**Script**

**EUomo's fourth online webinar on Active Surveillance:**

**“Active Surveillance: Lessons learned from Recent and Actual Specialists and Patient Testimonials**

**What is really fundamental to know?”**

**Thursday, March 29, 2022 from 5:45 pm to 6:45 pm CET**

Cosimo Pieri = CP

Tania Estapé = TE

Prof. Hein Van Poppel = HVP

Chris Banga = CB

Monique Roobol = MR

Riccardo Valdagni = RV

Ioannis Vanezos : IV

Thrainn Thorvaldsson = TT

Laura Bellardita = LB

**CP:** Good evening to everyone. I am Cosimo Pieri from Europa Uomo Italy, aslo part of Europa Uomo Europe.

With me is Tania Estapé from Barcelona who organized this fourth webinar with me on active surveillance.

We did last year last year (2021) three webinars on active surveillance with many medical specialists, many patient testimonials and many people attended and these were put on YouTube.

You will question why we do a 4TH one? The idea was that we thought it could be useful because for two reasons:

1. To give the possibility to people to attend something that could be a sort of ‘the best off Active Surveillance webinars, something shorter which could give a general introduction idea and then motivate the people to listen to the full webinars.
2. We thought it could be useful to do a sort of virtual round table by taking some clips from the different webinars trying to create a logic conjunction between the specialists presenting the arguments.

The first 3 webinars were related to Early Diagnosis and in particular Active Surveillance. How to [*coexist*](https://context.reverso.net/traduzione/inglese-italiano/coexist) with low grade PCa with also maintaining an high QoL?

The arguments were:

* Early diagnosis and AS, how to balance under/over-treatment?

(How to peacefully [*coexist*](https://context.reverso.net/traduzione/inglese-italiano/coexist) with low grade PCa, maintain an high QoL?)

* Which are the needs of AS patients during their patient journey?

In this forth webinar we want to provide a Summary of the lesson learned on Active Surveillance putting in evidence:

1. A brief view of Prostate Cancer, the evolution of the medical approach, the Active Surveillance Strategy.
2. Better quality of life with Early Diagnosis and in specific in cases where active surveillance may applied.
3. How Active Surveillance Strategy was developed and the evidences of this solid and valuable strategy which gained a top level of reliability for the patients with low grade of prostate cancer.
4. Patient testimonials and Which support to patients may be given by local patient organizations and by mental health psychologists.
5. Which recommendations may be done to cancer patients and his family to cope with active surveillance anxiety and other psychological problems related? The need of professional help in this journey.

In order to cover what above we have selected specific sections of the above presentation integrating with our indications.

Specialist speakers were Hendrik Van Poppel, Monique Roobol, Ricccardo Valdagni, Chris Bangma and Lara Bellardita.

Testimonials Ioannis Vanezos, Thrainn Thorvaldsson and Cosimo Pieri.

I will introduce the first 3 video clips and Tania, who is a psychologist, will introduce the 2 others which are more related to testimonial and psychological aspects.

At the end we will do a Q/A session but obviously this is something is a going on activity. You can ask some questions now or we can discuss later through the Europa Uomo contact part.

**PART 1**

Now to start I will introduce the first part of the video. The first speaker that I have selected is Prof. Hein Van Poppel. Hein Van Poppel is the Adjunct-Secretary of the EAU - specific for education, co-founder of Europa Uomo and chair of our Scientific Committee.

1A

The introduction of Professor Hendrik Van Poppel points out the number of prostate cancer cases through Europe and explains the difference between the danger represented by the different types of prostate cancer and how the specialists may classify this level of danger between one and the other types of prostate cancer.

**HVP:** Today we know that one out of seven men in Europe will develop prostate cancer, and it's the most common male cancer in the European Union these days. I give just an example in Germany prostate cancer today kills more men then colorectal cancer does. In the UK more men die from prostate then women from breast cancer, which is not the case yet in Germany as you can see.

Now, do not forget that prostate cancer, although it is not killing like for instance pancreatic cancer like lung cancer, and there is incidental prostate cancer in the general male population at autopsy in more than 50%, do not forget that the Tigers, the bad ones, are responsible for 11% of all male cancer deaths. Which is enormous and we need to do something about it. But this makes also that we are feared about prostate cancer because it is still a killing disease, it is not a disease of old man that die with it instead of from it.

And this has to do with the differentiation of the tumour. A tumour can look very much like normal parenchyma of the prostate, or it can be very aggressive where you hardly can recognise that this is prostate and this is the different Gleason. Mr. Gleason has made this classification from one to five and a pathologist will say that the two most common grades in the specimen that he sees, in the biopsy, or in the radical prostatectomy specimen, is for instance a grade 3 plus grade 4, and this will then make a Gleason score of 7. Everything that is above 7 is bad. Gleason score 8, 9 and 10. Everything that is below 5, we do not even consider this to be cancer any longer these days, it's not even mentioned in the pathology report.

**CP:** Now, I introduce the part where Prof. Van Poppel explains how we can try to differentiate between the treatment between the cases of prostate cancer, in particular he will introduce the concept that was started in the beginning of the PSA anti-gen blood test, that was important in the beginning but also created the concept of overdiagnosis.

1B

After having classified the level of danger of the prostate cancer, Mr. Van Poppel went in details of explaining why we always try to find the best treatment for each type of prostate cancer. During the presentation also he gave us the indication that the original instrument to detect prostate cancer, the PSA was good but not good enough, because a lot of cases, which were not so bad in terms of danger, they were wrongly seen as very dangerous. So it created problems in overdiagnosis , over treatments and over side effects

**HVP:** If we would treat all these people, we are overtreating, obviously.

**HVP:** PSA was introduced in the early 80s in Europe, and you see that what was the immediate consequence by PSA testing, is a high number of more cases of prostate cancer were detected. So we have diagnosed people that some of them did not know, did not need to know that they had prostate cancer.

1B

**CP:** You have seen the concept of overdiagnosis comes out. Now I introduce another specialist who was presenting in the 2nd webinar, Prof. Bangma, who has a very important role in active surveillance as he is was one of the visionaries of this strategy treatment and he is part of the urology department in Rotterdam Erasmus. He will again explain about the PSA and the concept about overdiagnosis aspects ; he showed us that this basic idea was good, but to add another issue that it was creating a lot of overdiagnosis

**CB:** I can only start with telling you the story of screening and prostate cancer, because in the 90s we started with PSA. PSA was an easy test, it was a blood test and everybody could get their PSA from the GP or from any physician. It was cheap so from that moment onwards there has started some kind of awareness that you could find prostate cancer by means of PSA triggering biopsies in the general population. And that's what people did, so more or less PSA started the anxiety. And so we introduced screening, there was an enormous screening activity amongst Europe. A large randomised study and that showed in the end that screening could reduce mortality. So the mortality due to prostate cancer could be reduced by the screening, and fortunately it also introduced an enormous amount of recognition diagnosis of these harmless and slow growing tumours that Thrainn was telling us about. And that’s what we call overdiagnosis. Actually, you're being diagnosed with the cancer, however this cancer is harmless for you because it never gives you symptoms and therefore you live with the anxiety. Because it has to be checked again and again and again.

**CP:** Now we have seen more or less that prostate cancer which were the start-up of this way to understand the first ideas of possible understanding of early diagnosis.

Now we will go more in details about the aspects of active surveillance and what it is, what is this type of strategy of treatment and we will see also the way to control. Because this is a decision and this is a decision on strategy in attending to other treatments. We will start again with Hein Van Poppel, which is now giving the idea what is the basic concept of active surveillance.

**PART 2**

2A

**HVP:** So there must be another possibility to recognise which patients could just be observed without treatment. And this is what we call active surveillance, but this indeed means you are under surveillance. This is not nothing you need regular monitoring, doctor visits, you need to have a delayed invasive treatment if there is tumour progression. But it's the only strategy to diminish the over treatment of minimal cancers.

2B

**CP:** Prof. Van Poppel was also explaining the use of different treatments and in particular active surveillance and pointing out that it is a treatment which is easier as there is no physical treatment but in the same time it is more complex because it requires a long work during the years with the patients.

**HVP:** Now there is an increased use over the years of active surveillance and you see it here in red. That's increasing. Luckily for low risk tumour, ADT is less and less given. Still in 2009 far too much, this is a disease that should not be treated with hormones. There is still an increase in radical prostatectomy and radiotherapy.

2C

**CP:** Now Prof. Van Poppel explains the criteria which are used to manage and define the patients journey and also the importance of being able to be ready in every part of the active surveillance strategy to turn to active treatment in case it is needed.

**HVP:** Quality of life as shown by your team in Europa Uomo is best when a patient is on active surveillance. So how can we eliminate the second most killing cancer without having any problem and not forgetting that there is active surveillance. We need to use PSA properly and we should treat actively with radical prostatectomy or radiotherapy those at risk to die from prostate cancer. And manage with active surveillance, those with low and part of those with intermediate risk and this will decrease the costs of prostate cancer, decrease the mortality and improve the quality of life.

2D

CP: Now we have a session where professor Chris Bangma, another authority and innovator of the active surveillance, describes again in more details the use of active surveillance and warns about the over treatment

**CB:** And therefore active surveillance was invented and it had to be done in protocols because we did not know the behaviour of all these tumours that were diagnosed but were Gleason 6, they did not seem to be aggressive. So this was overdiagnosis with this overdiagnosis also introduced overtreatment and that is a little bit the Ettore story. There was a Gleason 6 tumour and it was operated upon with side-effects for many, many many years and the same goes for radiotherapy. And these side-effects, of course, were unnecessary if you looked at the biology of the tumour because you could have lived a very long time and maybe forever without an operation.

2E

**CP:** Now we will give another view to classify prostate cancer tumours and then he gives us the idea when it is possible to apply active surveillance.

**CB:** But everybody is familiar with the fact that there are multiple, let's say aggressiveness, levels of these cancers. And some of them they act like slow turtles and others acts like birds, you cannot catch them, they are very aggressive and whatever you do, even if you try to screen them early, they will results in metastatic disease and you will die of it. And then there is a large part of towards in between that grow, they need to be treated because they will become symptomatic before the end of your life, but unfortunately you will suffer the side-effects of that. We are talking about the turtles, very slow and non-progressive cancers in prostate cancer.

2F

CP: Again now professor Van Poppel explains the criteria of applying active surveillance and how the medical community is able to use effectively these type of decisions in order to keep under control and without treatment patients in active surveillance and also at the same time to be able to detective immediately when people need to go out of active surveillance and go to a heavier treatment.

**HVP:** The other question, how do we detect the cancers that might be available for active surveillance? The most important is the information of men, to tell the patient that what is his risk for having prostate cancer, and when he finally has prostate cancer, that it might well be that you not gonna treat him, because if the patient does not know that beforehand he will say you detected cancer in my case, and I want to have treatment, I want to get rid of it, but he must understand from the beginning from the initial information that there is a likelihood that he can go on active surveillance.

**PART 3**

**CP:** We have seen that Active Surveillance has a very knowledgeable protocols and very careful protocols that can manage the journey of the patient leaving active surveillance when it is possible and be ready to go to another type of treatment when needed.

Now, we selected some clips from Monique Roobol who is a Professor in the Erasmus Rotterdam and is in particular epidemiologist. Monique was doing a lot of work starting from the 90s and that was very important work because at that moment it was not clear if it was possible to use the technique/strategy like active surveillance.

3A

**MR:** So this is the reason why we started the European Randomised study of Screening for Prostate Cancer. It started in 1991, the year that I started to work in urology and you can see that over time approximately 260,000 men have been randomised in Europe in eight countries to a control arm where we do nothing, only follow up. We see what happens to these men in daily clinical practices. In addition we had an intervention arm where we actively screen these men with the use of the PSA test and the TRUS-guided systematic prostate biopsies. We already knew at that time that there was a lot of prostate cancer around, and then there was prostate cancer that never causes any problems and that there was no difference between treatment and surveillance. So already at that time we realised that when we started active searching for prostate cancer it could very well be so that we would detect a lot of prostate cancer that would not harm the patient if left undetected and untreated.

3B

**CP:** So from this few clips you understand that active surveillance was started very carefully with very important data. So what we are using now, is experience done in tens of year. What is important obviously, once we know that it is a very important and effective technique, it is important to speak with the patient. Because obviously, the patients can be at the moment of diagnosis in a situation where he is a little confused.

**MR:** And that is something that obviously refers to active surveillance. But then immediately comes the question what is the risk if we do not treat actively, with for instance radical prostatectomy or radiotherapy?. Because it's a very strange message for recently diagnosed men. You tell them in one consultation ‘Okay, I'm sorry to say this, but you have prostate cancer’ and the next sentence is ‘but we will not treat you actively’. That is a strange message and people will start worrying and thinking: OK, what's going on here and then immediately obviously the good messages of active surveillance must be there.

3C

**CP:** This very important aspect needs to be put in front of the patient in a very clear and important way. Now another point that gives validity to this technique, is the fact that the journey is not a one-shot treatment. So Monique now gives the idea on how this is handled by the specialist.

**MR:** I take this example of the PRIAS study. Perhaps you have heard of this. PRIAS is a global study which actually is an interactive website open for all urologists worldwide who can have a login and use this interactive website to follow their patients, which have opted for active surveillance.

3G To end with this session we had a very good explanation that we want to report here about professor Chris Bangma which points out the need of a personalized treatment and diagnosis and patients journey which is now available to patients

3D

**CP:** Now we leave Monique and selected the clips from the presentation of Prof. Valdagni. Riccardo Valdagni is an authority at least in Italy but also over the world. He is part of the community which started actively to propose active surveillance. In fact, since 2003 he is been managing the prostate cancer program in the national cancer institute in Milan. So he has a lot of experience. We invited last year professor Valdagni in order to explain us ,if “active surveillance can be confusing for patients?“. In specific to explain which are the elements that give the patient enough understanding and fast understanding of the benefits and the effectiveness of active surveillance?

**RV:** The answer, from my experience, is that the patient should receive clear, unambiguous, balanced information about three very critical points. First, that low risk prostate adenocarcinoma is not a malignant disease. It is not a beast, as Ioannis said. And this is the true reason why active surveillance is proposed as one of the available options, alongside radical prostatectomy, radiotherapy and brachytherapy. The second critical point regards our medical language, that should be evidence based: that means based on scientific truth as expressed by national or international guidelines. And the third critical issue regards the decision of choosing active surveillance among the three treatment options, because this is more complex than the usual decision making process in medicine. As literature data teach us, radical therapies are equally effective in terms of oncological outcomes, but they are different when we consider the possible risks of side effects caused by surgery or radiotherapy.

3E

**CP**: In particularly, the next question was how to choose between the treatments. How to support the patient to allow an effective shared decision. Professor Valdagni gave also us a very good explanation of the clinical evidence of the value of using active surveillance for low grade malignant lesion

**RV:** to share the decision-making process with our patients. The choice should be the result of this shared decision process.

In medicine we know there is a linear path: the patient asks the clinician and in general the clinician prescribes the optimal therapy. Due to the availability of different options, the scenario in prostate cancer is more complex. I mean that clinicians should not prescribe – rather propose to the patient the possible therapies/observational strategies and then they should explain the possible treatment-related side-effects as well as the rough percentage of risk of that specific toxic event.

I think the message for patients is be an empowered patient. From a practical point of view, do not delegate your decision to clinicians or relatives – we physicians sometimes see the pressure on the relative to choose one or the other option.

Another important point, if anxiety is a problem for the reasons that we have seen: ask for psychological or social support. Search for multidisciplinary prostate cancer centres or units because this is the optimal way to manage the possible physician bias and minimize regret. And ask to be supported by patients’ associations like Europa Uomo. That is really fundamental.

3G

**CP:** After this fast indication from Riccardo Valdagni we have select some indication from Prof. Chris Bangma, which is going in the same direction and explains and points out the aspect of personalised treatment when the specialist meets the patient immediately after the diagnosis.

**CB:** We have checks and controls and we're getting into risk evaluation that is personalised.

This is what we are working at in Europe at this moment. That is a personal risk assessment as you can understand the MRI in one person is not the same as in the other person and the PSA decline or improved increase is not the same. We are not the same people like we're sitting here, we all have our individual stories. These individual stories are full of individual risk elements and we would like to see to say to the one patient OK you need a biopsy next year but to the other patients you can wait five years with your biopsy. And that is exactly what we want to accomplish with a personalised risk strategy.

**PART 4**

**CP:** With this, we finish the 3rd part of this selection of video clips. Obviously as I said in the beginning this is a selection and this is the selection, from one side gives a good overview and from the other side gives motivation to further understanding. As I said, this is a selection, you can also have a look on all the complete webinars. Now I will leave the speech to Tania. We have the other two parts which are related to a selection of patient testimonials and a selection of the indication that was given by Lara Bellardita, specialist.

**TE:** Hello, let me introduce myself. I am Tania Estapé, clinical psychologist and happily recently elected as a Board members of Europa Uomo. That is for two reasons because one is because I am a women and a women is part of the Board of Europa Uomo and the other positive thing, I think, is because I am a clinical psychologist working with prostate cancer patients from 2000. Maybe for different points of view, to help, to improve quality of life of cancer patients. And I want to thank Cosimo, to have shared and have done the main work to build up this webinar. Now, as he said, we have testimonials that is a very interesting part. We need to have the voice of the patients and we are beginning with Ioannis Vanezos who is from Cyprus and is a very kind person and part of the Board Europa Uomo. I think he, and Cosimo and me can gives the point of view of Mediterranean culture which is different from some other countries.

4A

**IV:** Good afternoon to everybody. It is my pleasure to be with you and have this opportunity today and share with you my medical journey towards reaching the Active Surveillance. As Cosimo indicated, my name is Ioannis Vanezos and I am of Greek Cypriot nationality and right now based in Cyprus. When my PSA jumped, about 10 years ago, my local urologist requested a MRI and then a biopsy resulted in a Gleason score 2 over 3. As I was travelling before I took any decision, I have checked with specialists urologists in Cyprus, in Egypt, in Dubai, in Bahrain and then the “theatre” started. Every doctor, depending on his specialty, he was recommending his way of treatment. That, based on my previous experience, I took it very calm, very simple, very very slow to my decision and I have decided to go for the proposal that I have got from one doctor in Dubai and one doctor in Cyprus that they have suggested Active Surveillance. Believe me, I was very much confused but I can tell you honestly, with my hand on my heart, that I wish on that time that I knew the existence of Europa Uomo. I think they were just at the beginning at that time. We were depending on information we were getting from professionals, from people who had the experience and even from some patients. Now, you will ask me … Ioannis what is your resume out of this journey. Awareness and early detection is the pillar to start your journey. And we all know the fantastic work Europa Uomo is doing concerning the above two pillars. Being on Active Surveillance for some years, I think, I have ONE and only one concern and this is the very simple expression: WHEN THE BEAST WILL WAKE UP ??? My major problem is the psychological stress and I am very happy to today we will talk about the psychological stress. Till now, I have to admit that it showed that it was a perfect decision but at least today I know where I am standing and what I can expect if things go the wrong way. In spite of normal ageing health complications, at least I am enjoying a normal family life. My major “headache” is the bloody MRI and the agony till the results are written and given to me in my hand, to give it to my urologist, I say to myself OK Ioannis you escaped it once more

**CP:** OK, now there is Thrainn. Thrainn Thorvaldsson is our friend from the association from Iceland. And I have selected some parts of his testimonial.

4B

**TT:** Active surveillance has made a huge impact on my life. If I had not thought of active surveillance in 2005, my life would most likely have been different, and I would have missed considerable quality of life. My active surveillance story is a little bit special. I started PSA testing over 20 years ago in the year 2000 when I was 56 years old. No reason for starting, I just read in a newspaper that PSA blood test could be of importance. My PSA value had reached 10 and I needed to have a biopsy. The result was that I was diagnosed with prostate cancer, Gleason score 6 (3+3). Second opinion showed the Gleason score 7 (3+4). I asked the doctor what to do. I’ve booked you for a surgery next month was the reply. At that time, almost all men diagnosed with prostate cancer went into treatment. The second question is the importance of second opinion. I think it's most important to get different opinions in diagnosis not least when decision has to be made that can affect quality of life or the person in question.

**CP:** The 3rd testimonial is from myself also as I am under strategy of Active Surveillance since 2017 and now every confirms it is stable.

4C

**CP:** So the treatments were the surgical prostate removal or the radiotherapy. And one was the strategic method of control, as we say and as I knew at that moment called active surveillance. Together with the urologist we find out that due to the general situation of the age and the grade which was low grade of prostate cancer, active surveillance could be the most logical choice. Also, the urologist alerted me immediately that there are possible psychological issues because many patients do not want to keep the cancer inside their body. Here what I want to say is that in this approach, even if it was only one doctor, only one urologist, the approach was multi-disciplinary. So this was a very good approach in my opinion from the urologist, because he didn't push in one direction or the other. I think I was lucky to find an association like Europa Uomo in Italy. Because it gave me two possibilities. One to understand more about my choice. And the second point is the auto-help groups because in our association we strongly support the auto-help groups where patients meet together, they speak together and share experiences and suggestions with psychological support.

**TE:** We have listened to this very interesting testimonials. We have some things that they have pointed out that are very interesting. That is for our basic knowledge, we feel that if you have cancer, you should have it removed from your body and so this is a very difficult exercise to take this decision to live with the cancer because it is not fear of recurrence but fear of progression because every morning, as one patient of me told me, you wake up knowing that the cancer is inside you and I think the 3 have explained it very interestingly. Ioannis has pointed out on the difficulty on having information and on the dangers of navigating for the search on Google because you can have good information but also information that is scaring. So it is good to be careful with information you can find on the web.

And the last video is from Lara Bellardita. Lara Bellardita is a colleague of me, who is a clinical psychologist, psychotherapist and Phd in psychology. And she is very involved in health, psychology and behavioural medicine. And has a longstanding experience in collaborating with prostate cancer unit in Milano, Italy. Her search and clinical focus has been on psychological implications in prostate cancer but interestingly, she has focus on Active surveillance because Active Surveillance is a focus very important for psychologists because as the testimonials ha said, the fact of not having consequences of surgery for instance may lead to other consequences for instance high anxiety and in terms of quality of life thoughts or feelings that cancer can come or that you have cancer inside. She has developed also specific interest in healthy lifestyle and health promotion together with quality of life and of course psychological well-being. And for me is a pleasure to present her and to say to men that if some patients need to go to a psychologist, is not because he is crazy but perhaps needs some help to cope with the situation of anxiety because you have a tumour inside.

**PART 5**

5A

**CP:** Specifically, how does active surveillance impact on quality of life from your experience? What are the psychological implications?

**LB:** The base of anxiety is fear, and fear is good because it's a primary emotion that is related to survival; it allows us to survive. We need fear, so it's good to have a little bit of fear because that fear brings us to take things seriously. And being on active surveillance has to be taken seriously. Men have to be compliant in monitoring their disease. They have to be proactively involved in their journey as Professor Valdagni was saying before. So we shouldn't say that anxiety, a little bit of anxiety in active surveillance is evil. It can be useful. We need to know how to deal with anxiety and somehow monitor the psychological state just as clinical parameters of prostate cancer are measured and monitored throughout active surveillance. So it is very important that the journey is a family journey from the beginning. The decision making process has to involve the partner because, once again, it is something that affects the psychological well-being of the entire family. You need to talk to the patients and together find the right solution, find the right path.

**CP:** Good, it was very clear, your presentation. Another subject that we cover sometimes is the lifestyle. So what is the importance of lifestyle for patients specific with active surveillance?

**LB:** Acting surveillance can be considered in some way in a window of opportunity because men become patients but at the same time they are not sick and so it's a good time to become proactive in learning about overall health, learning about disease prevention. So if you're choosing active surveillance because you want to maintain your health-related quality of life, you should be thinking prospectively. And thinking about, you know, aging well, healthy aging and healthy aging has to do with stress, has to do with sleep, with exercise and diet. All these factors, this is very well known nowadays, impact the body ability to fight illness and promote health. When it comes to healthy behaviours, exercise is the bottom line. Everyone should keep moving, and that particularly applies for men with prostate cancer on active surveillance and generally for men with prostate cancer. The indication is exercise as much as you are physically able to do. We can start by mentioning the functional aspects of quality of life; based on scientific literature, and on my clinical practice as well, I can say that, compared to patients that choose active treatment, patients on active surveillance are more likely to maintain health-related quality of life in terms of erectile and urinary functions. But when we talk about health-related quality of life, we're not talking only about functional aspects. We're also, of course, talking about mental health, about coping strategies, post traumatic growth; the concept of quality of life is very comprehensive and a lot of different factors fall under its umbrella.

**Associations support**

**TE:** We have listened to Lara that it is very interesting to learn to cope with Active Surveillance and take the advantage of its benefits not to have the prostate removed, no erectile problems, no urinary incontinence but sometime anxiety may interfere this advantage. Anxiety is not good as she said when it interferes with health behaviours when it is too high, when it is too high. But if not, a bit anxiety may help patients to be pro-active and engage in exercise, in diet, and health lifestyle and take the benefit of having Active Surveillance as a non-aggressive treatment.

**CP:** I think that Tania gave a very important indication about what we have seen in the testimonials and with our friend Lara, the psychologist specialist.

So now we arrive at the end of this virtual webinar. We hope it has been useful as it was a selection of elements it cannot be totally complete and it could have opened some questions. And that is good, because you can have material, you can go and have a full view of these presentations or other information that you can find on the website of our association Europa Uomo.

We are constantly trying to understand the needs of the patient so we do something which can be tactically work like supporting the multidisciplinary world. Active Surveillance is now a tactical application, a tactical way and how to help our groups. We are also, as an association, looking to strategy, today we are looking what could be the need of tomorrow so for instance the fact of early diagnosis which is the basic of improving the quality of life as we did some survey which has been put on the European Community, which is one of the elements that is supporting now the guidelines of the European Community on having early diagnosis all over the countries in Europe. This is improving quality of life and obviously as another aspect it is reducing the cost. Because supporting patients with first spot actions is less expensive then supporting patients with metastases which requires long and expensive treatments during many many years.

Having said that, I hope it is useful and we can open question and answers and we hope that you can give us some good questions that we can try to answer now or in the future with email or other aspects.

In this case, when we wait for possible questions, this webinar will go on our website. The idea here for this one specific is to create an opportunity for our people who wants to have a fast overview of the items, of the arguments and so as I said it is a selection that gives an overview and could be the way to have a first glance.

**IV:** Cosimo, if you allow me for one minute. Thank you for one minute only.

**CP:** Yes, please.

**IV:** Thank you very much for the summary that you have presented to us of the previous three presentations. It is true, and it is a fact, talking with people and with organisations that there were extremely interested for the Active Surveillance approach that we took as Europa Uomo. But I believe to go through the three videos or through the three recordings, it was quite a lot of time-consuming so it was a great idea to summarize it all in a new presentation of 50-55 minutes and I will say it was very important to keep the subject on the top and to refresh it every now and then. And I hope that in the future we will have one more with a little bit of the latest developments from a professor or from more specialised people about the latest news and updates on Active Surveillance and I believe that our Quality of Life report that is coming in July will gives us more push to go for it and to have a latest update on the subject. Thank you very much.

Questions CHAT:

**1. How often should PSA be done?**

**CP:** I can answer from my experience which is also coming out from the information that I got from all these webinars. First of all, you saw that there is a lot of data that the specialist collect since the 90’s. This is the way they understood which guideline should be applied. In particular, Monique Roobol presented the PRIAS study which is a website devoted to specialist where they can co-relate the data of their specific patient with the total database and get a guideline on the things. Normally Active Surveillance, as in my experience, has some important steps which are related to MRI or biopsies especially in the first years. And then depending on the situation of the specific cases there are more MRI, or more biopsies or less. What is the standard in the journey of the patient in Active Surveillance is the PSA. The information of PSA as an absolute value, is not a cancer evidence element. PSA is more an element of ongoing situation for instance if you have a stable PSA, it is a good information considering it is low but it is better to have stable PSA then a growing PSA. In Active Surveillance where the cancer is inside the body as we say, it can not go to zero. But in fact the specialist look after this carefully if it does not grow too much. But to answer specifically, the timing is 6 months. So every 6 months we do a blood test which is a PSA.

**2. I am on ADT treatment for prostate, I get checked every month. I have had brachytherapy and radiotherapy, PSA each month below 0.01.**

**CP:** That is obviously as we saw apart from starting and suggesting and choosing with the patient PSA Active Surveillance, you saw in many of the clips that there is a constant patient to the situation. While every urology hopes that Active Surveillance goes on forever, the important way to understand if there is the need to change treatment. It is like a sort of emergency that we as patients don’t see, don’t want to see. We hope that every urology say yes when we do the visits. The visits is normally once a year. You do PSA every 6 months and you do a visit at least once a year. But the important tools and guidance to be able to put the patient in a way to decide the difference between what they choose, consider to move to active treatment. The information we saw in these videos are only to active surveillance. When you move to another type of treatment, you normally need to go to an urology if it is surgery or to radiotherapy or to oncologist. In that case you will be put in contact with the right specialist and this is the important point of the multidisciplinary units. We are pushing patients to go since the start, since the beginning to a multidisciplinary unit. Which are normally in many hospitals. Because if you are in a multidisciplinary unit, you have a higher safety because you are on active surveillance hopefully. But you know that whenever there is a need you will be in the same effective treatment way with other specialists.

**IV:** One very important point Cosimo that we have to repeat every now and then. We are patients, we are not doctors. Every patient should check with his direct doctors to get the professional approach from a doctor from the right direction. We, as Europa Uomo, we are patients and we can give our colleagues the information and the experience only that we personally have. For each and every individual patient, there should be a direct contact with his doctor.

**CP:** We are mostly giving information but we are not doctors. Our mission is to present the needs of the patients which are sometimes also important. Doctors are mostly related to take out the cancer or treat the cancer but sometimes they forget that there are side-effects. For instance, for early diagnosis, the doctors are very good in treating but if we as patients are able to avoid some type of treatments, it is a lot better for all of us.

OK, I think we are at the end. I don’t see other questions. Thank you for participating. We hope it was useful. As Ioannis has said, it was the first time we tried to do it this way to put together this review so some things could have maybe been better but we tried and we hope it is useful.

Thank you to all.