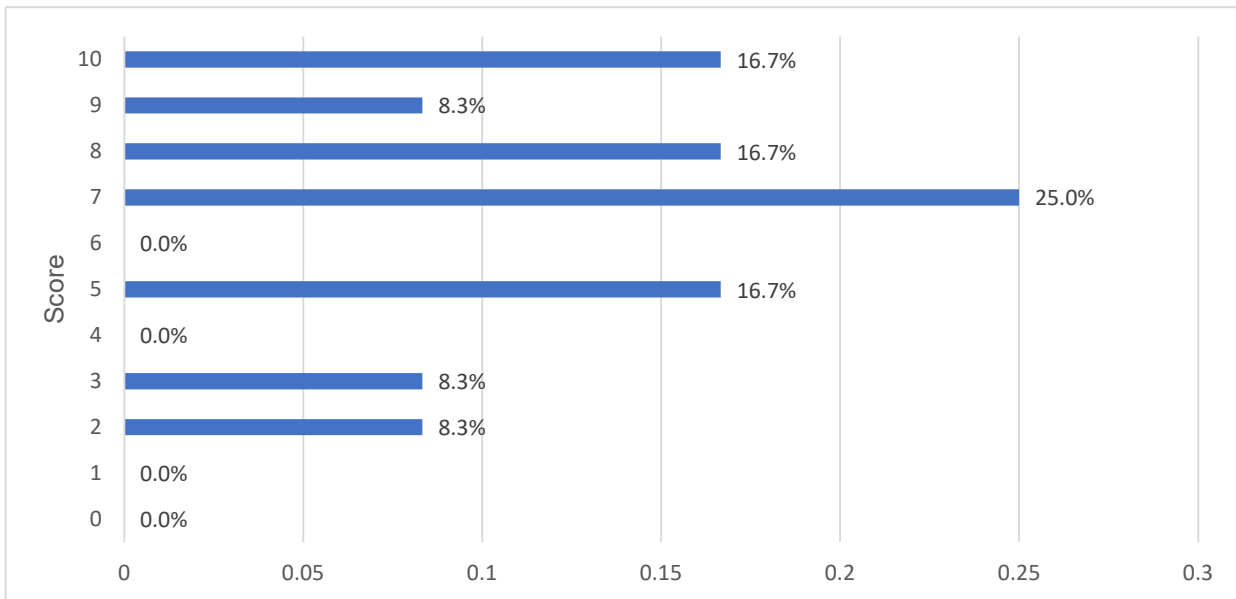
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	0	1	0	0	1	2	2	5	0	1

Q4: The assignments and questions for reflection were very helpful to better master the topic



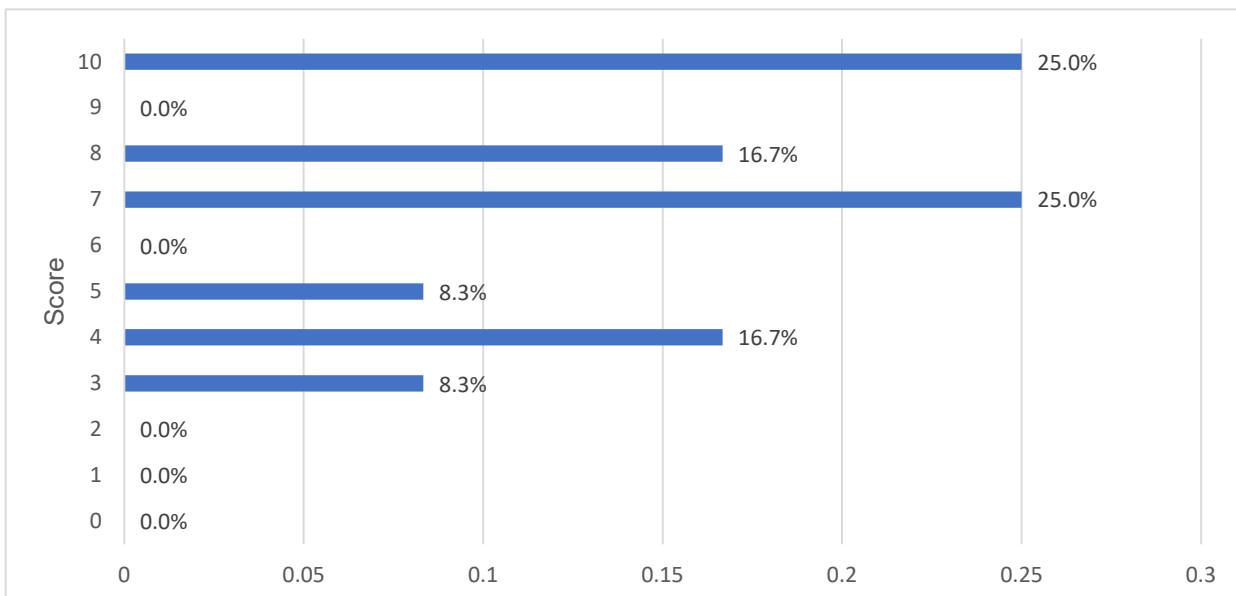
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	0	1	1	0	2	0	3	2	1	2

Q5: The self-assessment questions at the end really helped me to test my knowledge about the topic



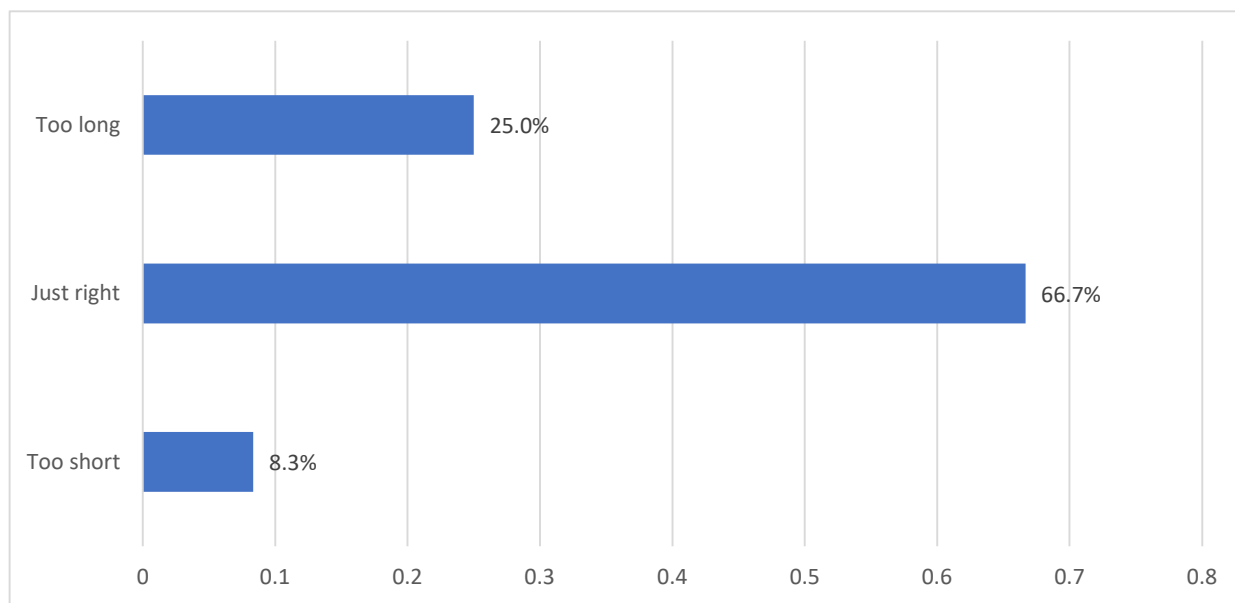
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	0	0	2	0	1	1	3	0	1	4

Q6: The overall quality of the images/graphs/videos/PowerPoints imbedded in the content was excellent



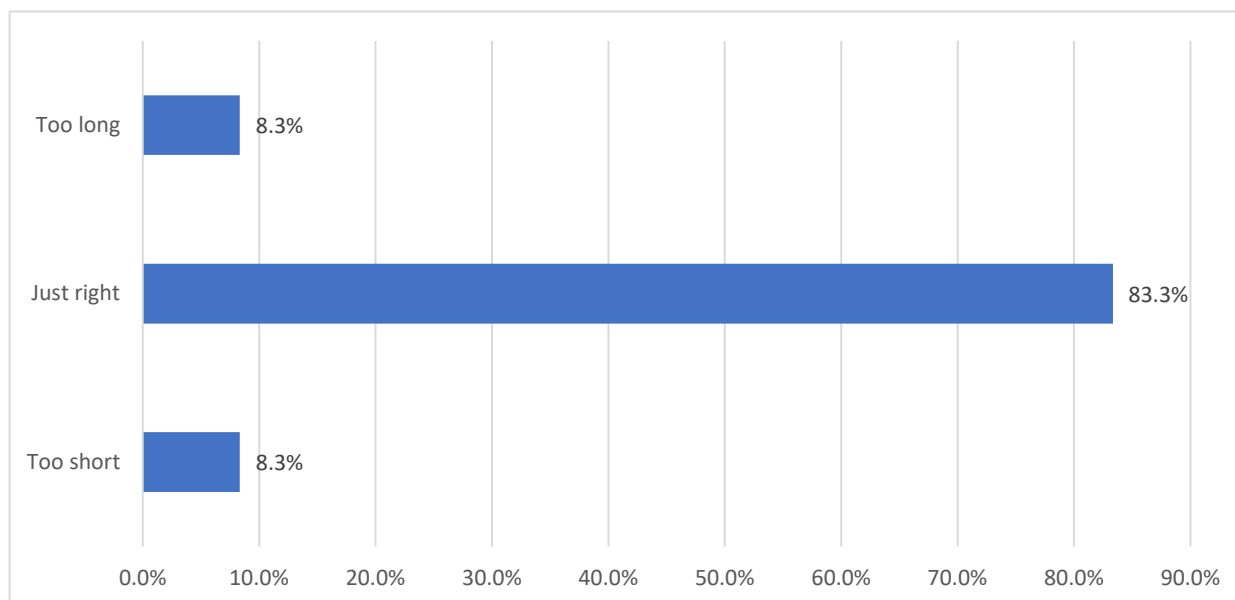
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	0	0	1	2	1	0	3	2	0	3

Q7: The amount of text for this module was:



Response	Too short	Just right	Too long
Count	1	8	3

Q8: The study time estimated for this module was:



Response	Too short	Just right	Too long
Count	1	10	1

What are the three best features of this module for you?

Videos; Reference cards; The opinion of the PRPs
mix of videos, text and diagrams/graphs.
Understanding search criteria for scientific publications; Learning about the use of publication criteria
This particular chapter contains lots of course content that is new to me as a prospective patient research partner. To be honest I had assumed that this chapter on Critical Appraisal would be one of the easier chapters in this course, since I have already studied the EUPATI Patient Expert Course, and I qualified as a EUPATI fellow last October. I really wish to thank the EULAR School of Rheumatology for opening my horizons and learning opportunities about critical appraisals; The reference cards are very beneficial to me and serve me as tools to summarise the course content; The drop down menus for further reading are of utmost importance to me because they continue to highlight the importance of each study topic.
Interesting to learn how to be critical to RCTs, before I thought that they always were of good quality. I didn't know anything about publishing of research protocols and publication checklists.
This was a huge learning curve for me and I will need to go back and relook this to get a good understanding
A short but meaningful introduction into scientific literature; A number of criteria that can be systematically used in evaluating literature; A number of illustrative examples that clarify what is being explained.
Contextual factors, critical appraisal and Bias

Please give any suggestions or comments here

Once again, some questions on topics that either hadn't been mentioned in module or not explained properly; Question 8, Espacomp guidelines were not covered (as far as I am aware) in module content; Question 11, polypharmacy was mentioned in module but not explained/defined Please can you include a time left bar or some indication of study time left as we work through the modules. It's difficult to set aside time for study without a more accurate guide on how much study time we have left to do for each module as we work through them.
More questions in basic and advanced learning The questions with the tables are very confused!
In my opinion more examples of literature of less or no quality could have been presented with explanations why this literature is of low quality.
Most subjects are very well described, but sometimes it is really too much information. for example the overview of all the checklists; For me it is not clear which information is 'obliged', and which information is in-depth study material.; The overview of checklists seems to me in depth study material, but there was als a question in the assessment. (could be done by good reading, but is that what you are testing??);
I disagree that inclusion in pubmed can be used to measure quality.

Module 5 - Development of recommendations

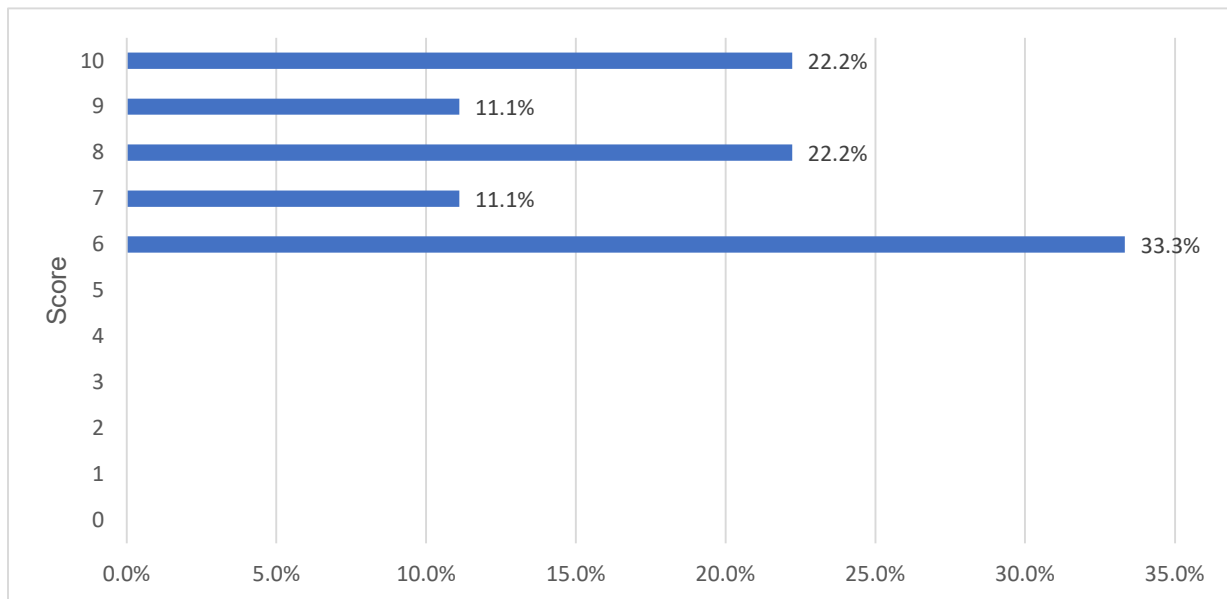
Number of survey participants: 9

Survey participants were asked to give a score between 0 to 10.

0 being very poor.

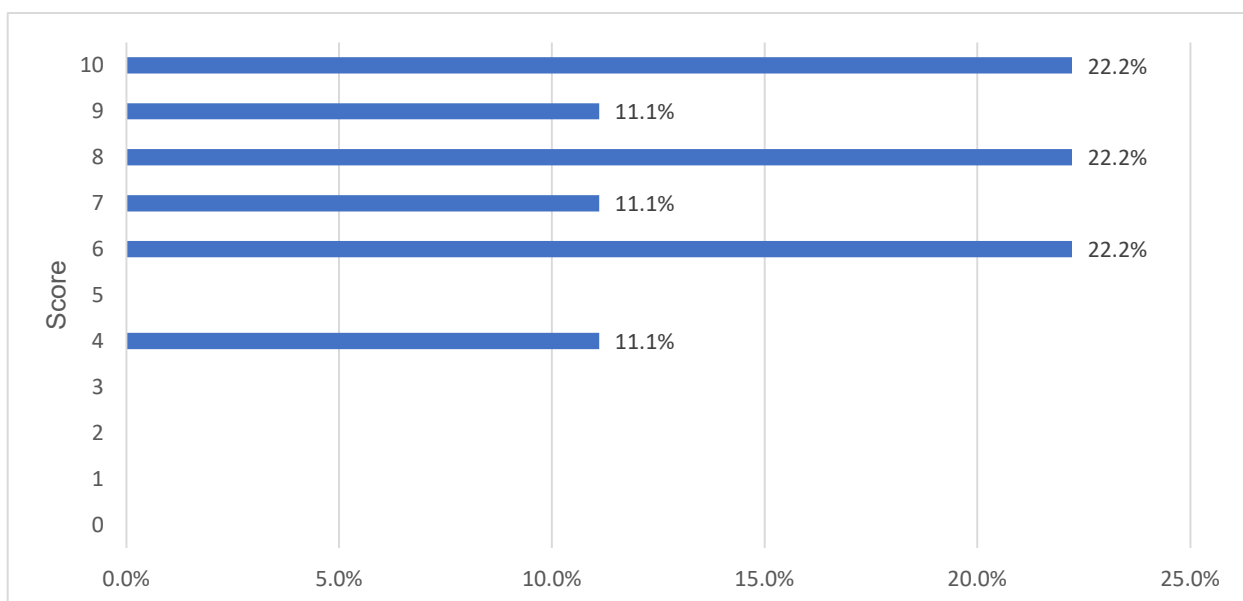
10 being excellent.

Q1: The module was very well organised



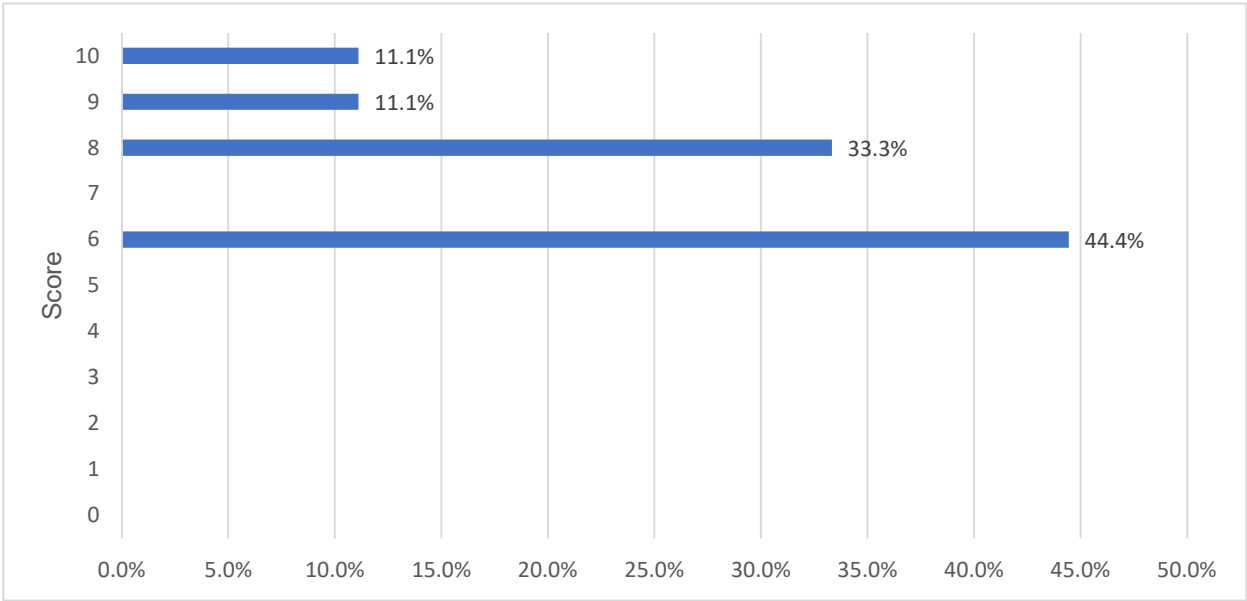
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	0	0	0	0	0	3	1	2	1	2

Q2: The learning objectives and actual teaching content matched well



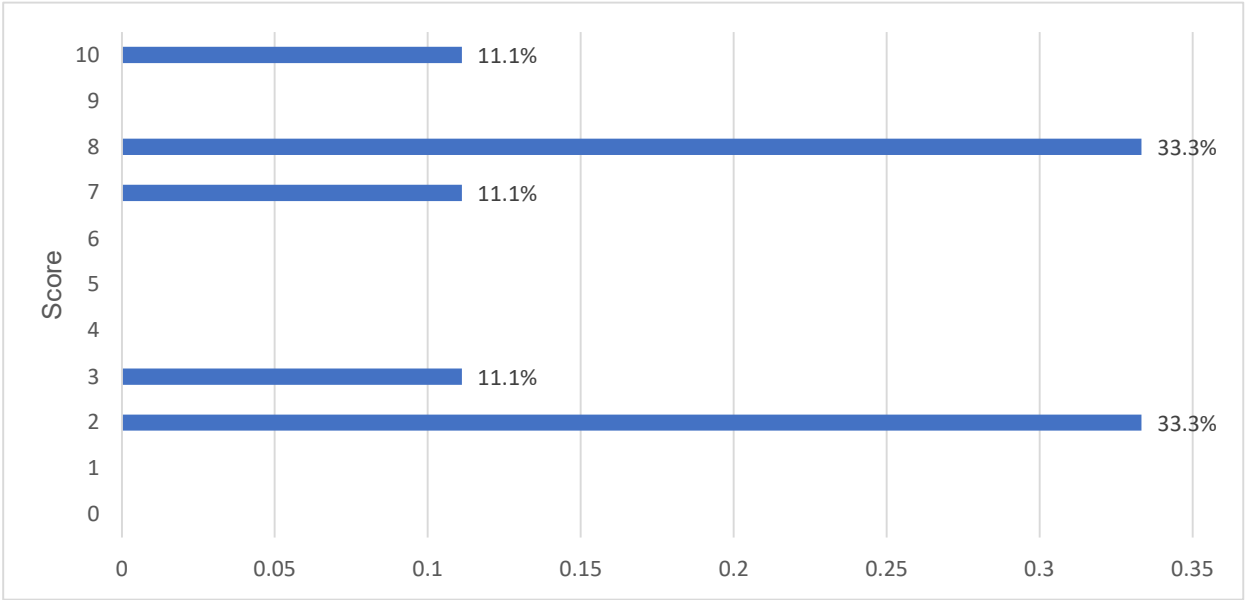
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	0	0	0	1	0	2	1	2	1	2

Q3: Overall the learning material was well presented and clear



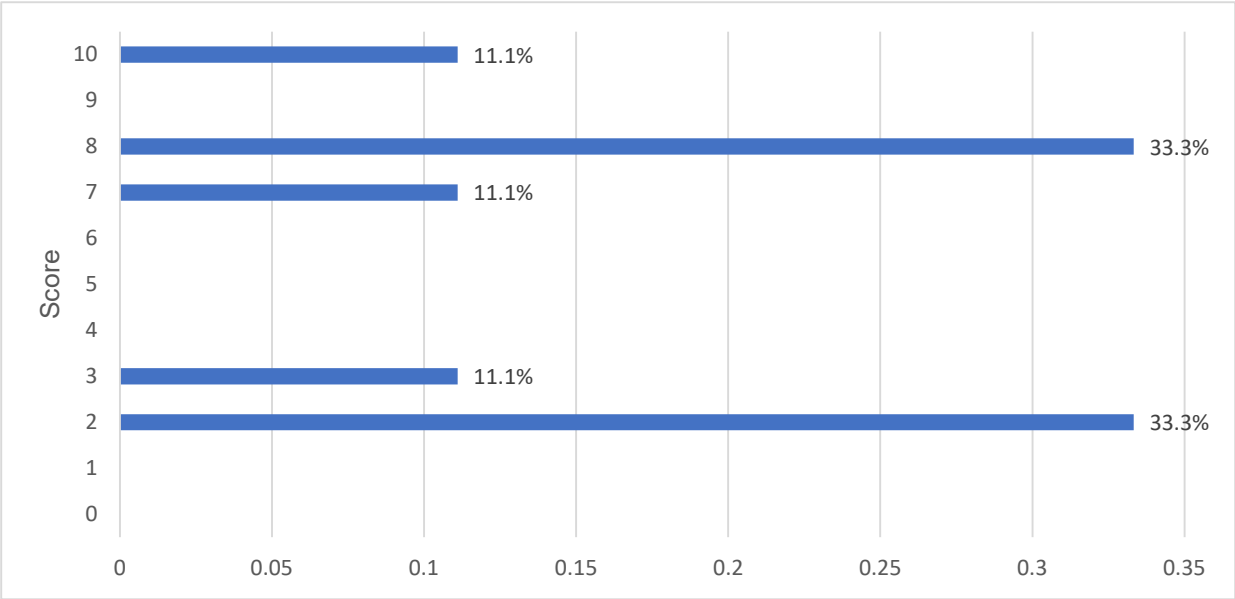
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	0	0	0	0	0	4	0	3	1	1

Q4: The assignments and questions for reflection were very helpful to better master the topic



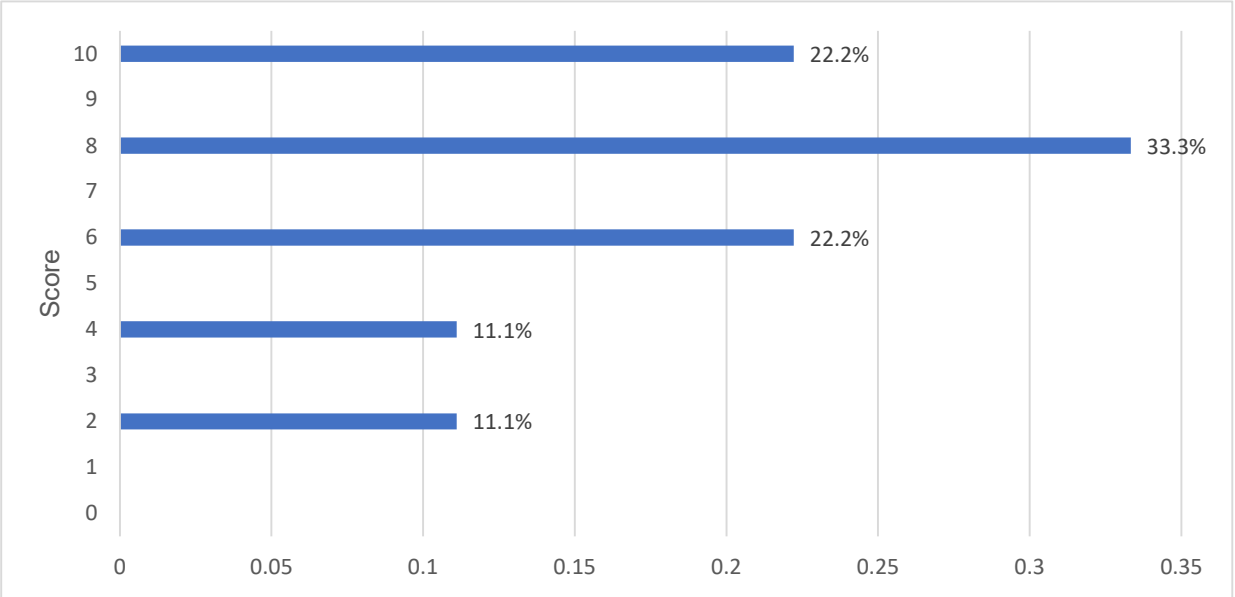
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	0	3	1	0	0	0	1	3	0	1

Q5: The self-assessment questions at the end really helped me to test my knowledge about the topic



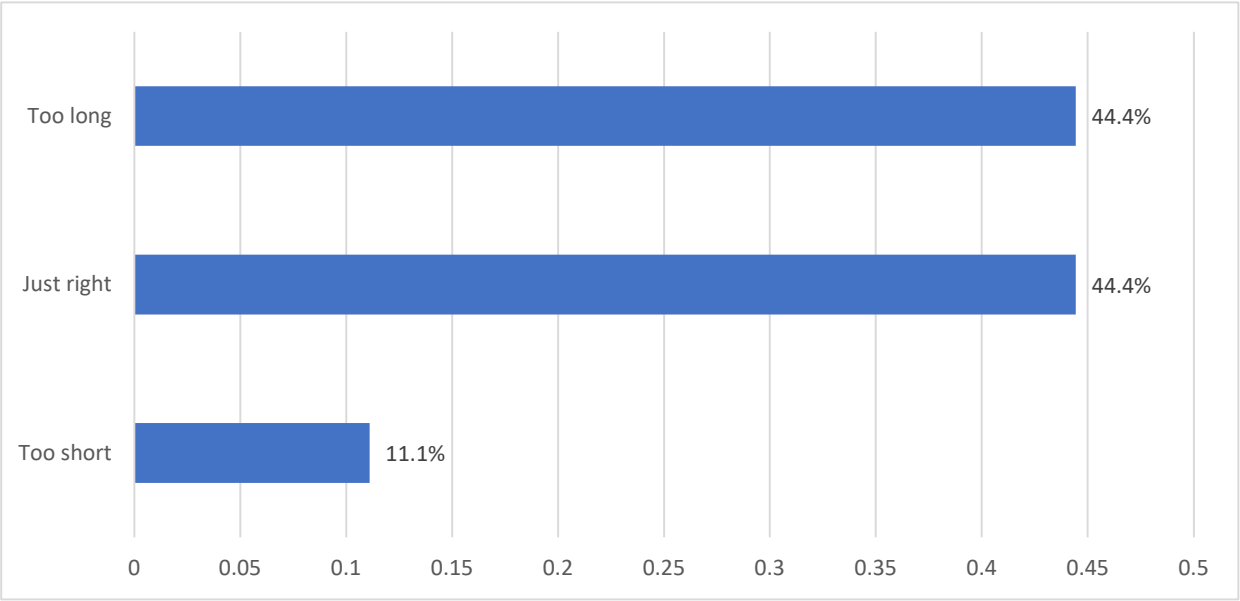
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	1	2	0	0	0	0	0	3	1	2

Q6: The overall quality of the images/graphs/videos/PowerPoints imbedded in the content was excellent



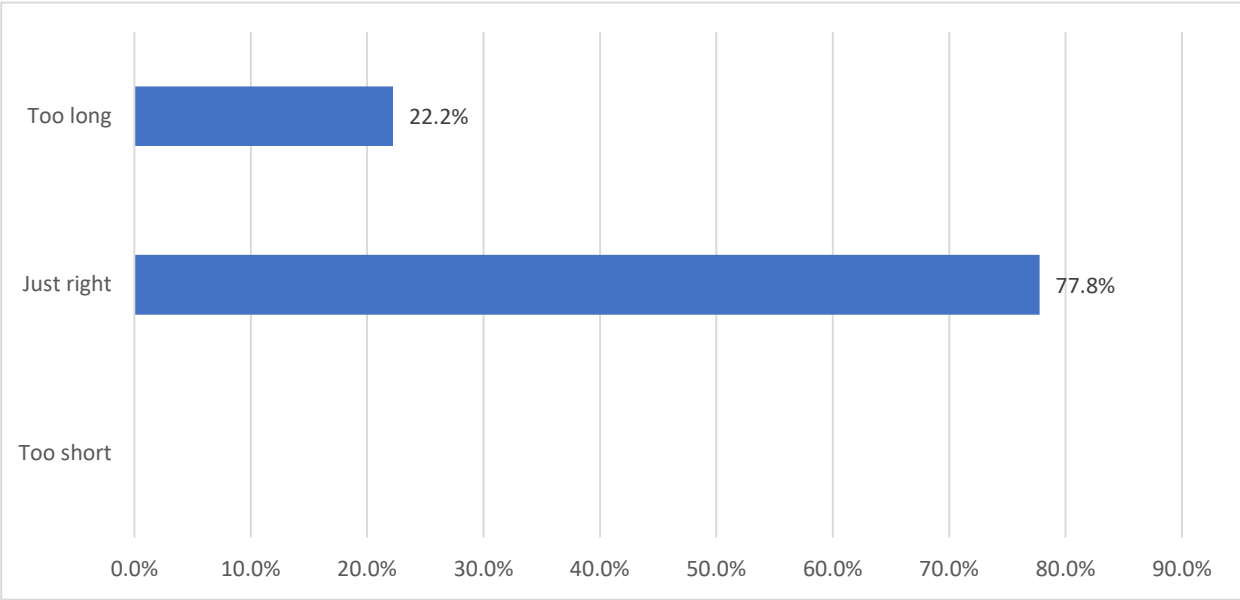
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	0	1	0	1	0	2	0	3	0	2

Q7: The amount of text for this module was:



Response	Too short	Just right	Too long
Count	1	4	4

Q8: The study time estimated for this module was:



Response	Too short	Just right	Too long
Count	0	7	2

What are the three best features of this module for you?

I feel that this module help me truly understand what Patient Research Partnership really means. The role of the patient research partner is very well explained, especially in view of the challenged that PRP's face throughout the process of SLR's.

The explanation about the differences of GRADE, OXFORD methodology, etc is very well presented. However, on a personal level, I will need to dig deeper into the differences so that I can pinpoint the different methods used in the recommendations projects.

The reference cards are amazingly helpful to me

I liked the advanced part most. It gave more information on the difficulties that you can encounter as a PRP and it stimulated me to think more about the importance of PRP's even when scientific evidence is lacking to support your views.

After reading this module I feel more confident about my role as a PRP.

The module gave me a lot of insight in the proces of how recommendations are established. The explanation on SOPs was very helpfull.

Videos, case study examples, summary cards

Assesments; Videos slides of powerpoint

Real life examples of both good and bad experiences

Good insight in development of recommendations

All topics are interesting.

1. How to ensure your participation, and not being a "token"
2. The differences between Recommendations, Points to consider and Guidelines
3. The SOPs

I have just been asked to participate in recommendations in South Africa and this is the first time a patient has ever contributed. This module could not come at a better time.

Please give any suggestions or comments here

The basic part gave very much info on several systems (e.g. GRADE, OXFORD etc). I am not sure that this information is not too much for a PRP. When necessary as a PRP you can ask other task force members (the methodologist) to be "educated" on these topics.

The links/references in the module often did not work.

I missed the Oxford reference card. I think the GRADE reference card was shown twice.

Once again some questions in the assessment were not covered in the module. Also, some questions related back to previous modules rather than focusing on the module just taught.

The "time for brief reflection" box for notes doesn't always save my text. There seems to be a word count limit and it's low, and you don't know you've exceeded it until you try to save your notes - you end up losing your notes. I am now saving notes as I go along in a separate word document on my computer.

Several links do not work; the blue Euler balk in the base of the screen is too big
The assessments could more focus on the most important topics, instead of the focus on easy to examine topics.

I am really concerned about the final exam: so many text and facts to (re)learn and remember after more than 1 year study. And when not passing the exam a new attempt only after 1 year, instead of 6 to 8 weeks. I think this model is not really fair after all studying and self assessments.

I don't watch the videos because it takes a lot less time to read the transcripts. The self assessment questions are too detailed in my opinion. Remembering acronyms and small details from a long is not really learning, I miss questions about the bigger picture.

The 'Cochrane' url's do not work properly, however I managed to find them just the same. In one of the assignments, although my reply was correct, the online e-learning platform marked it as incorrect.

Module 6 - Researcher-PRP communication

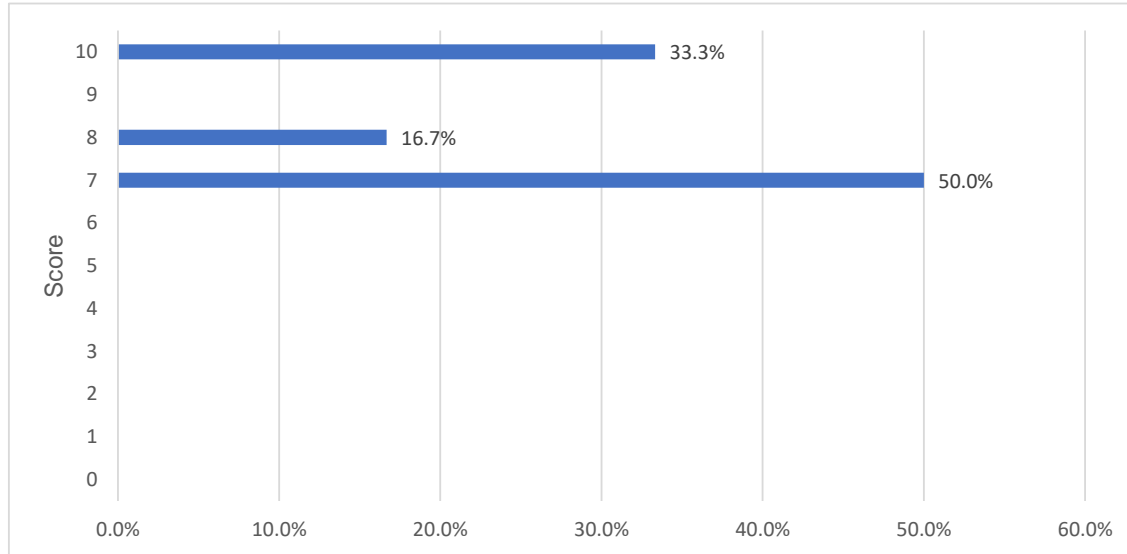
Number of survey participants: 6

Survey participants were asked to give a score between 0 to 10.

0 being very poor.

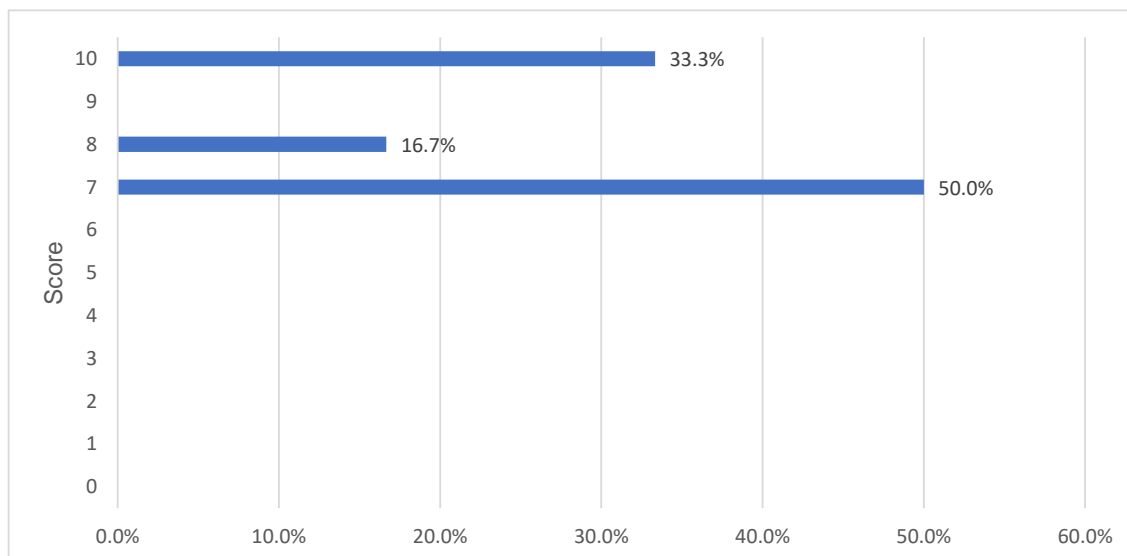
10 being excellent.

Q1: The module was very well organised



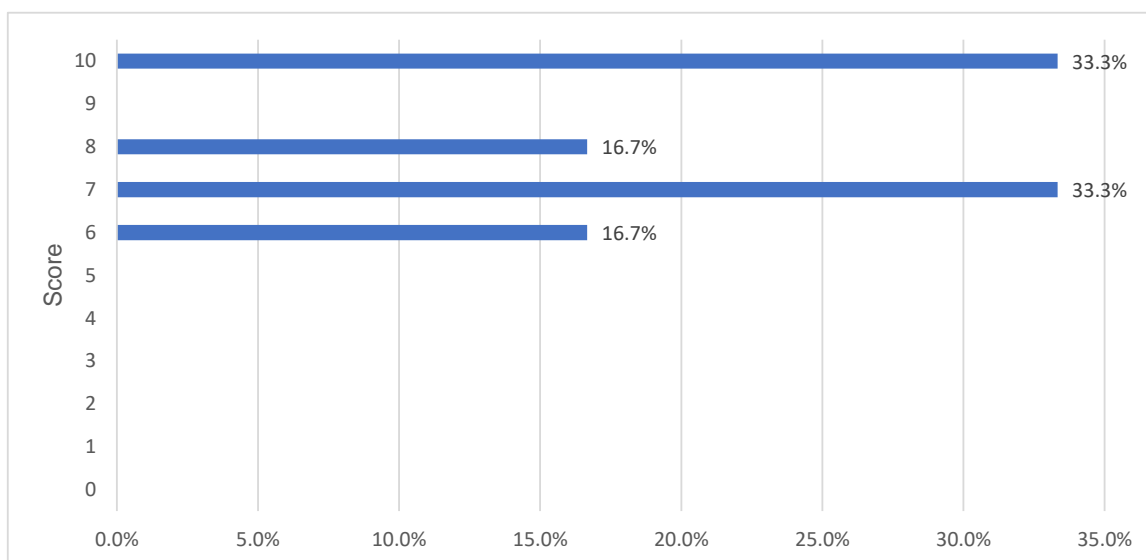
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	0	0	0	0	0	0	3	1	0	2

Q2: The learning objectives and actual teaching content matched well



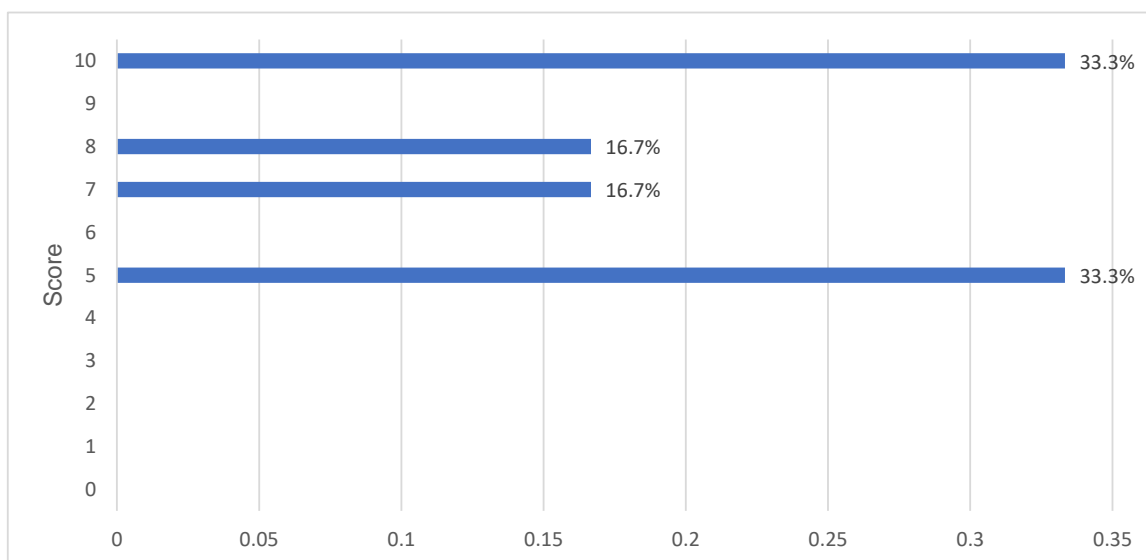
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	0	0	0	0	0	0	3	1	0	2

Q3: Overall the learning material was well presented and clear



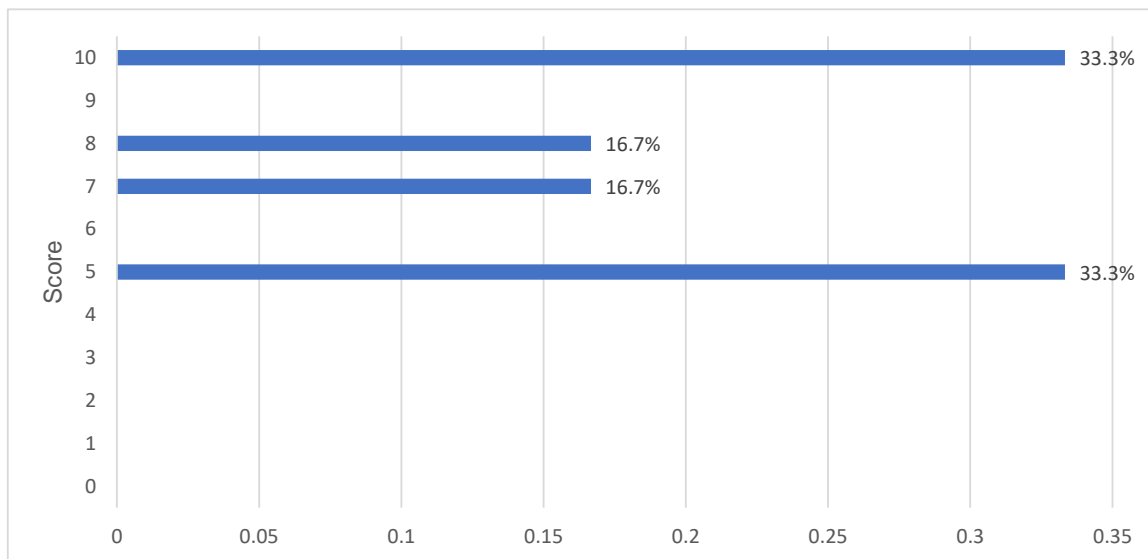
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	0	0	0	0	0	1	2	1	0	2

Q4: The assignments and questions for reflection were very helpful to better master the topic



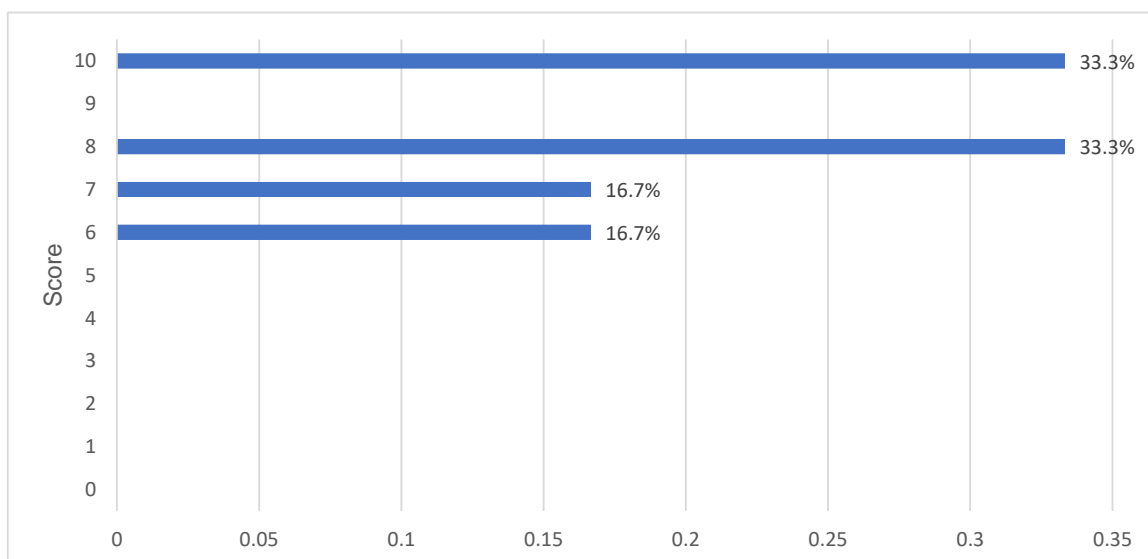
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	0	0	0	0	2	0	1	1	0	2

Q5: The self-assessment questions at the end really helped me to test my knowledge about the topic



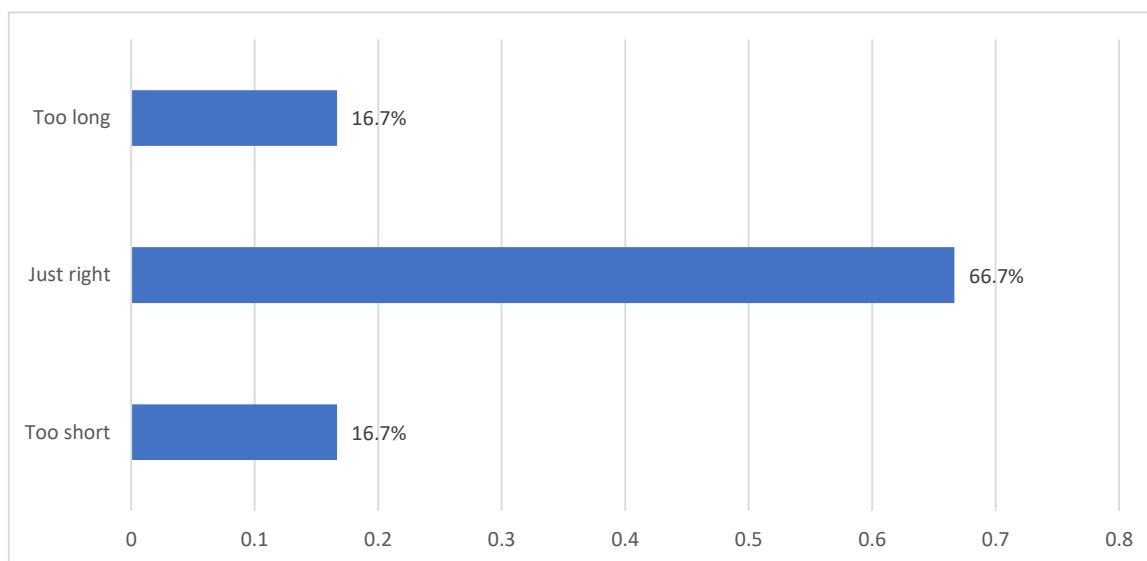
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	0	0	0	0	1	0	0	2	1	2

Q6: The overall quality of the images/graphs/videos/PowerPoints imbedded in the content was excellent



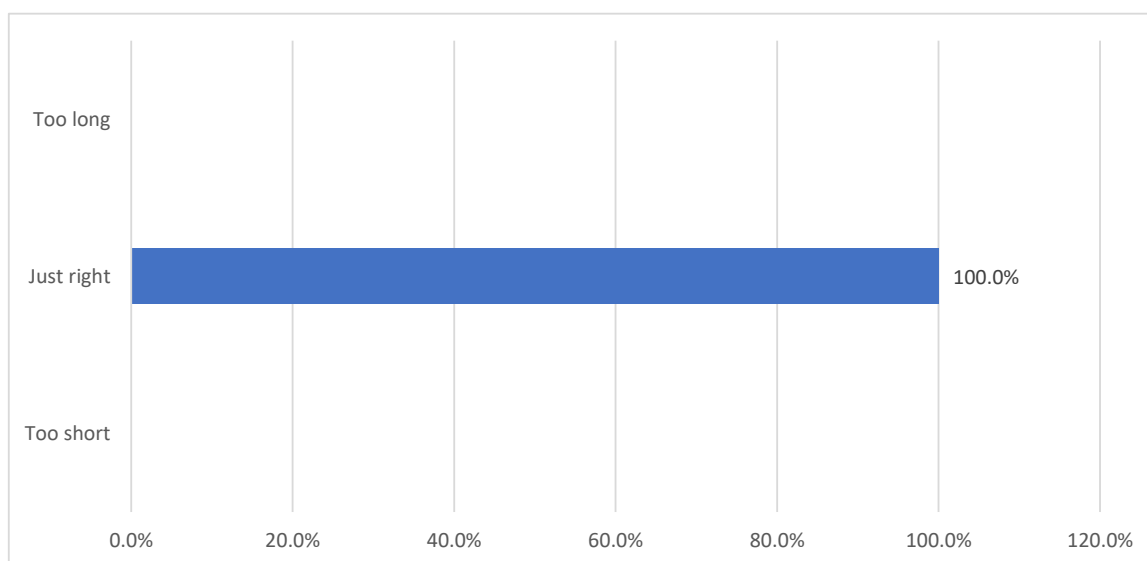
Score	0	1	2	3	4	5	6	7	8	9	10
Count	0	0	0	0	0	0	1	1	2	0	2

Q7: The amount of text for this module was:



Response	Too short	Just right	Too long
Count	1	4	1

Q8: The study time estimated for this module was:



Response	Too short	Just right	Too long
Count	0	6	0

What are the three best features of this module for you?

The reference cards are brilliant
The contribution of Karim Raza
The practical tips shared in the module for effective communication The reference cards The video clips from the PRP Meeting recordings by Professor Karim
The text was clarify and helpful The study was very interesting
The reference cards. The fact that the PRP has to do it together with the researchers, that s/he has to be pro-active Saying NO is also an option
Enhancing confidence that I can make a usefull contribution to a project Emphasizing my unique role and expertise as a PRP Emphasizing a cooperative, constructive and open attitude and at the same time being proactive critical and assertive towards professionals when working together in a project.218:218

Please give any suggestions or comments here

The links in the text often do not function. E.g. the link to the reference cards was not working and it was only after a while that I "discovered" these cards in the content of this module. I think this topic is something where interaction with other future fellow PRP's (and maybe professionals) could be helpful for the development of confidence and assertiveness in acting as a PRP.
Most of the links do not work Communication is a difficult subject for this course: there is very much information, but you can only learn communication bij doing! I really miss interactive settings with other participants in this course. Like before: the assesment questions are not always really suitable for multiple choice
I truly enjoyed this module. It provided great insight about the challenges faced by PRP's. I think that before PRP's should be involved in real-world research projects, they ought to have further face to face training in mock research projects.