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Uncertain words have been indicated with ?? before and after the part. Parts that could not be understood at all have been indicated as [Audio Not Clear].

# Shared decision making

**Dr Oprea:** Good evening, everyone. I will start sharing my screen. Okay, so, it is my very pleasure to talk today about shared decision-making in breast cancer care. So, before we move to our overall presentation, I would like to give you an outline of our topic of today. So, first I will make a short introduction about the context to make sure everyone is on the same page in terms of the concept used for this topic, then, I will move to the scope of the research. I will talk briefly about the state of arts and what is exactly the gap that we are trying to fill. Then, I will move to methodology, and finally, I will make a presentation of the results, both of the literature review and of the survey. Everything to be wrapped up at the end with some takeaway messages. So, before we start, I would like to make sure that what we understand why shared decision-making is an understandable concept. So, in the last decade, let's say in the last three decades, more and more strategies to optimise patient outcomes have been searched from, have been seen from the light of improving the quality of cancer care. Now, shared decision-making has been more and more seen as a good quality clinical practise and perceived as a hallmark of patient-centred care has been coined and determined in the early '90s. Shared decision-making is associated with less regret about the decision taken. It supports patient in coping with the disease, and overall, enhances the adherence to the treatment. So, what we understand by shared decision-making is a process of collaboration where patients and clinicians are actively engaged in deliberating and deciding the best course of treatment, which first of all, takes into consideration patients' preferences and values. So, in a way, it brings patients and clinicians on par in terms of their expertise, clinicians, as their knowledge and expertise from the clinical practise, and patients as experts of their lived experience. Now, one of the main questions is how do we support shared decision-making if this represents one of the hallmarks of patient-centred care? Well, let's say that in the last case since such an emphasis has been put to share decision-making, different interventions have been designed to facilitate, and which broadly can be categorised as those that target either healthcare professionals, broadly speaking, so these can be both surgeons or medical oncologists as well as nurses, or patients, and both which is one of the most important aspects because it targets the relationship. So, these interventions have been very often called as decision support intervention, or shortly called decisional aids, which aim at supporting the active engagement of patients in three important aspects. On one side, it provides evidence-based information. It offers, in many cases, valued clarification exercises as many times, patients can be themselves confused or overwhelmed by the diagnosis, so, it offers a support in clarifying their values. And finally, it is about guidance or coaching in the process of decision-making. Now, it is important to emphasise that decisional aids do not replace clinicians' counselling. They rather supplement it. So, in a way it offers more tools to the clinicians to support an active engagement of patients. We know from the literature already, that this is related to better knowledge of options and outcomes. It increases patients' feelings of comfort with choices, and in particularly breast cancer care, it has a clinically positive effect on body image. So, in order to make sure that we are all on the same page, I will give you just some illustration about what do we mean by decision aid? So, what you have here are two examples of decision aids. One on the left-side you can see is a computer interactive based decision aid that was developed in early 2000, and it was meant, and it is still currently used, was meant to support patients diagnosed with early-stage breast cancer. So, once the patient would enter into the application, then, different models would guide the patients throughout the whole process. It is important to say, however, that this decisional aid, when it was designed, it was purposefully meant to support patients who were naive computer users, or specifically coming from ethnical groups. Whereas, on your right-side, you can see a paper-based picture option grid that supports the patients in their process of making stepwise decisions. What I would like to emphasise is that decision aids should not be confused with health educational material, as they have not only the purpose of providing knowledge and information to patients, but it specifically targets active patients' participation in the decision-making process. So, once we have set out the perimeter of our discussion, I would like to pass to what is the state of art, because as I was mentioning, the research in the last years has given particular attention to the topic of shared decision-making and decisional aids. So, in terms of evidence, we have both systematic reviews and meta-analyses. And what we know so far is that decision aids are associated with positive impacts on patient's knowledge and reducing decisional conflict specifically, when it comes to treatment choices, and it is less so when it regards screening. And we found there quite an important attention from the literature, we found there more than eight systematic reviews that have analysed the impact of decision aids. Whereas on other sides, or other aspects of shared decision-making, in particular, the clinical practise guidelines and the implementation of this intervention into practise, then there, our knowledge is much more sketchy. So, for instance, a quite recent systematic analysis on the clinical practise guidelines have found that actually shared decision-making isn't sufficiently addressed in the current guidelines and need further improvement. Whereas, in terms of analysing what is the feasibility of implementing shared decision-making interventions in practise, then, there we have more mixed results. So, this in a sense opens a whole space of analysing and delving into the topic of what is actually the right strategy to adopt, at the organisation in the clinician settings, in order to foster shared decision-making and routine practice. As you can see from these sketchy reviews, is that more focus has been paid to intervention's efficacy, and less so was done on what concerns their effectiveness. So, given this overview of what we currently know in terms of knowledge, I would like to make clear what is the scope of our analysis. So, our research has the aim to analyse existent approaches and interventions that foster shared decision-making, including patient decision aid from two different perspectives. On one side, we are carrying out a theoretical analysis of what is there in the academic literature. And on the other side, we are trying to map the existent practises of shared decision-making on the ground in a clinical setting as I will mention next, through a survey. All this in order to understand what are the strategies and their prevalence to foster shared decision-making, and how we can rather support organisations that would like to adopt their use into practise, following a robust approach. So, before moving to our methodology, I would like to remind you that you can send your questions, or doubts or comments at any time during this presentation and we will make sure to address them at the end of my presentation. So, as I was saying, how did we achieve our research scope? Well, we had two important streams. On one side, we decided to go through a very traditional scoping review, and using a robust framework to analyse the results. And in the second stream, we have decided to adopt rather a survey, a quantitative methodology in order to understand what are the practises at the level of clinicians across Europe. Just to make sure what we have looked at, so, we have looked at treatments that are focused from early to advanced stage of cancer, excluding the diagnosis and the screening phase, as well as the follow-up stage. We have focused on tools that are either used by patients, or in interactions with the physicians. And finally, we have included all formats of delivery because you will see in a while that, sometimes, these interventions can regard very complex structures and approaches. And once we have conducted this first stage, we have developed, we have decided to adopt the PRISM framework in order to interpret the results of our review. And that is specifically because PRISM helps in a robust way to translate the available research into regular use by practitioners. So, in a way, it is a way to support the implementation at the clinical level. Finally, as I said, we decided also to carry out a survey of breast students professionals, and I will talk about this second stream of analyses in my second part of the presentation. Okay, so, this was our methodological approach. I will now give you an overview about what have we found in the literature. So, here you have the first overview of studies. So, from almost 2000 potential citations that we found, we have selected 184 potential titles to screen more in detail. And of that, a total of 82 full text articles were actually analysed in our review. These studies followed either mixed methods approach, experimental or a qualitative design approach. And it is important, however, to say that this wasn't the total number of studies. Whereas, when we go on analysing the individual interventions, then, we talk about 51 individual interventions that all had inside an educational component, which was meant to encourage patients' active involvement in the decision-making process. Now, the most surprising, or maybe less surprising number, was the fact that only 15 studies have actually looked, so, they explicitly described or analysed the strategy of implementing the intervention into routine clinical settings, from a total number of 82, only 15 have focused on how to actually adopt interventions into clinical setting. So, that in a way opens the whole ground of research for our analysis. So, let me just dive a little bit more, so when exactly are these studies being published? So, you can see from the graphic above, that most of the studies have been published in the last four years, so you see that more than 60% of studies have been published since 2018, emphasising a need and increased importance of decision aids in the academic literature. And let's say that this renowned interest is heavily influence triggered by the interest in the North American context. So, you can see that the majority of studies, 61% actually, have been published in North American context of both Canada and the USA, with an important exception in Europe, as far as Europe is concerned, in the Netherlands and the UK. So, what is the intervention... most often used format for this intervention? Well, most of the time we see that interactive web-based are those that dominate, but paper-based decision aids are still very relevant. And we have noticed that paper-based decision aids are particularly used, for instance, with groups that come from a low socioeconomic status, or have lower levels of education, or are older patients. So, paper-based decision aids are still heavily relevant in the current use of decision aids. And finally, on your right-side, you can see that most of the time, decision aids are used either before consultation, so, in a way, preparing the patients before meeting the clinician, the surgeon, in many cases, or during the consultation, and less so after the consultation. So, that was the first part in a way, the descriptive general part. What is however very important is to mention that to assess the effectiveness of an intervention, the characteristics of recipient and their perception should be accounted for when actually decided to adopt, because they can heavily influence both the outcomes and the adoption of this intervention. So, as I was mentioning, we used a framework in order to assess these current studies and we have looked in particular on four main dimensions on the intervention, on the recipients, the external environment infrastructure. I will spare in going into detail, but I would like to give, to send some important messages. First of all, that more and more patients are heavily involved in the development of decision aids, which means that later adoption is more facilitated, thanks to their participation. On the other side, often, professionals stress issues related to scalability, to system support, or even consultation time. Nevertheless, there is a heightened interest, both from policy makers and professional associations. And just to mention some of them, for instance, last year, the UK NICE have published a whole guideline supporting shared decision-making. So, in a way, that emphasises more and more the interest from national policy makers, but also, as professional organization, in supporting shared decision-making. So, what I would like to stress as some takeaways from this part of the presentation is that there is considerably a renewed interest in decision aid supporting shared decision-making, as we saw or most of the studies have been recently published in the last four years. At the forefront are interactive online decision aids in a way these might be explained by the expansion of the internet use, but also, of the diffusion of digital health system. And we also saw that very often, interactive decision aids are used specifically in cases of surgery. So, when we talk about breast reconstruction, or breast conserving surgery, because there is a particular need of visualising and interacting for patients. We saw also that there is a high prominence in developing and testing the decision aids with patients. Nevertheless, these attention does still presents a gap in our knowledge and sense of how does this participation in the decisional phase later translates into their adoption in practise? And finally, what I would like to stress is that what we see is still a very persistent experience coming from the North American cases, and less so about European experience. So, and that is important to take into account first of all, because very often in the European countries we have, although it is a heterogeneous context, we still have the models of healthcare are slightly different from the North American ones. And even the relevant variables that should be taken into account are these things. So, in a way, that calls our attention and emphasises the need to understand what is actually the practise, what is going on in Europe, and how shared decision-making is supported in European countries. I would like once again, to remind you that you can ask, send us questions, or doubts, or comments during this presentation, and we will all address them at the end of my presentation. Now, I will pass to the second part of my speech of today. And in particular, as I was mentioning that we have decided to go on and carry out a survey directed to European breast cancer units in order to take a snapshot of the current use of tools and strategies across this unit. This is a survey directed only to professionals, so, only to clinicians. It does not involve patients. So, I would like now to present a bit what we have done in this part of our research. So, first of all, after carrying out the scoping review that provided the basis for our survey, we developed the questionnaire itself. We have pre-tested the questionnaire with clinicians, and the questionnaire itself has received the ethical committee approval. Here you have a very sketchy presentation of what the survey is about. In the first part of the survey, we ask some questions that want to try to understand the communication patterns between clinicians and patients. In the second part of the survey, we focus, we drilled out on the patient decision aids, their use, their frequency and what potential barriers professionals see in their use. And finally, we ask some very broad and general demographic questions regarding the activity of the breast units, and the country of practise, but it is important to stress that we do not collect any kind of personal or identifiable information from our respondents. It is a very straightforward survey. We have sought to make it simple and very easy to interact. Actually, I put here some snapshots of the survey itself. So, it is online, on a platform. I will talk about the dissemination later in my slides. So, this is just to give an overview about how accessible, easy, and very interactive is our survey. I will now present, since it is important to mention that we have launched the survey about a month ago. So, we are still collecting answers. It is important that we keep it running in order to get as many responses as possible in order to have a highly representative sample of respondents. And I will talk about later how you can also contribute to the survey. But before going to that, I would like to give you a flavour and overview about what we have actually have now in terms of responses. So, once again, please, do send us questions or curiosities that you have. And now, I will pass to the presentation of the results. So, let's say that, as I was saying, the questionnaires, or the survey is still running, we're still collecting answers. We have received many answers, but here, we just took a snapshot, in the half, the other half of May. And from all the responses that we received, we analysed 113 responses as fully provided. And you can see here, the respondents by country. Our responses are still heavily influenced by Italy, also explained by the dissemination strategy, I will later tell. And in terms of breast units, well, most of the respondents come from certified European level breast units, but also units that are certified at the national level, and less so units that are not certified at all. So, who are our respondents? Well, as you can see, the majority of respondents are either surgeons or medical oncologists. These are the main four categories we have inserted, but we also have the possibility of other, where other professionals involved in breast cancer care can actually contribute with their response. And in other, we have received gynaecologists, pathologists, even nurses. So, it is going to be also interesting to see who are other figures involved in breast cancer care in Europe. And in terms of seniority, you can see that we have a sample that it's quite experienced. The median here is 20-years of seniority, and we count this as the number of years since the respondents took their residency. So, we see that most of our respondents have more than 20 years of experience. Now, what about the use of decision aids? Well, we asked whether there is decision aid available at the organisational or country level, and as you can see, 54 respondents have answered yes, there is a decision aid available that I can use in my daily practise. Whereas, we received 59 responses in terms of no, or don't know. And zooming on these responses, we actually asked respondents if decisional aid were available in your practise, would you use it? And it is encouraging to see that 52 of those respondents said yes. Going back to those respondents who actually mentioned that there are decision aids available at their organisational levels, 45 of them, so, the greatest majority actually use them. So, in a way we're making a distinction that availability does not translate necessarily into use. So, you can see here, however, that if a decision aid is available, professionals do use them. And those who use decision aids, as you can see on your right-side, are especially experienced professionals. So, you can see that respondents who have more than 30 years of seniority answer yes, and without no answer. And then, less so as what concerns respondents with less experience. That might open a whole debate about what is actually going on, but we don't have yet the final results, so, we will talk about this at the end of the survey. So, in a nutshell, with these numbers, so, once again, the survey is ongoing, so, these are just very preliminary results, but what we can see from these numbers, and I took just some questions out of the questionnaire, well, the fact is that most of our respondents performed in breast units that are certified at the European level, these are either surgeons or medical oncologists who have more than 20 years of experience. Half of our sample respondents reported that they actually do have their available a decision aid in their organisational country. And what is most encouraging is that professionals either use or are willing to use a decision aid when this is available. So, that is quite encouraging. So, going back to the dissemination right now, the survey has been supported at the European level by Breast Centres Network and EUSOMA. We have also the support of SenoNetwork and EuropaDonna in Italy, which that in a way explains why we have such a skewed sample of respondents from Italy, because SenoNetwork is a network of almost all breast centres in Italy, so, there, we have quite important participation. And currently we are in touch, and we have some positive feedbacks from other national and European associations. Now, as I was saying, we are very much looking forward to receive more responses to contribute to our current knowledge, because as we saw, it's quite scarce in Europe. And what I put here is a QR code that you can scan and contribute to this survey. We are very keen to receive your answers, and you can do it anytime. It is completely free, anonymous, and it is important to mention that you are actually giving a contribution to our current knowledge. So, because I'm short of time, I'm running out of time, I will just wrap-up all this presentation and saying that there is a vigorous interest in shared decision-making and the tools that support shared decision-making in breast cancer care. Interactive web-based tools have received considerable interest also because very often the development of process of these tools is longer and actually, evolves throughout its whole process patients. However, the availability of decision aids does not necessarily translate into their use. And in a way, this calls the attention to understand which are the factors that influence the factors that are either at the individual, organisation level that influence sustainable adoption in critical settings. So, finally, what we need is actually to diversify the implementation strategies that support the adoption and the sustainability of shared decision-making practises in the clinical setting. I would like just to remind that this presentation is part of a collaborative project that is carried out by us together with two clinical partners, one in Lisbon, and one in Udine, the Academic Hospital in Udine and Champalimaud Foundation, in Lisbon, with the technical partner, IDDI in Leauven, and a Patient Advocacy Association that is EuropaDonna in Italy, all financed by Pfizer Global Medical Grants in partnership with SPCC. Please do reach for us, and now, I'm open for your questions and for the lively discussion. Thank you.

**Dr Bertolaccini:** Thank you so much, Natalia, for your presentation. Real interesting and beautiful. We have some questions from the floor. The first is, if you could define the term "seniority".

**Dr Oprea:** Yeah, so basically, we define "seniority" as the number of years since respondents took their residency, so.

**Dr Bertolaccini:** Okay.

**Dr Oprea:** In order to make it clear and straightforward for everyone, because we know that there are different approaches in Europe in terms of how to define experience in a way. So, that was the clear-cut hallmark, let's say.

**Dr Bertolaccini:** Okay, thank you so much. I know that your results are only a part of the results, but a comment should be done about the decision aids' use and the seniority. It's really strange that a senior specialist, surgeon, oncologist, and so on, uses a modern, really modern technology, and young a specialist doesn't use.

**Dr Oprea:** That is true. Actually, I was also quite, let's say, positively surprised by these results. Well, that could be interpreted in many ways. First of all, you could see in my, let's say in my previous to that slide, the fact that actually our sample of respondents have higher seniority. So, that could be one explanation. But on the other side, what we know from the literature is that sometimes younger professionals, if they are not supported in their organisation, they have more fears in adopting new tools, right? So, that in a way calls the attention to exactly to the organisational level, in a way that more experienced professionals should give a support to younger professionals in the sense of using decision aids, but not only what I would like to say that this should be across the whole organisation, right? It shouldn't come only from senior professionals, so those who have a longer experience, but also, from the top management. So, let's say, this should be an embedded practise at the organisational level. And in this way, this could foster and support those younger in a way, to adopt these tools and use them in the daily practise. So, that would be my answer to your very nice observation.

**Dr Bertolaccini:** And in your opinion, the role of patients' organisations, what could be in decision-making, because in Europe, the patient organisations are really important. In Italy, only for some organs, there is a really a well-structured patient organisation for breast cancer, for instance, not at all for lung cancer. What's the role in your opinion of the patients' organisations for this?

**Dr Oprea:** That is quite an interesting observation as well in the sense that we saw from the literature that in many cases, patients' advocacy organisations almost play a complementary role, for instance, in the United States. Now, in Europe, it is quite heterogeneous. And in Italy, more specifically, since, as you said, there is a very strong advocacy group, then, their role is quite important. And since we were also very curious about the role of patient advocacy associations, which was scarcely, which is still scarcely covered by the literature, by the way, we have introduced this question now as service. So, we really do want to see what is the role of associations in a way in supporting shared decision-making in the daily practise. So, I think, I will have a much more accurate answer to what is their role in Italy, but overall, in Europe, once we will finish our survey. But it is absolutely one area that should be covered, and the literature is quite, let's say, sketchy on the role of patient advocacy association, definitely.

**Dr Bertolaccini:** Another point of your preliminary results is that from the number of breast unit without certification is quite relevant, and it's a problem, because we know that the certification sometimes is equal to best outcomes and high-volume.

**Dr Oprea:** That's true, that's absolutely true. Indeed, it is, so once again, these are just 113 responses, so we consider it to be very low compared to, let's say, that there is a gap in our knowledge, in the sense that there is no survey at the European level. The most recent, and let's say closely-related to our topic is the survey carried out in Spain and Argentina last year. But there we have, in the sense of Europe, we have only Spain as a picture. So, going back to what you were saying, I think we have still a very small number in terms of non-certified, but it is true that normally certified breast units are also related to better outcome. Now, it would be interesting, I think in the second-step to see if this breast units are also associated with non-adoption or non-availability of decision needs, right? So, that would be also interesting to see, because maybe they are not necessarily, they are not certified, but they do use decisions, so, more, let's say, modern strategies to support your decision-making, so, yeah, that would be my answer.

**Dr Bertolaccini:** The last question is a personal curiosity. How much long is the time to complete the questionnaire, because all practitioners are very busy?

**Dr Oprea:** Very short on time.

**Dr Bertolaccini:** Yeah. So, half an hour?

**Dr Oprea:** No, no, it takes really short, as I said, it is really short. It takes about 10 minutes. It's very easy to interact. And another thing that is, I think is positive since you mentioned, is that you can start it, leave it, and go for a surgery, for instance, come back and complete it. So, you have enough time and enough possibilities to really contribute to our current knowledge. So, yeah, I thank you so much for your question, because I think this is important in a way to give incentives to our respondents to answer to the survey. So, the survey is really short. It takes about 10 to 12 minutes to answer all the questions until the end, and yeah, we really hope to receive more and more answers in the nearest future.

**Dr Bertolaccini:** Okay, thank you so much. We have no other questions from the floor. Thank you to Dr. Natalia Oprea for her time, and for this beautiful presentation, and the idea of this survey. Really, really interesting. Thank you so much for all the attendees, and have a good morning, afternoon, and night.

**Dr Oprea:** Thank you so much. Thank you so much, Dr. Bertolaccini, and thank you for giving us this opportunity to present our research. And of course, I would like to thank also my colleagues who together with me carried out this research. Thank you so much.