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Practical clinical tools for enhancing patient engagement

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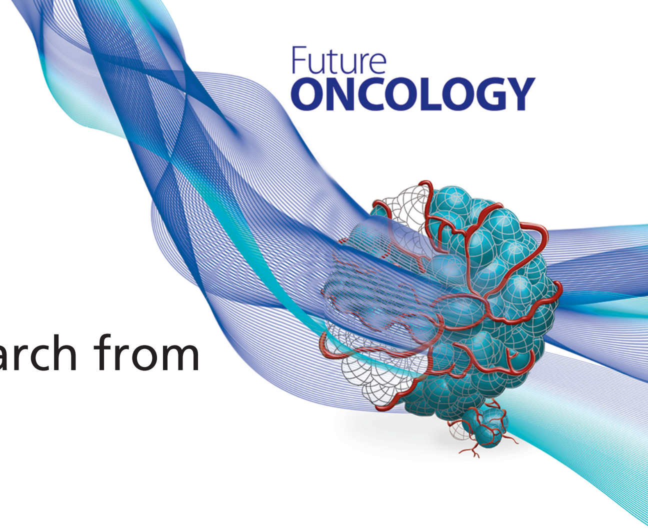

Patient engagement in cancer research from the patient's perspective

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Patient engagement in cancer research involves the inclusion of patient voices into research to ensure knowledge generated will improve the lives of all cancer patients. Patients involved in research have an interest in science, an experience with cancer and want to work directly with researchers to ensure patient concerns are heard. There are many opportunities for patient engagement in laboratory and clinical research, throughout the lifecycle of the project from conception to completion. Researchers and patient advocates can take practical steps to ensure their engagement is effective and meaningful. Adding the patient voice in research honors those who have died, so future cancer patients have access to new therapies to live longer and better lives.

Tweetable abstract: Adding the patient voice in research honors those who have died so that future cancer patients have access to new therapies to live longer and better lives.

First draft submitted: 25 November 2020; Accepted for publication: 22 April 2021; Published online: 2 July 2021

Keywords: cancer research • patient advocate • patient engagement • patient voice • research advocate

Cancer patient advocacy has been around for many years, and there were key inflection points in the trajectory of patient advocacy that shaped the current landscape of research advocacy and patient engagement in cancer research [1]. One early influencer was Terese Lasser, who was instrumental in initiating Reach-to-Recovery in 1952, a patient-centered program through the American Cancer Society. In the 1970s, First Lady Betty Ford and others raised public awareness about breast cancer, which spurred the formation of several grassroots cancer advocacy organizations. In the 1980s and 1990s, two prominent breast cancer advocacy organizations emerged and are still leaders today, Susan G. Komen [2,3] and the National Breast Cancer Coalition [4–6]. These organizations set expectations for patient engagement in cancer research, including scientific research grant review. Today many cancer-related organizations advocate for various cancers. One relatively new phenomenon has been the emergence of cancer advocacy organizations focusing on a subset of common cancers or specific patient populations [7–11]. An important program supporting consumer advocate involvement is the US Department of Defense's Congressionally Directed Medical Research Program (CDMRP), establishing the Breast Cancer Research Program in 1993. Currently, there are multiple CDMRP programs covering at least seven cancers. The involvement of consumer advocates has been required from the beginning and led other programs to do the same, including the California Breast Cancer Research Program, which involves patients from strategic planning to their inclusion on every funded project [5,12]. By 1996, a patient advocate was nominated for an NIH, National Cancer Institute (NCI) Intramural Council. After considerable discussion, the patient advocate position was approved in 1998, which has resulted in the continuation of inclusion of patients on key committees and boards at the NCI today. Currently, the NCI supports patient advocate involvement through the Office of Advocacy Relations [13,14], and many more institutions value and encourage patient involvement in cancer research.

Although progress has been made in the inclusion of patient advocates in research over the past 30 years, there are still challenges to ensure consistent and meaningful patient engagement in research. This narrative review article is a patient's perspective on what researchers and patient advocates can do to enhance their ability to work together to ensure meaningful engagement adds urgency and purpose to cancer research with the goal of improving the lives of all cancer patients.

Research patient advocates

Patient advocates are people who have had a diagnosis of cancer, been a caregiver of someone with cancer or affected by someone with cancer and patients can advocate for different causes in different ways. For example, patients can advocate for public policy by talking to government officials and encouraging them to pass legislation to improve the lives of cancer patients. Other patient advocates focus on fundraising for patient programs or research. Still others may be more interested in providing direct support to patients in a variety of ways. The type of patient advocacy addressed in this article is research patient advocacy. Research patient advocates focus on research, have a willingness to become educated in the science of cancer and want to make a broader impact in cancer and its treatments.

In 2011 the NCI published the recommendations of the Advocates in Research Working Group, which was convened in 2007 “to consider how to most effectively and consistently engage individual advocates in the research process to accelerate progress and benefit patients” [15]. The working group defined a research advocate as someone “who brings a nonscientific viewpoint to the research process and communicates a collective patient perspective. A collective patient perspective is created when a person has knowledge of multiple disease experiences and conveys this collective perspective rather than his or her own exclusive experience” [15,16].

Patients who engage in research are not all the same. Different types of patients can be involved in research in various ways [16]. For example, some projects benefit from learning about the experiences of patients. Engaging individual patients who have the specific disease can inform the project about their experiences; however, most patients do not have basic knowledge about research methods or the scientific process. Other projects may benefit from the engagement of research patient advocates. They not only have personal experience with the disease, they also have learned about research and scientific methods. Research patient advocates bring a broad perspective versus a singular personal experience to the discussions. Research patient advocates can be involved and provide relevant patient perspective throughout the entire research project from conception to completion. They can provide valuable contributions in both laboratory and clinical research projects.

As with many areas in science, diversity is beneficial among research patient advocates. This is even more important in cancer advocacy because patents differ from each other in many ways; their only ’common bond’ is a diagnosis of cancer. Their backgrounds and life experiences vary widely, in addition to their cancer experience. Different life experiences can influence a patient’s perceptions and guide their feedback on projects. For example, opinions and experiences differ by cancer types, stages of cancer, geographic areas, socioeconomic situations and race/ethnicity. For a true representation of the patient perspective, involving multiple patients can enhance engagement to be more meaningful and effective.

Patient advocacy in cancer research

Many articles have been written about patient advocacy in cancer research. One of the earliest in 1998 addressing the different types of advocacy as well as several areas of research advocacy [17]. Interestingly, the difference in perception between patients and researchers was highlighted, especially noting that research advocacy was a relatively new concept. Their perceptions were different, and at that time sometimes confrontational. However, patients did challenge some areas of research and changed the interest of some funding organizations, specifically regarding environmental causes of cancer. These activities set the stage for including patients in cancer research.

Early in the inclusion of patient advocates in cancer research, there was an obvious need for structure around engagement, a strong framework for research patient engagement communicated to all participants that fits the specific purpose of the engagement. In one analysis of 65 frameworks, five categories were identified [18]. This study concluded that a single, off-the-shelf framework may not be useful; however, a menu of resources to design a framework may make more sense [18]. Developing a strong framework based on a clear agreed-on purpose and goal is key to keeping patient engagement in a research project focused, effective and meaningful. People have a tendency to try to fit everything in one box – a one-size-fits-all approach – but patient engagement is diverse and specific needs can vary, so identifying the purpose for engagement should be the first step for any project. In general, one often-used purpose of patient engagement is to enhance research by improving and accelerating new treatments for cancer patients [1]. Another common purpose for involving patients is to put a human face on cancer, which will add urgency to research [19]. Patients can also ensure research maintains a patient focus, add diverse perspectives,

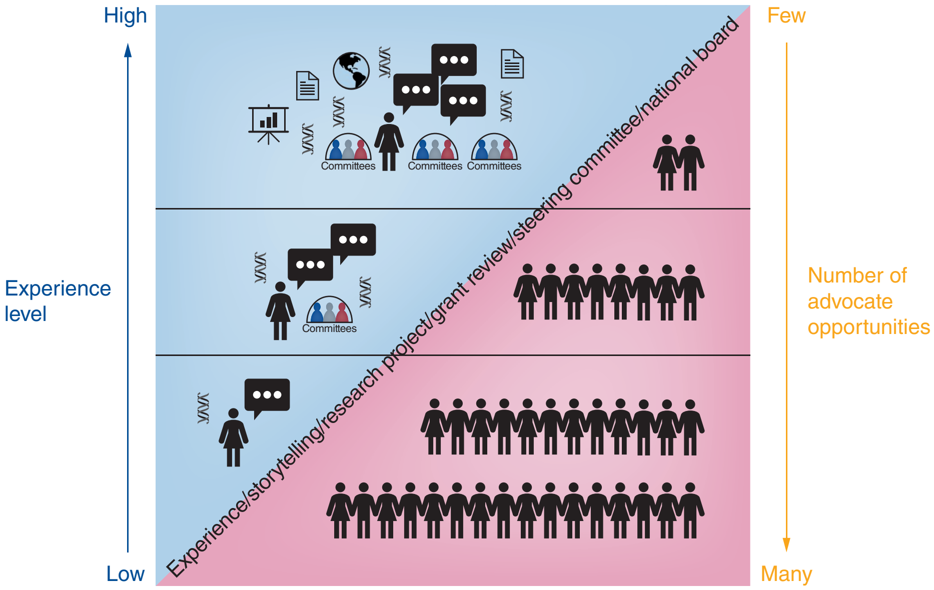


Figure 1. Numbers of opportunities and experience level needed for patient engagement in cancer research.

encourage discussion and spur innovation [19]. However, these purposes are broad and hard to quantify or measure their effectiveness. Putting some effort into developing a framework of patient engagement can make a meaningful measurable difference and will enhance the overall engagement experience for both the researcher and the patient.

There are many opportunities for patient advocate involvement; however, there are differences in the types of engagement and the experiences of the patient advocate needed (Figure 1). For example, some opportunities do not require patients with high levels of research advocacy experience. These low-experience opportunities provide a majority of engagement opportunities for patient advocates. For example, many patients are engaged in storytelling and providing individual experience knowledge. Other opportunities require patients to have a higher and broader level of experience. However, not as many of these opportunities are available for patient advocates. These include participating in research grant review, involvement on research teams, speaking at meetings and participating as panelists in workshops. There are also rare opportunities (e.g., on national advisory boards) that require a patient advocate with a higher level of experience.

The experiences of research patient advocates are multifaceted. A research patient advocate, like all patient advocates, brings the experience of a cancer diagnosis to the discussion. However, as research patient advocates gain more awareness and understanding of the field, they do not focus solely on their own experiences and instead consider a broader perspective, representing all patients. They also build an understanding of the research process and scientific methods: they do not study a specific topic, but learn the basics so they can learn more about specific projects and be able to understand the way the project will affect patients. It is easier for patients to be involved in research if they have a basic understanding of not only research, science and cancer but also of the research environment. Many patient advocates have never been in a research laboratory and are unfamiliar with the academic hierarchy and regulations. Learning these basics helps the patient advocate understand the entire project and increases their ability to make a meaningful contribution in the context of this knowledge. On the other hand, some patient advocates focus on one area of research, topic or cancer type and become very knowledgeable in that specific area. However, even the most knowledgeable patient advocates will always be looking at research through the lens of the patients; they are not going to provide input on experimental details. They will always bring a nonscientific viewpoint to the research and a broad patient perspective.

There have been several articles written about the areas of research where patient advocates are engaged [15,19–25]. Although there are multiple areas of research for engagement, following are examples of engagement in clinical research, laboratory research and in advisory roles. In general, clinical research refers to involvement in clinical trials compared with laboratory research, which refers to research done in a laboratory. Laboratory research is a broad category spanning very 'basic' or foundational studies conducted in test tubes to translational research, which may involve research in mice or human tissue. Each area is broad and can include many ways advocates can be involved.

Clinical research

Research patient advocates are involved in various areas of clinical trials [19,25], including drug development [20,21]. The US government-funded National Clinical Trials Network (NCTN) has been engaging patient advocates in clinical trials for more than 25 years as of this writing [26]. Each network group involves patients in different ways. In 2012, Katz *et al.* [27] published a survey to learn about the role of patient advocates in an NCTN group, CALGB (now the Alliance for Clinical Trials in Oncology), from the patient and investigator perspectives. Interestingly, they found that a majority of both patient advocates and investigators thought there was benefit from engaging patients. As expected, patients had a higher value of their role than investigators, and investigators pointed out areas for improvement, including training, communication and clarifying the role of the patient advocate [27]. A recent project from another NCTN group, SWOG Cancer Research Network, mapped a novel framework for patient engagement [28,29]. This includes a roadmap to involve patients throughout the development of clinical trials and addresses two unmet needs, training and assessment. It will be interesting to evaluate the implementation of this framework to determine whether it can enhance engagement of patients in SWOG clinical trials in a meaningful way. Another example from SWOG was the development of an external stakeholder advisory group of patient advisors to work with the research team on the TrACER study (S1415CD) [30]. They published best practices and co-presented a poster on stakeholder influence on the trial. This is a good example of how patient involvement within the NCTN can be structured and successful. Currently many patient advocates are fully integrated in NCTN activities and specific studies.

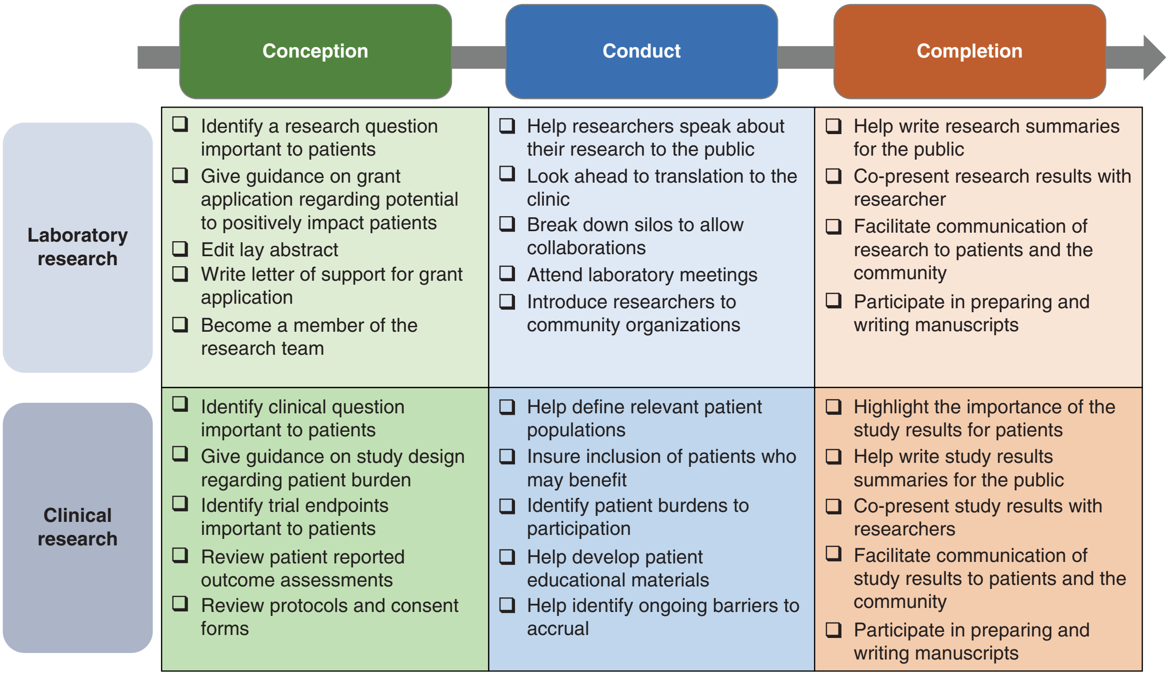
Opportunities for patient advocate engagement exist in the pharmaceutical industry and even some smaller biotechnology companies. These opportunities vary in extent and purpose and can include working on specific trials or on overarching topics such as patient-reported outcome measures, implemented across many trials. Patient advocate involvement is increasing in some, but not all, pharmaceutical companies. Unfortunately, there is no easy way to find out about potential opportunities at companies. In addition, there is a lack of transparency around current practices in patient advocate engagement within companies. Few publications or presentations acknowledge the inclusion of patient advocates. It is important to remember that there are differences between patients involved in government-funded compared with pharmaceutical-company-sponsored clinical trials. One key difference is in compensation. Pharmaceutical companies always compensate patients engaged in their clinical trials. Another difference is in the overall goals. Many government trials are to improve patient care and gain more knowledge, whereas pharmaceutical trials are to gain drug approval. Patient advocates interested in engaging with companies need to be proactive, attend meetings and network with patient advocacy directors at pharmaceutical companies. Pharmaceutical companies approve most new drugs, so patient involvement is important.

Patients can be involved throughout the lifecycle of the clinical research from concept to completion (Figure 2). For example, during conception patients can give guidance on study design relating to patient burden, endpoints important to patients and which patient-reported outcome measurements are appropriate. During the conduct of the study, patients can help with ongoing barriers to accrual and additional patient information and educational materials. Upon completion of the study, patients can help communicate study results to the community and patients. Involving patients in clinical trial development will ensure the trials answer questions important to patients and have considered patient burden, broad inclusion and patient-relevant endpoints.

Within clinical research, patients are interested in a variety of topics. One of these is biospecimen collection [31–33]. There are programs where patients are treated as partners in research not merely tissue donors [33]. They have a voice and collaborate in running the biobanks. In one program at the UK Institute of Cancer Research Clinical Trials Statistical Unit patients are engaged in biospecimen collection. For example, in two breast cancer clinical trials requiring multiple mandatory biopsies the influence of patient advocates was documented [32]. Patient advocates were involved in trial design, consent review and clinical site training. They learned along the way and had an impact. One of the key components was to educate site staff that patients will be willing to participate in trials with multiple mandatory biopsies if fully informed about what to expect and shown the rationale for the multiple biopsies. Clinical trials are becoming more complicated and biospecimen collection more common. Engaging patient advocates to review the acceptability of biopsies and other biospecimen collection protocols and processes can facilitate patient acceptability of the trial and enhance accrual.

Laboratory research

Patient advocates engaged in laboratory research projects is a considerable area of involvement and can be viewed from many angles. For example, some advocates concentrate on increasing funding for research by educating the



	Conception	Conduct	Completion
Laboratory research	☐ Identify a research question important to patients ☐ Give guidance on grant application regarding potential to positively impact patients ☐ Edit lay abstract ☐ Write letter of support for grant application ☐ Become a member of the research team	☐ Help researchers speak about their research to the public ☐ Look ahead to translation to the clinic ☐ Break down silos to allow collaborations ☐ Attend laboratory meetings ☐ Introduce researchers to community organizations	☐ Help write research summaries for the public ☐ Co-present research results with researcher ☐ Facilitate communication of research to patients and the community ☐ Participate in preparing and writing manuscripts
Clinical research	☐ Identify clinical question important to patients ☐ Give guidance on study design regarding patient burden ☐ Identify trial endpoints important to patients ☐ Review patient reported outcome assessments ☐ Review protocols and consent forms	☐ Help define relevant patient populations ☐ Insure inclusion of patients who may benefit ☐ Identify patient burdens to participation ☐ Help develop patient educational materials ☐ Help identify ongoing barriers to accrual	☐ Highlight the importance of the study results for patients ☐ Help write study results summaries for the public ☐ Co-present study results with researchers ☐ Facilitate communication of study results to patients and the community ☐ Participate in preparing and writing manuscripts

Figure 2. Patient advocate engagement through the lifecycle of laboratory and clinical research.

public and lobbying for support [19,23,25]. This effort is important for many reasons, including to increase public trust in research by communicating the importance of research in plain language [15,19,22]. Research patient advocates can be a liaison between researchers and the community [23]. Patient advocates are interested and usually very good at communicating with the public. Being a member of a research team allows them to know the research and be able to translate it into plain language for the public to understand. This is demonstrated in a unique program in science communication at Cornell University, where scientists connect with local advocates and community members while learning to communicate science to the public [24]. This puts a human face on cancer and exposes scientists to patients.

Patient advocates can be involved directly in research projects as a member of the research team [19,22]. It is always important to remember that although a goal is to be a valued and equal member of the research team, the patient advocate needs to be able to maintain independence so that they can truly advocate for patients during discussions. Although patient advocates will have general knowledge about research, they will appreciate learning more about the specific research project as they engage with researchers over the conduct of the project. They are not there to become a research scientist; however, they will learn concepts and ideas that can help identify how research may influence patients. Research patient advocates can be involved along the entire research continuum from conception to completion (Figure 2). Patients can add value in identification of the research question and giving guidance during grant application submission. Patients can help write a lay/public abstract and help convey the importance of the research to patients. At the completion of the project, patients can facilitate communication of the results to patients and the community. Their involvement can enhance research to be more patient centered and can instill a sense of urgency in research throughout the conduct of the research project.

Advisory

In addition to being involved in clinical and laboratory research projects as part of research teams, patients are often involved in oversight and are members of advisory committees and boards [23]. In these roles, patients can influence policy and strategies [19,22,23]. There are opportunities for advocate involvement in advisory committees and boards at several organizations and institutions, including the NCI, US FDA, American Society of Clinical Oncology and American Association for Cancer Research. Many large cancer centers have opportunities for advocate involvement on Institutional Review Board (IRB) and various scientific review committees. These opportunities give patients a voice where decisions about new directions in research are made. Another area where key decisions are made is in deciding funding of research grants [5,13]. Many organizations engage patient advocates in scientific grant peer review. One popular program that involves many consumer advocate reviewers is the CDMRP [5]. It not only has consumer reviewers but also requires consumer advocate inclusion on the research team, and this must be identified before grant submission. Some funding mechanisms require more than one consumer advocate, realizing that larger granting mechanisms require more participation. Other organizations also require patient advocate involvement (e.g., Susan G. Komen, Stand Up to Cancer) and have patient advocate reviewers (e.g., Susan G. Komen, American Society of Clinical Oncology, Metavivor, Patient-Centered Outcomes Research Institute). Most cancer organizations are interested in funding translational projects – that is, research that will make a difference in the treatment and survival of patients. Patient reviewers focus on potential patient impact and evaluate whether the applicant has a clear understanding about how their research may benefit patients, even if the benefit is many years away.

How to engage patient advocates in research

The role of patient advocates can vary as widely as each project varies. In general, their role can include advisory, designing the project or clinical trial, reviewing projects and disseminating research [15]. However, each project and each engagement should be assessed individually to maximize appropriate and meaningful engagement.

Key factors to enhance patient–researcher engagement include assembling a good team of advocates, building a foundation with common mission and goals and establishing clear roles and responsibilities [34]. Having a purpose and opportunities to engage early in the research process is also an important aspect of a good patient engagement program [19,35]. One part of patient engagement often forgotten is to assess the impact of patient involvement. Unfortunately, there are few examples, and measurements vary depending on the project [28,36]. Ideally, assessments should measure whether expectations were met by both the researcher and the patient [19].

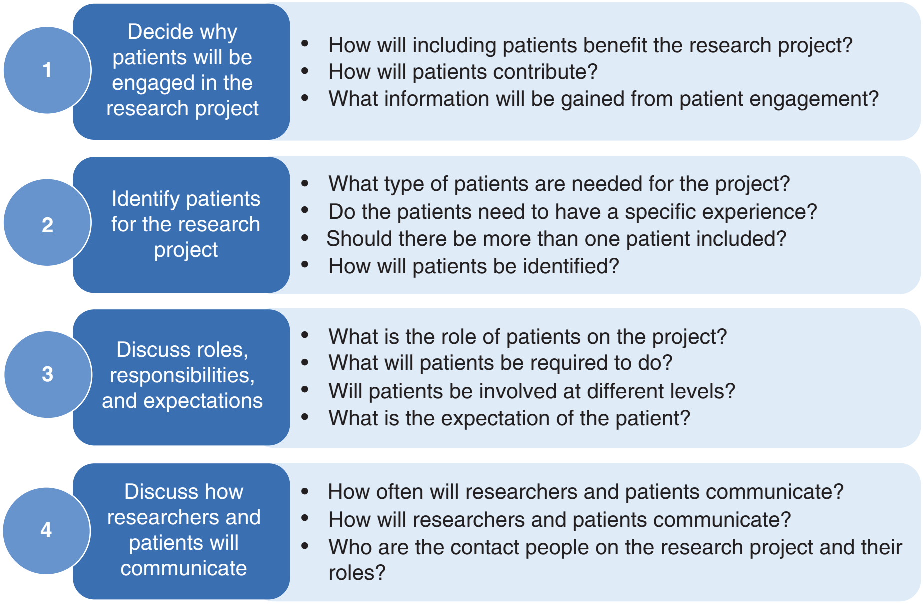
Having an environment of respect, equitable power and trust is also important [35]. This is developed through establishing clear communication from the beginning and throughout engagement [1,15,35,37]. Clear communication is essential for setting common goals and expectations, meeting frequency and defining the role of the advocate in each phase of the project. Patients must be willing to be objective and bring a broad cancer patient perspective to the conversation [1,19]. It is also important to value the patient's time and expertise to the project, which can be done by offering compensation [35]. This can be in honorarium for participation or to provide travel expenses for advocates to attend scientific meetings, which will increase their knowledge about the project. It is important to have this conversation when the engagement begins.

The process of patient engagement in research is unique to the setting and the specific research project. However, there are a few overarching steps that can be taken to ensure good patient advocate engagement in research based on prior literature and personal experience. What follows provides a road map for researchers and advocates outlining what to consider when participating in research projects together. This is a unique relationship, so a few key steps will ensure a meaningful contribution.

For researchers

Researchers can take a few practical steps to ensure effective and meaningful engagement of patients into their research projects (Figure 3). The inclusion of patients in research projects begins with the researcher deciding, or sometimes being required, to include patients in their research. It is the responsibility of researchers to contact patients and invite them to participate. To do this, researchers should have a clear idea about why they want to include patients in their research. This is an important first step, often overlooked in the process of patient engagement.

Once researchers decide to engage a patient advocate, they need to find a patient to include in their research project. This is not an easy task, but there are some practical steps to take to begin the process. On the basis of research needs, determine what type of patient or research patient advocate would be best for the project. It is not only important to match the need with the appropriate patient, but also to match the expertise and experience of the patient with the project. For example, if the research project focuses on metastatic breast cancer, it is a good idea to engage a patient with metastatic breast cancer to join the research team. Some projects may benefit from the engagement of several patients because the collective view of many allows for multiple opinions and mentorship opportunities for new advocates. Identifying patients for a specific research project can be challenging. Asking mentors or colleagues is a good starting point. Researchers can make an effort to meet patient advocates at scientific meetings like American Society of Clinical Oncology or American Association for Cancer Research



1 Decide why patients will be engaged in the research project
- How will including patients benefit the research project?
- How will patients contribute?
- What information will be gained from patient engagement?

2 Identify patients for the research project
- What type of patients are needed for the project?
- Do the patients need to have a specific experience?
- Should there be more than one patient included?
- How will patients be identified?

3 Discuss roles, responsibilities, and expectations
- What is the role of patients on the project?
- What will patients be required to do?
- Will patients be involved at different levels?
- What is the expectation of the patient?

4 Discuss how researchers and patients will communicate
- How often will researchers and patients communicate?
- How will researchers and patients communicate?
- Who are the contact people on the research project and their roles?

Figure 3. Steps researchers can take to ensure effective and meaningful engagement of patients into research projects.

Annual Meetings. Taking advantage of community events, including speaking for local cancer organizations, will increase access to patient advocates. If the grant funder is requiring patient advocate involvement, ask them for recommendations. As researchers commit to always engaging patients in their research, it becomes easier as working relationships develop.

Once a patient advocate is identified and accepts the invitation to participate, the real work begins. The first thing to do is to discuss roles, responsibilities and expectations. This is the most important discussion to have at the beginning of the project. Many items should be discussed; however, items will vary depending on the specific project, the specific need and level of engagement expected. This is also a great time to get to know each other and begin building a working relationship.

Communication is key to a successful engagement of advocates in research. At the beginning of the project, the researcher and patient advocate should agree on how often and in what way communication will be maintained throughout the conduct of the project. This will ensure fewer misunderstandings and reinforce expectations of both researcher and patient.

For patients

Patient advocates can follow the following advice to ensure effective engagement in research. Being an effective patient advocate on a research project requires some effort and motivation.

Represent a collective viewpoint

An experienced patient advocate learns from each experience, talks to other patients, facilitates support groups and can represent a collective patient perspective. Research patient advocates do not represent their personal individual, experiences; they represent the broader patient population. Therefore, although the patient story and experience is important in some situations, in research meetings, it is not appropriate to ask personal questions about your cancer and rarely appropriate to start a comment with a personal cancer story.

Learn listening & effective communication skills

Two main skills all patient advocates need is to learn are how to be a good listener and how to communicate effectively. Keeping up with scientific conversations can be challenging, so it is important to develop skills to help follow the conversations. One option is to avoid distractions so that you can listen and to take notes. Then previous conversations can easily be referred to. Communication is a skill that will develop over time. One helpful hint is to be aware of time constraints and try not to monopolize the conversation and to stay on topic and be succinct.

This should not discourage patients from speaking up; it is just a reminder to be respectful of the situation. In addition, many times agreeing with previous comments or complementing a speaker is a good way to engage and acknowledge the researchers. There is an art to disagreeing without being disagreeable, well worth the effort to learn.

Participate in conversations

Many times advocates are hesitant to speak up in a scientific meeting because they are afraid they will be 'wrong.' Patients provide their perspective and opinion, so they are never 'wrong.' It is a perception, not a test. Their opinion may change after facts they were unaware of are revealed; however, their initial opinion is important for researcher to hear. The patient is not there to evaluate the science but to speak on a broader patient perspective, so it is not necessary to speak in scientific jargon; plain language is appropriate. For patients to feel more comfortable speaking up, having one-on-one conversations with researchers can boost confidence. This skill improves over time and after many opportunities to engage with researchers.

Network

Effective patient advocates network with researchers and among other patient advocates. Patient advocates should make an effort to meet researchers studying a topic that interests them. Join patient advocacy communities to learn and meet other patients. One very active advocacy community network is the Patient Advocates in Research email list, founded by Deborah Collyar. Scientific meetings offer exceptional opportunities to network and taking advantage of the collaborative environment will enhance a patient advocate's experience.

Set realistic expectations

Patient advocates should set realistic expectations about their contribution and time they are able to commit to a project. Being able to discuss these issues with researchers is important. Do not expect to make a huge difference on every project. Sometimes it is small or may even seem underwhelming. Other times it will be substantial and very satisfying. Knowing that all engagements are different will help set realistic expectations.

Keep learning

Each patient advocate, regardless of previous experience, should never stop learning. Newer patient advocates should seek out learning opportunities, in-person or online [4,38]. Being prepared to participate on a research project, can take time and discipline. The alternative is being unprepared and not being able to contribute to a project. Advocates can ask a researcher to help them learn more about their specific project. Seeking out a mentor can also be helpful if one-on-one interactions are preferred. Several on-line training resources [39–43], trainings during scientific meeting [44–46] and comprehensive training programs [47–50] are available to patient advocates. One long standing breast cancer training is Project Lead® Institute conducted by the National Breast Cancer Coalition [4]. Project Lead is an intensive, multiday training [47]. Keeping up-to-date with new research can be overwhelming; however, learning will always be a part of participating in research. Accepting challenging opportunities may add to their knowledge, even if they feel uncertain at the beginning.

Conclusion

Including patient advocates in research is important. They can make valuable contributions in both laboratory-based and clinical research projects. It is highly recommended to involve advocates from conception to completion so that patients can help form the research questions and identify patient concerns early in development. Researchers should put concerted thought into how to involve advocates specific to their project and needs in a meaningful way. This may mean engaging more than one patient advocate or finding someone with appropriate experience for the project. Giving concerted effort and thought into specific ways patients can be involved to make a meaningful difference will enhance the overall engagement experience for both the researcher and the patient. Patient involvement in laboratory research can enhance research to be more patient centered and can instill a sense of urgency throughout the course of the research project. Patient involvement in clinical trial development will ensure the trials answer questions important to patients and have considered patient burden, broad inclusion and patient relevant endpoints.

There are some practical steps researchers can take to engage patient advocates. This article proposed the following suggestions to ensure meaningful engagement: decide why patients will be involved in the research project; identify patients; discuss roles, responsibilities and expectations; and discuss how researchers and patients will communicate.

Patient advocates can also follow some practical suggestions to ensure effective engagement: represent a collective viewpoint, learn listening and communication skills, participate in conversations, network with researchers and patient advocates, set realistic expectations and keep learning.

Effective patient engagement requires effort of both the researcher and the patient advocate; both must be committed to the process and communicate throughout the engagement. Patient engagement must not be about checking off a box on a form, with minimal contact after funding is secured. It is about making a difference to the way science is conducted, with urgency and value of the patient perspective and experience.

Future perspective

Engaging patients in cancer research is both challenging and rewarding. However, the goal "to generate knowledge and insight that will improve the lives of all cancer patients" should always drive the engagement of patients as partners in all areas of cancer research [51]. It is important to acknowledge the significance of early patient advocacy in cancer that has led to the current landscape of patient engagement in cancer research. Without their efforts, the patient voice in research would be much less if present at all. Although patient advocacy has come a long way, there is still work to be done to ensure the inclusion of patients in cancer research is universal and leads to the improvement of the lives of all cancer patients.

One major concern is a lack of diverse representation of patients involved in research. The opportunities to engage in research, although increasing, are not expansive. For example, there are more opportunities to be involved in research at academic institutions in large cities and fewer opportunities for those who live in rural communities. This limits opportunities for many patients who may be interested and can add an important community patient voice to clinical and laboratory research. Although some research patient engagement opportunities are not location based, it is harder for rural and underrepresented patients to be identified and asked to participate. The lack of opportunity is not the only barrier; there is also the dogma that patient advocacy as a purely volunteer activity. To ensure representation this is a huge barrier to overcome. Many times incidental costs (e.g., travel, parking, time off from work, childcare) are not reimbursed. Acknowledging the importance of the patient voice in research through compensation for their expertise and time can begin to overcome this barrier. There are likely more reasons for the lack of diverse patient representation in research, beyond the obvious ones mentioned here. More research is needed to evaluate the barriers to patient participation in research and to determine how to overcome these barriers to improve diverse representation of all patients in research.

Matching patient advocates to research engagement opportunities is still a challenge. It is sometimes hard for new advocates to find out about opportunities, and it is hard for researchers to find patient advocates interested in research. It is not clear what the solution will be; however, it is difficult to envision broad coordination across all cancers, so matching may be more effective when facilitated by cancer type. It is not only important to match patients with opportunities; it is also important to train advocates and have a path for new patient advocates as opportunities increase.

Training of research patient advocates has been an ongoing challenge. Most trainings are offered by individual cancer organizations by cancer type and are hard for patients to navigate. This creates a barrier, specifically for patients who advocate for rare tumors. Currently there is a lot of competition for in-person trainings, highlighting limited training opportunities and the increase in number of patients seeking training.

Assessing the impact of patient engagement in cancer research needs to be addressed. Having information and evidence on the impact of engaging patients in research will help patients and researchers understand their roles and clearly define ways patients can influence research.

Even though there are challenges, it is important to engage patients in research. Patients bring urgency to research. Too many patient advocates have died from cancer, and others are currently waiting for the next treatment to be discovered to give them more time. This adds an urgency to research that is hard to quantify. The loss of patient advocates is devastating; those of us left behind have an obligation to make sure their life and death are remembered and can motivate researchers to find new therapies and cures quickly. Keeping the voice of patients in research is one way to honor those who have died so that future cancer patients have access to new therapies to live longer and better lives.

Executive summary

Research patient advocates

- Patient advocates can provide valuable contributions in both laboratory and clinical research projects from concept to completion.
- Involving more than one patient can provide diverse representation of patient perspectives and enhance engagement to be more meaningful and effective.

Patient engagement in cancer research

- Putting some effort into specific ways patients can be involved to make a meaningful difference will enhance the overall engagement experience for both the researcher and the patient.
- Patient involvement in clinical trial development will ensure the trials answer questions important to patients and have considered patient burden, broad inclusion and patient relevant endpoints.
- Patient involvement in laboratory research can enhance research to be more patient centered and can instill a sense of urgency in research throughout the course of the research project.

How to engage patients in cancer research

- Researchers can follow the following steps: decide why patients will be engaged in the research project; identify patients; discuss roles, responsibilities and expectations; and discuss how researchers and patients will communicate.
- Patient advocates can ensure effective engagement by representing a collective viewpoint, learning listening and communication skills, participating in conversations, networking with researchers and patient advocates, setting realistic expectations and continuing to learn.

Future challenges and opportunities

- There is a lack of representation of diverse patients engaged in research.
- Matching patient advocates to research engagement opportunities is still a challenge.
- Keeping the voice of patients in research is one way to honor those who have died so that future cancer patients have access to new therapies to live longer and better lives.

Financial & competing interests disclosure

The authors have no relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript. This includes employment, consultancies, honoraria, stock ownership or options, expert testimony, grants or patents received or pending, or royalties.

No writing assistance was utilized in the production of this manuscript.

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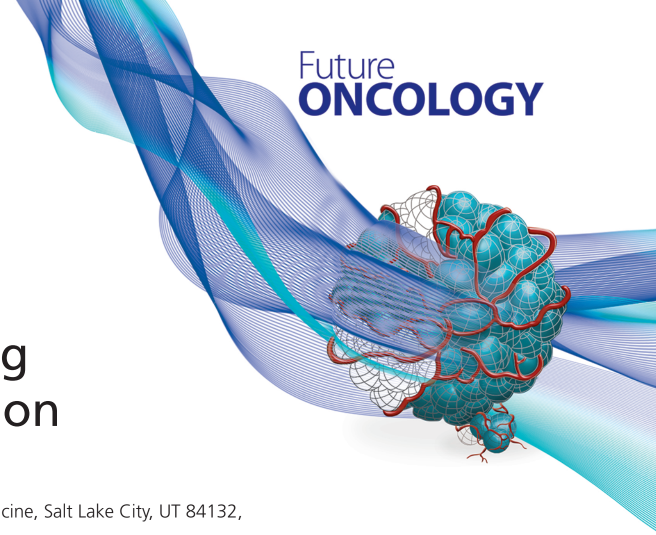

Commentary

What is the alternative? Responding strategically to cancer misinformation

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> “In the current unregulated information climate, it is difficult to view the struggle between evidence-based medicine and alternative cancer therapies as nothing less than a battle. We urge medical professionals to advocate for scientific medicine with boldness and empathy.”

First draft submitted: 5 May 2020; Accepted for publication: 3 June 2020; Published online: 21 June 2020

Keywords: alternative therapy • communication • internet • misinformation • oncology • patient trust • social media

In a 2018 survey, the American Society of Clinical Oncology revealed that nearly four in ten Americans believe cancer can be cured by alternative therapy alone [1]. This is alarming, given research which has found that cancer patients who elect to utilize only alternative therapies have higher mortality rates than those who receive conventional cancer therapy [2]. Confidence in the efficacy of alternative therapies can be extremely costly, often leading patients to fundraise online or travel abroad in search of treatments with no proven benefit [3,4]. Inaccurate information about cancer treatment has many sources: individuals with perceived medical expertise (such as celebrity doctors and ‘health gurus’), influential social media personalities, alternative medicine practitioners, politicians, activists and mass media have all been identified as vectors for misinformation [5]. Their influence is amplified by the internet, where, unfortunately, false information has been shown to spread faster, farther and more broadly than truth [6]. Such threats to patient safety are understandably disheartening. Fortunately, public trust in medical scientists remains high [7]. A 2020 survey of adults in the USA by the Pew Research Center found that 87% of individuals trust medical scientists – higher than any other professional group, including members of the military, clergy and educators [7]. Notably, levels of public trust in medical professionals could potentially have risen even higher during the ongoing COVID-19 pandemic. A national survey conducted among American adults in April 2020 found confidence in hospitals and physicians to be at 97% and confidence in scientists and researchers to be at 93% [8]. Furthermore, three out of five respondents in the Pew survey expressed a desire for scientists to ‘take an active role in policy debates’ [7]. Not only are medical experts trusted, but the public wants to hear from them.

To effectively counter misleading and untrue messages about cancer treatment, it might help to understand the spread of misinformation like a disease with an etiology, risk factors and promising treatments. With this framework in mind, we will explore: what constitutes an alternative therapy, how cancer misinformation spreads online, what makes patients susceptible to misinformation and how to counter misinformation, both in the clinic and in broader society. The aims are to assist medical professionals by defining important terms, identifying some of the common sources of misinformation, recognizing obstacles that increase patient vulnerability and finally suggesting how physicians and others with influence can combat misinformation.

Defining alternative therapy & complementary therapy

It is common for patients to utilize treatments that are not part of mainstream medicine. The NIH in the USA report that one in three American adults and about one in eight children use medical treatments that are not part of the established standard of care [9]. The NIH classifies unconventional therapies into two different categories: complementary therapies, defined as unconventional therapies utilized together with standard treatment as part of

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an integrative therapy plan created by a multidisciplinary care team and alternative therapies, which are used in place of the standard of care [9]. Alternative cancer treatments can be divided further into those which are unproven, those which are disproven, those which may cause indirect harm and those which may cause direct harm. Although complementary and integrative therapies can improve subjective outcomes, they can also pose risks. This is because their interference with mainstream cancer therapies may have a detrimental impact on clinical outcomes [10].

It is important to note that the manner in which a therapy is applied largely determines whether it is 'alternative' or 'complementary'. A treatment that might have begun as a complementary element of an integrative plan can quickly become an alternative therapy if the patient elects to discontinue the conventional elements of their care. Indeed, one of the greatest potential risks is that patients will misattribute the benefit from mainstream medicine to be from their complementary medicine, and thus commence using it as alternative medicine [11]. This is a danger underscored by the large proportion of individuals who believe that cancer can be cured by alternative therapy alone [1]. Much of this confusion stems from false or exaggerated claims about the curative properties of complementary treatments that patients encounter online [11]. In other words, patients may mistakenly perceive a complementary therapy as being an anticancer treatment rather than as a supportive treatment meant to improve symptoms during conventional cancer therapy. This kind of misinformation has the potential to erase the possible benefit of properly applied complementary medicine, mainly mind–body therapies, by leading patients to abandon conventional cancer treatments in favor of a perceived alternative anticancer therapy [12].

How cancer patients encounter misinformation

Although we often think of the internet as one entity, it is a multitude of very different platforms where information is shared in a variety ways [13]. This variation extends to user-generated platforms. For example, to post on Wikipedia, a user must follow certain policies such as verifiability, where citing reliable sources allows other users to check claims for accuracy. The website also has a hierarchical authority structure, where contributors who have earned trust have more capabilities. The product is an online encyclopedia with an error rate comparable to, if not lower than, the Encyclopedia Britannica [13,14]. Conversely, platforms that prioritize content sharing and social networking, like Twitter and Facebook, have proven more vulnerable to misinformation [13]. Often, a user's breadcrumb trail of clicks and 'likes' feeds into algorithms that can influence what and who he or she sees on these platforms [15]. While the details of the code running many of these algorithms is proprietary and thus unknown, their power to curate and amplify a user's perceived reality is widely appreciated, including signaling what is valuable and credible [16,17]. Two prominent examples of this are Twitter's 'Trends' list and Facebook's 'News Feed', both of which generate what has been termed the algorithmic real, 'where placeholders for trending topics and the like are presented as if they were faithful renderings of reality' [15]. Furthermore, social media platforms facilitate a user's ability to connect with others who agree with their preconceived notions, no matter how rare, by enabling users to create or join Facebook groups or selectively follow individuals on Twitter. This may contribute to the false consensus bias, where individuals believe that their opinions are more common and appropriate than they are in reality [18].

It is not simply the structure of many online platforms that eases the spread of misinformation about cancer therapies, it is potentially the way the stories are told. Information that patients encounter online and in news media is often presented in the form of personal stories [19,20]. Personal anecdotes can be particularly problematic in the context of false balance, where the media presents the anecdote as being in opposition to, but equally valid as, an expert's evidence-based opinion. False balance has been found to significantly distort perceptions of expert opinion [21]. The millions of dollars fundraised by individuals who are seeking help to pay for alternative cancer therapies on GoFundMe, a crowdfunding site, are a testament to the power of emotionally compelling, personal stories [3]. Personal narratives are thought to be a persuasive form of communication by increasing recall, eliciting21 an emotional response from the reader and increasing empathy [19,20]. Furthermore, although narratives hinder the persuasiveness of facts when they are strong, they appear to be particularly effective when the factual evidence within them is weak [22]. In this way, GoFundMe campaigns for alternative therapies may have the effect of making unproven and possibly harmful cancer treatments not only appear acceptable, but desirable. Furthermore, premature excitement and overexaggerated claims about new experimental findings by news media can also provide ammunition to proponents of alternative therapies by undermining the more meticulous scientific process inherent to discovering effective and safe cancer treatments. This science hype over unproven treatments, especially when told in the form of a poignant personal story, is the ideal fuel to propel misleading medical information throughout the internet. Research has found that practitioners of alternative medicine regularly draw upon science hype, as well as mainstream scientific and medical terminology, to give legitimacy to the products and procedures they offer, a phenomenon often referred to scienceploitation. In an even more deceptive move, many also cite publications in predatory journals, thus masquerading unproven therapies as evidence-based medicine [19].

In sum, the web often responds to a cancer patient's query about treatment with an avalanche of emotion, popular opinion and false advertising. Further research is needed, however, to clarify whether cancer patients are exposed to misinformation or whether they seek it out. Study is also needed to identify patients who may be more susceptible to the influence of online misinformation, including those who may have unmet needs and/or discontent with mainstream medical care paradigms caused by systems issues like poor access to healthcare, prohibitive costs and poor satisfaction with providers.

Doctor–patient communication

The challenge of navigating today's informational wilderness highlights the need for medical professionals to communicate with their patients more effectively. In the absence of drastic healthcare reform that would relieve the administrative burden placed on physicians and allow them the requisite time to spend with their patients, the need for efficient communication tools and aids becomes apparent. Presently, many of the educational resources available are in serious need of improvement. Numeracy (defined as the ability to understand and reason through numerical concepts), professional medical guidance and treatment decision aids have all demonstrated the potential to help patients make better care decisions. Higher-numeracy patients are known to better perceive risk than those less comfortable with numbers, making them more likely to avoid potentially harmful treatments [23,24]. However, it is important to note that both patients and physicians often struggle to understand health statistics because of their inherent cognitive biases or because the statistics are often reported in nontransparent ways [25].

In an effort to help cancer patients make wise care decisions, numerous materials have been created to educate them on their diagnoses and treatment options. Unfortunately, many of these are not evidence based [26,27]. A 2013 survey of the 77 cancer-related apps then available on iPhones found that about one in five were not backed by scientific data [27]. A separate review of decision aids for prostate cancer patients uncovered that they consistently failed to present patients with all mainstream options, they did not fully describe the treatments, nor did they explicitly summarize the comparative risks and benefits of each [26]. Poor quality educational materials may increase confusion about therapy options. Not surprisingly, cancer patients who are more unsure about their care plan have reported less trust in their doctor and a lower quality of life [28,29]. Research has found that cancer patients who feel uncertain about their diagnoses or therapy plans experience a greater sense of danger [29]. Such anxiety has been shown to lead cancer patients to begin a mainstream treatment, even when it is not clinically indicated and risks associated are high [30]. Oncologists often perceive their patient's anxiety as a desire to begin treatment quickly, thus putting the patient at unnecessary risk for adverse effects [30]. We now turn to response strategies, including improved communication between patients and doctors, that could potentially help ameliorate these outcomes.

Response strategies

While today's onslaught of misinformation may seem daunting, oncologists are well equipped to counter it. First of all, as physicians, they enjoy a high level of public confidence compared with their professional peers [7,8]. Data suggest that it is a person's perceived trustworthiness, not expertise, that makes them effective at correcting misinformation [31]. Where appealing online voices woo patients toward alternative therapy, oncologists can use their trustworthiness to steer them toward therapy that is evidence based. A patient's confidence in his or her physician is a reliable predictor of their adherence to treatment and continued enrollment in care – even more so than patient satisfaction [32–34]. Patients described trustworthy doctors as competent, honest and patient-centered [32]. For patients, 'competence' has less to do with academic credentials and more to do with a doctor's ability to communicate, build relationships, listen, act honestly and express care [32]. To be sure, responding to patient questions about unproven therapies can be tedious but a strong therapeutic alliance between doctor and patient has been found to give a patient a greater feeling of social support, increase their adherence to treatment and decrease illness-related grief [34]. A collaborative and effective doctor–patient relationship not only builds trust, but has also been shown to protect a patient's quality of life, even when they are deteriorating physically [34,35]. For these reasons, it appears worthwhile to incentivize the cultivation of patient trust in addition to or in place of, patient satisfaction [32,36]. Currently, a major obstacle to this is the absence of a reliable and validated tool to quantify patient trust [36]. Considering the potential a reliable and interpretable trust metric could have to improve trust in the doctor–patient relationship and counter misinformation, this remains an important area of research.

Furthermore, the coronavirus pandemic has only increased the urgency for the field to improve telemedicine and better understand how trust and compassion can be established when doctors are not face-to-face with patients.

An oncologist's communication skills with his or her patients in clinic is another important tool that can counter misinformation surrounding alternative cancer therapy. Communication research provides useful insights into how physicians can share health information with their patients effectively. In order to facilitate understanding, it is important to use frequency statements instead of single-event probabilities, absolute risks instead of relative risks, mortality rates instead of survival rates and natural frequencies instead of conditional probabilities [25]. Furthermore, when explaining treatments, physicians are encouraged to focus on the most important elements rather than delving into the details [37].

Well-designed educational materials can also play a key role in communicating accurate health information and dispelling confusion. Effective decision aids use a guiding approach to provide information about all treatment options in a balanced way [38]. They present the risks and benefits of each treatment in plain language, use patient narratives, disclose conflicts of interest and help patients to clarify and express what they value in their treatment plan [38]. Such resources have been shown to decrease patient anxiety and thus, improve decision making [39]. The use of pictograms, in particular, has also been shown to be a highly effective way of communicating treatment risks, especially to patients with low numeracy [40,41]. Pictographic representations of cure rates have also been found to reduce the undue influence of anecdotes when the two are presented together [40], suggesting that pictograms may have the potential to mitigate the harm of a narrative favoring alternative therapy.

Outside of the clinic, medical professionals should confidently and respectfully defend evidence-based medicine in public forums, especially in online user-generated platforms. As trusted members of society, their voices can have a significant impact on countering misinformation shared on social media, particularly when they respond quickly [7,42]. Since most members of the public rely on mass media for information, oncologists may reach a larger portion of their community by working through news outlets in addition to academic journals [20]. As they do so, defenders of evidence-based cancer medicine should share emotive and personal stories of their own, describing the benefits and efficacy of proven treatments [19].

Conclusion

We only need to look to the 2020 coronavirus pandemic to see the importance of countering medical misinformation. The Director-General of the WHO, TA Ghebreyesus, underscored the threat of health misinformation to international efforts to combat the spread of COVID-19, "*At the WHO, we're not just battling the virus; we're also batting the trolls and conspiracy theorists that push misinformation and undermine the outbreak response*" [43]. Oncologists are no strangers to this struggle. For decades, they, along with government agencies, lawmakers, courts and nonprofit organizations, have attempted to shut down harmful alternative therapy clinics, take sham products off the market and hold those profiting from misinformation accountable for their actions. And yet, cancer misinformation continues to spread through social interactions, personal stories and provocative anecdotes. It thrives in uncertainty and feeds on hope. In the current unregulated information climate, it is difficult to view the struggle between evidence-based medicine and alternative cancer therapies as nothing less than a battle. We urge medical professionals to advocate for scientific medicine with boldness and empathy. This paper highlights several strategies for effective communication for oncologists, as it is clear that we cannot rely on sweeping new laws or threats from government regulators to solve this problem.

Physicians will succeed in combating inaccurate information when they act genuinely and individually. This means professionally and patiently addressing questions about alternative therapy in the clinic and in popular media. When oncologists operate as people, separate from the intimidating and at times condescending faceless body of academic medicine, their patients can more clearly see them as trustworthy medical allies rather than out-of-touch whitecoats. Meet patients where they are: on Facebook, Instagram, Twitter and YouTube, just to name a few. After all, the person a patient trusts most is someone like them [44].

Financial & competing interests disclosure

The authors have no relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript. This includes employment, consultancies, honoraria, stock ownership or options, expert testimony, grants or patents received or pending, or royalties.

No writing assistance was utilized in the production of this manuscript.

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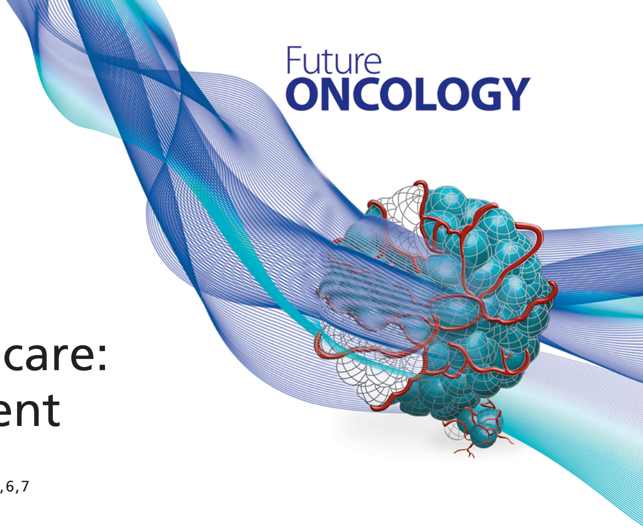

Navigating the high costs of cancer care: opportunities for patient engagement

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Over the past decade, the financial burden of cancer care on patients and their families has garnered increased attention. Many of the potential solutions have focused on system-level interventions such as adopting value-based payment models and negotiating drug prices; less consideration has been given to actions at the patient level to address cancer care costs. We argue that it is imperative to develop and support patient-level strategies that engage patients and consider their preferences, values and individual circumstances. Opportunities to meet these aims and improve the economic experience of patients in oncology are discussed, including: shared decision-making and communication, financial navigation and treatment planning, digital technology and alternative care pathways, and value-based insurance design.

Lay abstract: The financial burden of cancer care on patients and their families is a growing problem and action is critically needed to alleviate the high costs of such care. So far, potential solutions have focused on system-level interventions, with less consideration given to solutions at the patient level. This review argues that it is imperative to develop and support patient-level strategies that engage patients. Next, the review presents evidence of the interplay between patient preferences and values and the costs of cancer care. Finally, opportunities to enhance engagement and improve the economic experience of patients in oncology are discussed, including: shared decision-making and communication, financial navigation and treatment planning, digital technology and alternative care pathways, and value-based insurance design.

First draft submitted: 17 March 2021; Accepted for publication: 7 June 2021; Published online: 23 July 2021

Keywords: digital technology • financial navigation • financial toxicity • patient engagement • shared decision-making • value-based insurance design

Due to advances in detection and treatment over the last few decades, cancer incidence and mortality have declined [1]. Nevertheless, cancer remains the second leading cause of death in the USA, and cancer survivors represent a rapidly growing population that is expected to rise to 22.1 million individuals by 2030 [1,2]. Healthcare expenditures for cancer treatment have also increased significantly and are projected to skyrocket further over the next decade. In 2010 the total costs of cancer-related medical services and prescriptions in the USA were $157 million, rising to over $183 billion in 2020 and expected to reach over $245 billion by 2030 [1,3,4]. To be sure, high cancer costs are not exclusive to the USA and affect different health systems worldwide [5–8].

There are a myriad of factors driving the growing cost burden of cancer care, including misaligned economic incentives and the intensity of medical care delivered [9–14]. Advances in medical technology and the rising price of therapeutics are also significant drivers of increased cancer costs [9,11,15]. For example, prior to 2000, the average annual cost of cancer drugs was roughly $5000–10,000 per patient [16]. Since then, this cost has increased drastically, with some medications costing over $10,000 per month [16]. Such increases do not necessarily reflect value and in many countries, including the USA, few cancer treatments undergo value assessment prior to their adoption into

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practice. Not only can this result in higher costs, but it also contributes to the provision of unnecessary, low-value care. For example, the use of costly imaging for staging prostate or breast cancer patients at low risk for metastasis is common [17,18]. Moreover, in recent years, rates of contralateral prophylactic mastectomy in average-risk women have tripled, despite robust evidence demonstrating no medical benefit with additional surgery [19].

With the staggering costs of cancer care, more of the financial burden has shifted to patients. Often termed 'financial toxicity', such burdens can result in a range of economic, psychological and physical harms to patients and their families. For example, as a result of the significant costs they face, 22–64% of patients report financial struggles following a cancer diagnosis [20]. Such hardships can result not only from direct medical expenses, but also indirect (e.g., lost wages and productivity) and hidden costs (e.g., parking, childcare, travel) related to cancer care, which are often unexpected for patients and families and further exacerbate the financial distress of direct costs [21–27]. The accumulation of these costs can result in less income and assets, and significant debt; the average loss of wealth for cancer patients is over $92,000 within 2 years [28,29]. Consequently, patients and their families can experience trouble paying for housing, food and bills, and are often confronted with difficult decisions on whether to spend money on basic needs or their cancer-related bills. These challenges can push them to consider drastic measures, such as: filing for bankruptcy; using online crowdfunding platforms for unmet medical costs, medical travel and non-medical bills; and delaying or foregoing care [30–32]. The risk of being faced with these impossible trade-offs is higher for younger patients, women, low-income individuals and those who identify as belonging to a racial or ethnic minority, which can contribute to existing economic and cancer outcome disparities [30,33,34].

Equally distressing, the financial burdens experienced by patients and families can interfere with their ability to cope effectively with cancer and seek or maintain treatment, which can have adverse impacts on health outcomes, cancer prognosis and health-related quality of life [11,30,35,36]. Moreover, it is estimated that more than a third of patients borrow money from friends or family to pay for treatment [20], which can strain or threaten their relationships. Existing evidence suggests that patients who have social support throughout treatment are at lower risk of dying from cancer [37].

Over the last decade, potential solutions to address the high costs of cancer have garnered increased attention. Overwhelmingly, these strategies have targeted health systems and provider behavior through payment and reimbursement. This includes the adoption of value-based payment and delivery models; lowering or negotiating drug prices; and stimulating generic and biosimilar market competition, among other strategies. Notably, less consideration has been given to potential actions at the patient level to address cancer care costs. We argue that it is imperative to duly develop and support patient-level strategies that meaningfully engage patients and reflect and consider their preferences, values and individual circumstances, and that doing so is ever more critical given the growing burden of financial toxicity. In addition, compared with the more macro-level solutions outlined previously, investing in patient-level strategies could have a more immediate impact on alleviating high cancer costs.

In this paper, we first explore the interplay between patient preferences, values and costs in cancer care. We then outline and discuss opportunities to enhance patient engagement to improve the economic experience of patients in oncology.

Patient cost preferences & values in cancer care

Cancer care has long upheld the importance of incorporating the preferences and values of patients into treatment decisions. These considerations help guide and tailor treatments to fit within each patient's context and values, as well as facilitate shared expectations around quality and quantity of life.

In 2009 the American Society of Clinical Oncology endorsed cost communication between patients and providers [9]. Despite this, patient preferences and values have mainly centered on the clinical experience of care (e.g., side effects, comorbidities of treatment); to date, the costs of care and their implications have not been widely included in shared cancer treatment decisions [38,39]. In a survey of over 600 women with breast cancer, Greenup *et al.* found that 78% never discussed costs with their cancer team [23]. This oversight is particularly concerning given the growing financial burdens on patients and the fact that most desire whole-person care, where their personal circumstances – including finances – are considered throughout the treatment process [40–44]. From a provider perspective, while most believe physicians should consider costs, the majority report infrequently or never doing so when making treatment recommendations to patients. For example, Zafar *et al.* found that 75% of oncologists queried believed that patients should have access to cost information, but only 30% exercised cost transparency as part of their routine clinical practice [40]. Some physicians may be hesitant to discuss patients' financial concerns because they: are uncertain of the full extent of out-of-pocket costs incurred by their patient [45];

lack time or awareness of resources to help patients [43]; or do not have the training or accessible tools to talk about costs [42].

Individual patients are affected in different ways, however. While all patients care about costs, they are diverse in how they make trade-offs between clinical efficacy, side effects/toxicity, costs and other considerations in treatment decision-making, which may evolve and shift over the course of treatment. For example, in a discrete choice experiment with breast cancer patients, researchers demonstrated that at different times in the course of their disease, patients placed varying weight on life-extending treatment, side effects and cost of the care [46]. In another study and not surprisingly, Chebli *et al.* found that immediately after diagnosis, patients prioritized survival over financial concerns [47]. Variation in preferences is further supported by work with breast cancer patients that showed two distinct archetypes of patient preferences: those most concerned about affordability ('cost prioritizing') and those most preoccupied with their ability to work and interference with life events ('functional independence-prioritizing') [48]. Preferences may differ across different patient populations. Vulnerable groups, including those with a low income or without insurance, may place greater importance on cost no matter their stage of disease or other competing concerns. For example, Greenup *et al.* found that patients with lower reported household incomes (~$45,000 per year) prioritized costs over breast preservation or appearance [23]. However, cost of treatment is not the only economic concern that patients consider. In the aforementioned study, patients prioritizing functional independence more often had lower household incomes (<$40,000) or were on Medicaid [23]. Likely, treatment costs were important, but the greater concern was the ability to maintain employment in order to afford both medical and non-medical expenses.

These findings point not only to the need to engage patients around their economic experiences with cancer treatment, but also to the complexity of doing so in ways aligned with patient needs, preferences and values.

Opportunities for patient engagement to reduce financial toxicity

There are a range of strategies to support greater patient engagement across the cancer care continuum that could help mitigate the deleterious impacts of financial toxicity and the overuse of low-value care. In the following section, we focus on four areas of opportunity in particular – shared decision-making and communication, financial navigation and treatment planning, digital technology and alternative care pathways, and value-based insurance design – outlining current developments, key challenges and suggestions for improvement (Table 1).

Shared decision-making & communication

Shared decision-making (SDM) is a collaborative process that allows clinicians and patients to work together to ensure optimal healthcare decisions that align across the best available evidence, the clinician's expertise and patients' goals and preferences [49–52]. SDM is particularly beneficial in oncology, where patients are faced with complicated treatment decisions, of which most are preference sensitive, requiring patients to weigh efficacy and safety, quality of life and cost. SDM is associated with positive patient outcomes, including knowledge regarding available options, perceived quality of care and quality of life [53]. When SDM incorporates costs, it can be particularly beneficial to patients. Concordant with the patient preferences described above, one survey found that 83% of cancer patients felt that cost information incorporated into SDM decision aids was helpful or very helpful [54]. In addition, it has the potential to lower average total out-of-pocket spending without harming the appropriateness of cancer care [55]. Despite its potential, SDM is not widespread and has not been fully utilized to engage cancer patients in a discussion about the costs of their care [50,56–58].

There have been a growing number of efforts over recent years to address this gap. For example, the Choosing Wisely campaign, which is an international multispecialty initiative to avoid unnecessary medical care, employs patient-facing materials to encourage patients to engage in treatment discussions with their physicians. In particular, the campaign provides education modules, which include five questions patients should ask providers before receiving any test, treatment or procedure, with the final question focused on the cost of treatment and the availability of less expensive alternatives. A recent study examining the use of serum tumor marker tests for breast cancer survivors who are asymptomatic found that when patients were given a Choosing Wisely educational module on the guidelines, the rates of adherence to the recommendations increased [59]. Other research indicates that such SDM approaches result in patients choosing less invasive – and less costly – treatments [60]. In addition, Cost of Care Conversations, a collaboration between Avalere Health and the Robert Wood Johnson Foundation, provides education, guidance and other resources to help providers engage in in-depth cost discussions with their patients [61]. Other notable tools include the American Society of Clinical Oncology Value Framework [62] and the National

Table 1. Summary of strategies to engage patients in cancer costs.

Strategy	Concept	Challenges	Opportunities
SDM and communication	A communication strategy for clinicians and patients to work together on treatment decisions that align with patient preferences and values	• Limited number of tools that include costs; minimal evaluation for impact and effectiveness among those that do exist • Inadequate provider training and perceived loss of time • Patient hesitancy to bring up financial concerns • Lack of transparent cost information • Uncertainty around where, when and how often to engage in SDM	• Clinical decision support tools at the point of care • Alerts or prompts to discuss costs embedded within EHRs • Patient portals with 'prescriptions' to complete decision aids and review educational materials • Further development and evaluation of SDM tools that incorporate costs • Research on patient numeracy and processing of costs
Financial navigation and treatment planning	Comprehensive financial assistance to assist patients with decisions regarding insurance optimization, payment assistance and short- and long-term care planning	• Existing financial assistance basic and fragmented • Suboptimal education and staff resources, unclear responsibilities and competing time demands to assist patients in financial & treatment planning • Lack of user-friendly information on costs (and quality) of treatment	• Personalized financial navigation programs • Patient-centered treatment plans, including advanced care plans and directives and survivorship plans, with regular review throughout cancer care continuum
Digital engagement and alternative care settings	Use of technology to connect patients to financial resources and support and facilitate lower-cost settings of care (e.g., home, community)	• Lack of clarity regarding what information, tools or measures underlie online platforms to help patients address financial toxicity • Telehealth and other alternative care pathways may not reach certain patient populations; perceived concerns about patient–provider relationship	• Virtual care pathways or models • Evaluation of telehealth and other alternative care sites employed during the COVID-19 pandemic
Value-based insurance design	Reduce or eliminate co-pays for high-value care, while increasing them for low-value care	• Variable evidence to discern high value vs low value • Accounting for clinical nuance given patient heterogeneity • Differences in patient literacy around costs • Provider buy-in	• Focus on services with strong evidence base and areas in most need of improvement • More effective and validated patient-facing cost information tools

EHR: Electronic health record; SDM: Shared decision-making.

Comprehensive Cancer Network Evidence Blocks [63], which are decision frameworks that strive to assist providers and patients in taking clinical benefit, side effects, patient symptoms or quality of life and costs into account when comparing different treatment options.

Despite these developments, challenges remain. Most of these tools are still in their infancy, do not adequately consider patients' insurance benefit design or have not been evaluated for their impact on decision-making quality, patient-reported outcomes, patient out-of-pocket costs and/or perceived alleviation or decline in financial toxicity. More broadly, there are significant barriers to the incorporation of SDM into oncology practice, including insufficient provider training, the absence of revenue generation for such conversations, perceived loss of time, patient hesitancy to raise financial concerns and lack of transparent information or tangible supports to support cost discussions [51,64,65]. In addition, given the complexity of cancer care, patients typically engage with multiple providers and a broader care team, which raises issues around where, when and how often SDM should occur. A recent study, for example, showed that while an SDM decision tool focused on costs of care increased the frequency of cost conversations between providers and patients, clinicians were less likely to address or offer potential solutions to the patients' cost concerns [66]. This indicates that the use of SDM decision tools may be sufficient to trigger the cost conversation, but is inadequate to support patients over time or throughout the entire care continuum.

To more effectively incorporate SDM and cost communication into cancer patient encounters, solutions are needed to overcome the barriers currently in place. First, functional, point-of-care cost transparency and improved patient-centered communication methods must be available to patients and providers to actively use for cancer treatment decisions in real time. Clinical decision support tools, integrated into the electronic health record, could be leveraged to prompt physicians and other members of the care team to screen for financial toxicity risk. For example, simple routine queries around the affordability of care have potential to quickly and effectively screen for economic distress and alleviate some hurdles around time concerns and self-consciousness for patients raising a historically stigmatized issue [67]. For patients at high risk for financial toxicity, reminders may be embedded into the electronic health record that prompt the clinical team to engage in cost discussions, consider cost-reducing strategies (e.g., generic prescription drugs, off-site imaging), or to refer patients for financial assistance or ongoing navigation services. Such tools could also alert providers to low-value care services and provide higher value and less costly treatment alternatives, or deliver prompts to access a relevant patient decision aid or cost of care tool. Notably, socializing the concept of cancer-related financial hardship may normalize cost conversations and eliminate provider bias around which patients may or may not be at risk. Although existing literature supports that lower socioeconomic and minority patients are at higher risk of financial toxicity, all individuals undergoing cancer treatment may be vulnerable and should be considered for these supportive services. More research is needed to identify effective teaching methods for both practicing clinicians and trainees on SDM principles and ways to leverage SDM tools most effectively and equitably, particularly as it relates to conversations around cost.

Development and use of patient portals may also be an effective means of furthering SDM. Through the portal, providers could prescribe SDM tools or decision aids and education materials to patients, which would allow them to review and complete the tools in advance of appointments, on their own time and pace; craft and pose questions in an unrushed manner; and serve as a resource they can access outside of clinical visits. It also affords the opportunity for patients to bring caregivers, family members or other trusted individuals into cost discussions and treatment decisions.

Additional expansion and evaluation of SDM tools that incorporate costs is required. Ideally, such tools would allow patients and providers to compare total costs of care (encompassing direct, indirect and hidden costs) and estimated out-of-pocket outlays given a patient's insurance status and benefit design of available treatment alternatives. This information should then be presented with or alongside comparative evidence on effectiveness, side effects, quality of life and other patient-reported outcomes. Furthermore, existing research highlights the benefits of tools or aids that incorporate explicit values clarification and consider language and health literacy in relation to effective SDM [68,69]. Given the potential impact of these tools on treatment decisions, it is imperative to engage patients in their development and evolution [70]. Additional research is needed around numeracy as it pertains to cost transparency and communication, as well as patient processing of this information during the stress of cancer diagnosis and treatment planning.

Financial navigation & treatment planning

After a patient and provider decide on the best course of treatment – ideally through a shared decision-making process as outlined above – patients need financial navigation and case management planning to facilitate decisions regarding insurance, financial assistance and even the location of their cancer care. In addition to the challenges related directly to the costs of care, many cancer patients report distress related to navigating insurance and billing issues [71,72]. While many health systems provide some type of financial assistance programming, there is wide variability in the services offered, with most being of limited scope. A recent National Comprehensive Cancer Network survey found that the provision of basic financial assistance is common, such as help with drug costs for those who qualified, while formal preauthorization programs or assistance with claims and denials are not uniformly offered [73]. Any assistance that is provided can be limited to uninsured patients [74] and is often fragmented, with responsibilities spread across different registration staff, social workers, insurance navigators and clinicians [75]. Consequently, a significant proportion of patients are left without sufficient or consistent support, and providers and health systems miss key opportunities to improve the quality of care and patient outcomes while reducing costs.

In response, a range of nonprofit organizations have been developed to provide short-term financial assistance to patients for medical costs, transportation, lodging, and home and childcare, or to connect patients to these resources. For example, the Pretty in Pink Foundation, Pink Fund and Cancer*Care* provide such assistance for breast cancer patients. These can be vital sources of support for patients, provided they learn of them or have the resources to complete the required screening applications [76]. A survey by the National Cancer Institute found that 40% of cancer centers reported a lack of staff awareness about available financial navigation services and 46% reported that the pathways or workflows to connect cancer patients with existing financial services were unclear [63]. Noted barriers to identifying or delivering these services include suboptimal staffing, education and training of staff, unclear responsibilities and competing demands for time.

In addition, those involved – from providers and staff to patients – may not have the information required to make patient-centered choices that focus on high-quality, lower-cost care. For example, patients are not afforded access to consistent and reliable metrics regarding quality and cost of cancer care at different hospitals or cancer centers [77]. This limits the opportunity for active engagement among patients in deciding where to seek treatment and what costs can be expected during the course of their care. Some healthcare systems and payers have put

Table 2. Digital strategies for patient engagement on costs of cancer care.

Patient Engagement Strategy	Case Examples	Ref.
Shared decision-making and communication	WiserCare is an online platform that incorporates SDM for preference-sensitive decisions. Combining virtual patient education with rapid information sharing among patients, providers, and caregivers, WiserCare has been shown to improve patient satisfaction, perceived quality of treatment decisions, and reduce decision conflict among patients with prostate cancer	[109,110]
Financial navigation and treatment planning	Vivor is an online financial assistance application that matches patient profiles to its database of financial assistance programs. In a recent study, the use of the application was associated with higher likelihood to apply for and receive financial assistance TailorMed is a web-based software that connects to electronic health records to identify patients best suited for financial navigation and offers comprehensive services, including insurance optimization in addition to payment assistance, that are delivered by phone or through video calls	[111–113]

different price or cost transparency initiatives or tools into place to help patients become more informed 'shoppers' and compare the prices of different services or providers, but uptake and impact to date have been limited [78–80]. In many ways, the current tools have been unable to support the needs of oncology patients in particular, given highly individualized and ever-changing treatment plans and, as previously noted, multiprovider care teams [81]. Further, previous research suggests that available tools are not likely reaching patients that need them most, but rather those of younger age and with higher incomes and moderate annual out-of-pocket medical spending [82,83].

More work is needed to provide personalized financial navigation services for cancer patients. Such services should include dedicated and trained financial navigators that can proactively create comprehensive plans to meet the unique needs, preferences and values of each patient, and address both the objective financial burden and the subjective financial distress associated with cancer treatment. Ideally, financial navigators connect with patients before treatment begins and continue working with them throughout the duration of their care. Ongoing communication and support about financial burdens throughout the care continuum is critical, as the risk of financial toxicity varies in severity over the course of cancer care and may be cumulative for many patients. Furthermore, financial navigators should be considered essential members of a broader interdisciplinary care team, rather than as a billing or administrative function outside of it, considering their potential to improve care co-ordination, patient outcomes and shared decision-making. Indeed, available evidence on these programs suggests benefits for both patients and health systems. Patients receive concrete assistance in navigating the cost of care, experience reduced anxiety about financial burdens and greater satisfaction with their care, and save on out-of-pocket outlays [76,84]. In one recent evaluation, patients received, on average, \$33,265 in free medications per year and saved \$12,256 through enrollment in insurance plans, \$35,294 with premium assistance and \$3,076 with co-pay assistance each year [85]. Health systems employing these programs have seen significant savings, ranging from \$760,000 to \$19 million annually [76,86].

As part of SDM and financial navigation programs, patient-centered treatment plans that consider both short- and long-term financial impacts on patients and their families could be developed. This planning process should entail consideration of advance care planning and directives and supportive care, including a survivorship plan after treatment. Doing so would ensure that patients receive care that is consistent with their values, goals and preferences, as well as create a care pathway to reduce the risk of financial toxicity in alignment with those considerations. Such plans could reside on patient portals, as mentioned previously, to facilitate patient support and management across the care team and cancer care facilities. As patients move through the cancer care continuum, treatment plans should be revisited to activate them around ongoing care decisions and reflect any shifts in their financial and non-financial circumstances. This may be particularly important in the context of advanced cancer, given the expense of care at the end of life, which can average around \$100,000 per patient [2,4]. Patient–provider end-of-life conversations have been shown to result in significantly lower patient costs in the final week of life [87]. SDM tools focused on end-of-life options could be incorporated into treatment planning as part of financial navigation programs.

Digital technology & alternative care pathways

Digital technology offers interdisciplinary cancer care teams the opportunity to engage in and monitor care across the care continuum by allowing for tracking, follow-up and co-ordination of care. It also has the potential to activate patients around costs by expanding access to some of the strategies already discussed, in addition to creating opportunities for lower-cost alternative care pathways. As illustrated in Table 2, prior research has demonstrated the utility and potential of digital services to expand the reach and impact of SDM and financial navigation programs.

Outside of formal SDM or financial navigation programs, digital platforms afford a broader range of opportunities for patient engagement around the costs of cancer care. The virtual community 'Belong.Life', for example, employs machine learning algorithms to match over 1 million cancer patients with others like themselves. The platform provides tips and information to support the journey of each cancer patient. Recently, the company has begun to use the community to identify financial hardship in cancer patients [88,89]. Such resources could be extended to identify financial assistance opportunities for patients experiencing financial toxicity. However, caution is warranted, as there is considerable cancer misinformation on online platforms and even financial exploitation with unproven cancer cure claims [90,91]. As discussed, assessing financial hardship among patients necessitates accounting for variations in need, preferences and values. The clinical interaction therefore holds the highest potential to identify patients at risk for financial hardship, with online tools serving as secondary resources.

Recent years have seen increased focus on identifying care pathways in oncology and other therapeutic areas to improve quality of care, reduce unnecessary variation and lower costs [92]. The COVID-19 pandemic further reinforced the need to provide and support new approaches to or pathways of care delivery, with telehealth adoption and expansion being a critical strategy. The ability to receive care at home and/or in the community – meeting patients where they are – has the potential to reduce both direct and indirect medical costs for patients. For example, use of telehealth, home-based care and community-based care can help keep patients out of the emergency department or hospital and reduce unnecessary and low-value care [93–96]. Moreover, these approaches have potential to eliminate hidden and some indirect costs, such as parking, travel costs and lost work time. In addition to cost savings, use of these alternative care pathways may improve cancer care access and quality, align more closely with patient preferences, and provide additional opportunities for patient engagement around their treatment [97,98]. Oncologists, for example, have noted telehealth's potential to provide more frequent follow-up, patient convenience and opportunities for patients to ask questions and engage family members in treatment conversations [99]. A recent survey of patients with breast and gynecological cancer using telehealth during the pandemic found high satisfaction rates, agreement that telehealth services activated them around their health, and beliefs that these services should be available in addition to in-person services [100]. These alternative approaches to in-person care can also help reach patient populations who lack access to large, comprehensive cancer centers or experience other financial and non-financial barriers.

However, Heyer *et al.* identified provider concerns about the ability to establish or maintain a provider–patient bond and deliver sensitive or complicated information through telehealth [99]. They also reported that copayments for a telehealth visit could hinder patient uptake because of patients' apprehension about paying for a video versus an in-person appointment. Overall, oncology professionals were also concerned about telehealth access and engagement for older patients, non-English-speakers and those with limited socioeconomic resources.

Virtual care pathways might be a viable way to deliver integrated, tailored and affordable cancer survivorship care to patients, particularly those at low risk of recurrence. These types of models have mainly been employed in breast and prostate cancer to date, generally using simple technologies (e.g., telephone calls and texting, video conferencing) and a variety of allied health professionals [101]. As such, these models may offer lower-cost treatment alternatives for patients compared with conventional post-treatment cancer follow-up protocols. While not yet evaluating impacts on patient costs, existing research suggests these virtual care models are safe and cost-effective and yield positive patient outcomes (e.g., satisfaction, quality of life, functioning, anxiety, depression) [101].

The rapid pace of technological innovation, coupled with the requisite innovations in workflow and care delivery that were put in place due to COVID-19, will likely continue to shift the landscape of oncology care toward offering more virtual and community-based options to patients and oncology professionals alike. While these strategies are unlikely to replace existing inpatient care delivery models, they can serve to complement and advance current approaches to afford lower-cost pathways to patients and better align with patient heterogeneity in needs, preferences and resources. The pandemic provides an opportune time to grow the evidence base on the impacts of digital and alternative care pathways given the rapid and expansive uptake of these modalities, and to build on any best practices learned over the last year.

Value-based insurance design

Value-based insurance design, or VBID, is an approach to shape consumer decision-making by shifting or adjusting cost-sharing for medical services of different value. To expand access to high-value clinical services, VBID reduces or removes financial barriers through lower, or zero, patient cost-sharing arrangements. In parallel, this approach can be used to discourage use of low-value care by increasing patient cost-sharing for unnecessary or inappropriate care.

Such principles were incorporated in the Affordable Care Act, which eliminated consumer cost-sharing for specific preventive care services [102], and were employed during the COVID-19 pandemic to eliminate patient cost-sharing for testing, telehealth and vaccination [103]. Available evidence supports the potential for VBID to improve treatment adherence, reduce utilization of low-value services and lower patient out-of-pocket costs [104,105]. This approach may also improve racial and ethnic health disparities. Choudhry *et al.* found that eliminating copayments for secondary prevention therapies following myocardial infarctions increased adherence in all patients and significantly reduced rates of major vascular events or revascularization and healthcare spending in non-white patients [106].

While VBID has been primarily used outside of oncology to date, it could be used across the cancer continuum to encourage appropriate screening and use of high-value drugs and other treatments, and to shift patients to providers or institutions practicing high-quality, guideline-adherent care [107]. Such strategies would eliminate or lower patient cost-sharing for services that are clinically beneficial, while deterring the use of low-value – even potentially harmful – care that adds unnecessary costs for patients. Building off of VBID principles, in addition to reduced co-pays, some payers are paying patients to compare procedures and select lower-cost, high-quality options [108]. It has also been suggested that an 'inclusive shared savings' approach, whereby associated savings are shared by providers and patients when lower-cost but equally effective interventions are used in treatment, would provide more powerful financial incentives for shared decision-making toward high-value, lower-cost care [109].

Certainly, there are potential barriers to these strategies; most notably, the availability of sufficient evidence to discern between high-value and low-value oncology care and due consideration of clinical nuance given patient heterogeneity, particularly with regards to reflecting outcomes in diverse patient populations. Other challenges include regulatory hurdles around the information-sharing required to support VBID and similar approaches, variability in patient health literacy and comfort navigating costs, and provider buy-in [77,110]. Moreover, if there is unequal access to VBID across plans or patient groups, discriminatory impacts may result. To address some of these challenges, VBID programs can preference services with a stronger evidence base and high likelihood of being high- or low-value independent of clinical context, and consider areas in most need of improvement [111]. These approaches should also be designed simply to avoid adding unnecessary decision complexity and to reach patients with differing literacy levels. As noted earlier, more effective and validated patient-facing cost information tools would be beneficial to support these efforts. Finally, more evidence on the viability and impact of these strategies on patient costs and outcomes, including implications for equity, are needed.

Conclusion

Notable scientific advances have been achieved in oncology, with more innovative therapies on the horizon with improvements in precision medicine and immunotherapy. These developments, however, will have limited benefit if patients cannot afford them or suffer such financial distress that optimal health outcomes are unattainable. To effectively address this challenge, strategies are needed at various levels of the healthcare system, including at the patient level where financial toxicity is acutely felt by patients and families. We discuss four such strategies herein. As intimated throughout this article, a multipronged approach is needed, with complementary strategies that engage patients meaningfully and in ways that align with their needs, preferences and values. Such approaches should be integrated across the cancer care continuum to ensure a co-ordinated and comprehensive approach.

Future perspective

The COVID-19 pandemic may have introduced opportunities to make advances across many of the outlined strategies in this review. The rapid deployment and coverage of telehealth, for example, suggests that swift innovation in cancer care is possible. Many of the flexibilities and supports that were extended during the pandemic to make it easier and more financially viable for providers and patients alike to utilize telehealth and other alternative care pathways, and prioritize necessary care, should continue to be supported, especially if they are demonstrated to reduce costs, increase equitable access to care and enhance quality of care.

In addition, COVID-19 may have shifted practices around volume-based care toward greater commitment to and vision for value-based care, given the vast declines in non-emergent care and the spotlight the pandemic placed on existing system inefficiencies and inequities. There is immense potential to incorporate the strategies discussed herein into value-based oncology care models, such as Oncology Care First, that aim to achieve patient-centered cancer care. These models could incorporate lessons learned on telehealth best practices into their care redesign activities, enhance opportunities for remote monitoring and provide appropriate financial and non-financial incentives for both providers and payers to exercise SDM and use evidence-based, high-value and lower-cost treatments. Such approaches can also be tailored and targeted to populations most at risk for experiencing financial toxicity. In fact, value-based care models provide more predictable financial structures and associated investments in staff, data and care co-ordination that can help support adoption of these strategies over time.

To strengthen these various efforts, clinicians, trainees and other members of the care team need more frequent and effective socialization of cost discussions, SDM principles and techniques and value-based care approaches. More research is needed to identify effective teaching methods to meet these aims, ideally embedding them along different stages of medical education and training. Moreover, as discussed across the four strategies, further evaluation is needed to ascertain their impacts on outcomes and costs and how best to adapt these strategies to individual patients' health and numeric literacy, cultural backgrounds and beliefs, and psychosocial and emotional well-being.

Executive summary

Background

- Healthcare expenditures on cancer care are growing and more financial burden has shifted to patients.
- Patient-level strategies are needed to mitigate the high costs of care.

Patient cost preference & values in cancer care

- Patients have diverse preferences and values regarding the costs of care, and these may change over the course of their treatment.
- Patient engagement strategies around costs should align with their preferences, values and individual circumstances.

Opportunities for patient engagement to reduce financial toxicity

Shared decision-making & communication

- Shared decision-making (SDM) is a collaborative process that allows clinicians and patients to align treatment decisions with patients' goals and preferences.
- More robust research is needed to tailor the tools to the circumstances of each patient and to encourage broader implementation.
- Future SDM tools should include point-of-care price transparency, be integrated into the electronic health record and use patient–provider online portals.

Financial navigation & treatment planning

- Financial navigation provides counseling to patients on decisions regarding insurance, financial assistance and navigating cancer-related bills.
- Cancer institutions often provide some type of financial assistance programming, but there is wide variability in the services offered.
- Future financial navigation programs should consider both short- and long-term financial and care goals, such as advanced care and survivorship planning.

Digital technology & alternative care pathways

- Digital technology enables care teams to engage patients in the costs of cancer care.
- These include digital SDM and financial navigation tools as well as virtual support communities and telehealth tools.
- Future digital technology platforms should aim to complement clinical workflows and align with the heterogeneity of patient needs, preferences and resources.

Value-based insurance design

- Value-based insurance design is an approach to shape consumer decision-making by shifting cost-sharing for medical services of different value.
- Barriers to implementation include the availability of evidence to discern the value of care within the clinical and economic context of a specific patient.
- Future programs for value-based insurance design in oncology care should incorporate validated patient-facing cost information tools and focus on services with a robust evidence base.

Conclusion

- The benefit of innovative therapies and treatments is limited when patients are unable to afford them or suffer financial distress because of the costs of care.
- Strategies to address financial burdens that patients face should be integrated with existing health system-level actions to ensure a co-ordinated and comprehensive approach.

Author contributions

Substantial contributions to: the conception and design of the work (A Gunn, C Sorenson, R Greenup), the acquisition, analysis, or interpretation of data for the work (A Gunn, C Sorenson), drafting the work (A Gunn, C Sorenson); revising it critically for important intellectual content (A Gunn, C Sorenson, R Greenup) and final approval of the version to be published (A Gunn, C Sorenson, R Greenup); and agreement to be accountable for all aspects of the work (A Gunn, C Sorenson, R Greenup).

Financial & competing interests disclosure

The authors have no relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript. This includes employment, consultancies, honoraria, stock ownership or options, expert testimony, grants or patents received or pending, or royalties.

No writing assistance was utilized in the production of this manuscript.

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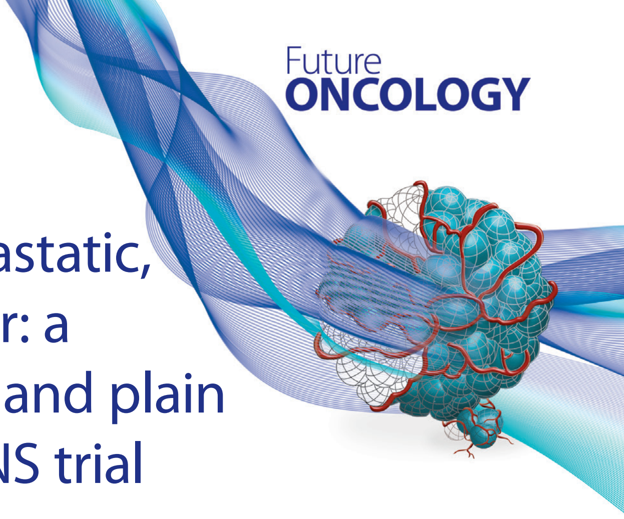
Plain Language Summary of Publication



Darolutamide and survival in metastatic, hormone-sensitive prostate cancer: a patient and caregiver perspective and plain language summary of the ARASENS trial

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First draft submitted: 27 April 2022; Accepted for publication: 17 May 2022; Published online: 3 June 2022

Summary

What is this summary about?

How to say (double-click on the icon to play sound)…

- **Darolutamide:** Dah-ruh-LOO-tuh-mide 🔊
- **Docetaxel:** Doe-suh-TAK-sul 🔊

This is a summary of a publication about the ARASENS trial, which was published in the *New England Journal of Medicine* in February 2022. The trial includes 1,306 men with a type of prostate cancer called metastatic, hormone-sensitive prostate cancer (also called mHSPC). In the trial, researchers wanted to learn if combining a treatment called **darolutamide** (also known by the brand name Nubeqa®) with two other medicines called androgen deprivation therapy (also called **ADT**) and **docetaxel** (brand name Taxotere®) could help treat patients with mHSPC better than **placebo** plus **ADT** and **docetaxel**. **ADT** with **docetaxel** is a treatment used for patients with mHSPC. **Darolutamide** is an approved treatment for a different type of prostate cancer called non-metastatic, castration-resistant prostate cancer (also called nmCRPC).

What were the results?

The trial results showed that combining **darolutamide** with **ADT** and **docetaxel** increased the chance of survival and lowered the risk of death by 32.5% compared to combining **ADT** and **docetaxel** with **placebo** instead. Compared to patients who received the **placebo**, patients who received **darolutamide** had a delay in:

- their cancer becoming castration-resistant
- worsening pain
- having cancer-related bone fractures or related symptoms
- needing additional therapies for cancer

The percentage of trial patients who had medical problems during the trial, also called adverse events, was similar between trial patients who received **darolutamide** and those who received the **placebo**.

What do the results of the trial mean?

Combining **darolutamide** with **ADT** and **docetaxel** helped treat trial patients with mHSPC better than **placebo** with **ADT** and **docetaxel**. **Darolutamide** in combination with **ADT** and **docetaxel** could be a treatment option for patients with mHSPC. Patients should always talk to their doctors and nurses before making any decisions about their treatment. This summary also includes perspectives on the ARASENS trial and prostate cancer from 3 members of the patient community.

An Animated Video describing this study is available online alongside this article. Scan this QR code to watch the video.

Future Medicine part of fsg

10.2217/fon-2022-0433 © 2022 The Authors *Future Oncol.* (2022) 18(21), 2585–2597 ISSN 1479-6694

Who is this summary for?

This summary is co-authored by members of the patient community and includes their perspectives to help patients and caregivers understand the results of the trial. It may also be helpful for patient advocates, the general public, and healthcare professionals, including those who are looking at treatment options for mHSPC.

What was the purpose of the ARASENS trial?

? The purpose of the ARASENS trial was to learn if combining **darolutamide** with **ADT** and **docetaxel** could help treat patients with mHSPC better than **placebo** with **ADT** with **docetaxel**.

What is mHSPC and what are some possible treatments?

m Metastatic	HS Hormone-sensitive	PC Prostate cancer
The cancer has spread to other parts of the body.	Sometimes also called 'castration-sensitive'. The cancer can be treated with hormone therapy such as **ADT**.	The cancer started in the prostate gland. In patients with prostate cancer, the body cannot control the growth of abnormal prostate cells. The abnormal cells form tumors in the prostate gland and may spread to other parts of the body.

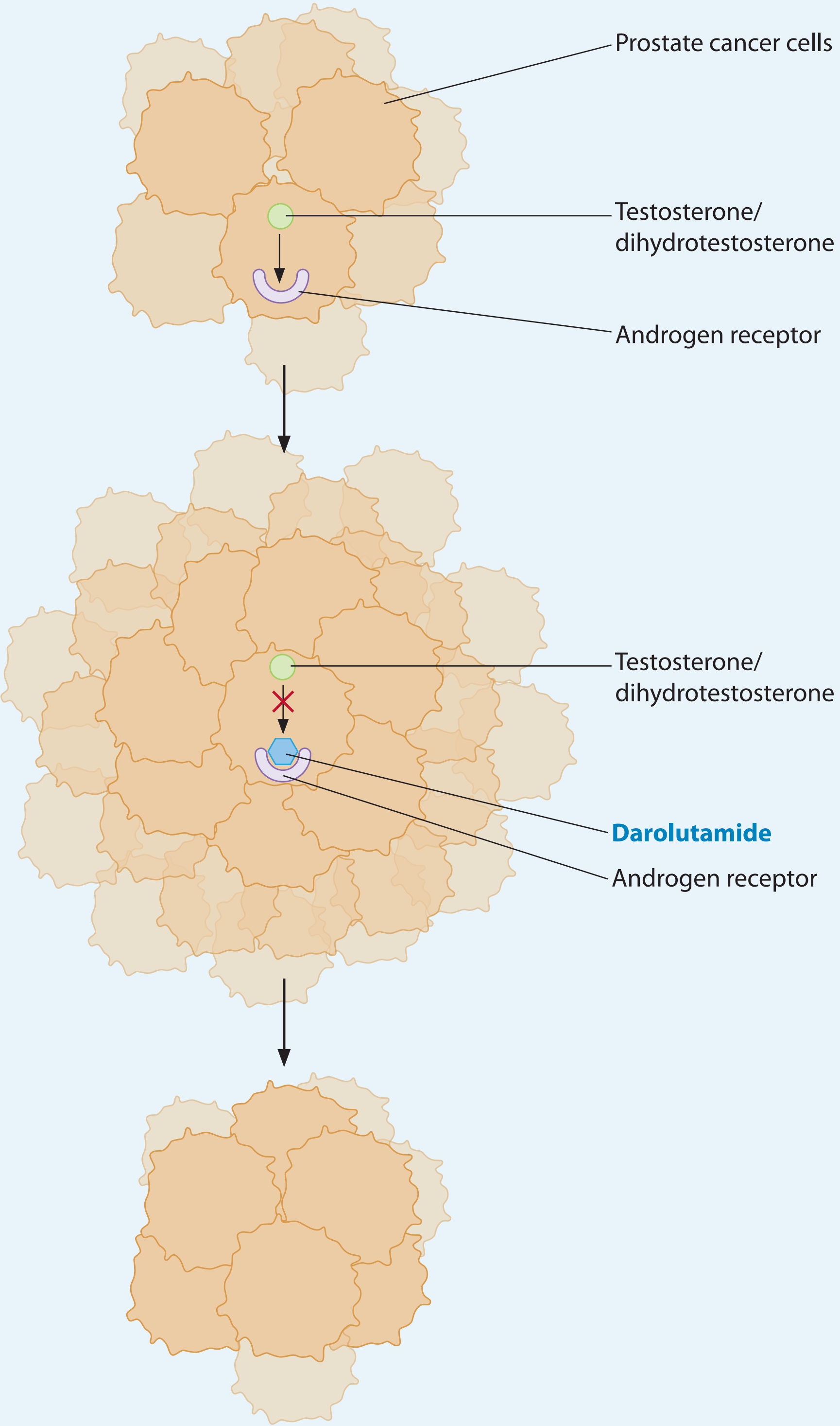
ADT is sometimes also called "hormone therapy". **ADT** is a hormone therapy given as an injection under the skin, also called a subcutaneous injection. **ADT** is also now currently available to be taken as a pill by mouth. **ADT** lowers levels of testosterone, which is a type of androgen hormone. Androgen hormones are a group of sex hormones that typically give men their "male" characteristics like facial hair. Lowering testosterone levels can reduce or slow the growth of cancer cells.
ADT with **docetaxel** is one of the current standards of care in mHSPC.

Docetaxel (brand name Taxotere®) is a type of chemotherapy used to treat many different types of cancer. It is given directly into a vein, also called an intravenous infusion or IV drip.
In the ARASENS trial, the researchers wanted to learn if adding a treatment called **darolutamide** could help treat patients with mHSPC better than **ADT** and docetaxel only.

Darolutamide (brand name Nubeqa®) is an available treatment taken as a pill by mouth. Results from another trial called the ARAMIS trial showed that **darolutamide** can help treat a different type of prostate cancer called non-metastatic, castration-resistant prostate cancer (nmCRPC). Results from the ARAMIS trial can be read here: https://www.nejm.org/doi/full/10.1056/NEJMoa2001342
and a summary of these results can be read here: https://www.futuremedicine.com/doi/10.2217/fon-2020-1291

How is darolutamide designed to work?

Darolutamide is designed to work by blocking signals from androgen hormones that can cause cancer cells to grow.



Prostate cancer cells have androgen receptors that respond to androgen hormones like testosterone. Inside the prostate cell, testosterone is converted to a slightly different version of the hormone, called dihydrotestosterone. When dihydrotestosterone attaches to the androgen receptor, it creates a signal that causes cells to grow.

Darolutamide was designed to work by **blocking** signals from androgen hormones that can cause cancer cells to grow.

About the ARASENS trial

started in November 2016 and is still ongoing as of April 2022.

Placebo-controlled
A placebo looks like a trial treatment but does not have any medicine in it. Researchers use a **placebo** to make sure the effects of the trial treatment are actually caused by the trial treatment. In this trial, in addition to **ADT** and **docetaxel**, about half of trial patients received a placebo and the other half received **darolutamide**.

includes 1,306 patients with mHSPC.

Double-blinded
None of the trial patients, researchers, or doctors knew what treatment each patient received. This means they were "blind" to this information.

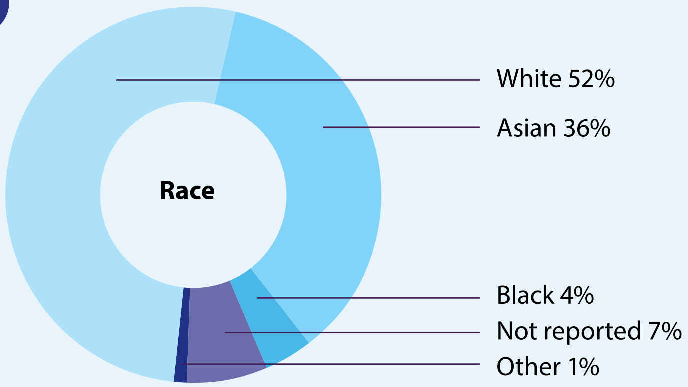
Randomized
Random chance was used by a computer to place trial patients into different equally sized groups. This is similar to flipping a coin.

About the patients in the ARASENS trial

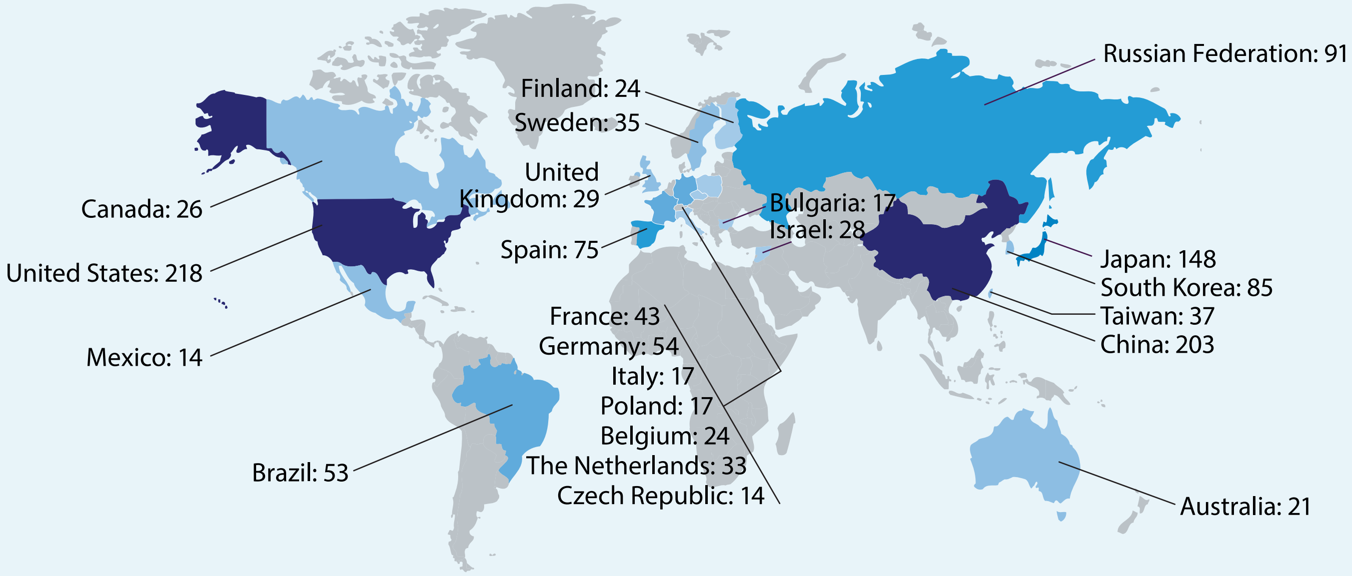
41–89 years
age range

67 years
median age

The median is the middle number in a list of numbers organized from lowest to highest.



Number of patients from 23 countries



In order to be included in the ARASENS trial...

all the patients have:

- confirmed metastatic prostate cancer.
- prostate cancer that could be treated with ADT and docetaxel.
- a score of 0 or 1 on the Eastern Cooperative Oncology Group (ECOG) test.
  The ECOG test measures how much cancer is affecting a patient's ability to complete daily activities. Scores range from 0 to 5, with higher scores meaning higher disability.
- healthy enough bone marrow, liver and kidneys.

all the patients do not have:

- prior treatment with certain hormone therapies, immunotherapies, or chemotherapies.
- prior treatment with radiation therapies within 2 weeks of starting the trial.
- previous metastatic cancer of a different type, unless it was treated and controlled well enough.
- any disorder of the stomach or gut that would affect the way the trial treatment is absorbed by the body.

What happened in the ARASENS trial?

1,306
patients were split into
2 groups

651
patients were put into the
darolutamide group
and received these treatments:

Docetaxel
6 cycles of 75 mg per 1 square meter of body-surface area on day 1 and every 21 days

ADT
As prescribed, throughout the entire trial

Darolutamide
600 mg taken twice a day, throughout the entire trial

655
patients were put into the
placebo group
and received these treatments:

Docetaxel
6 cycles of 75 mg per 1 square meter of body-surface area on day 1 and every 21 days

ADT
As prescribed, throughout the entire trial

Placebo
Taken twice a day, throughout the entire trial

The patients received **darolutamide** or the **placebo**, in addition to **ADT** and **docetaxel,** until any of the following happened:

- Their cancer got worse
- They had a change in chemotherapy
- They had treatment effects that were too toxic
- They or their doctor decided to stop treatment for a different reason

What were the results?

The purpose of the ARASENS trial was to learn if combining **darolutamide** with **ADT** and **docetaxel** could help treat patients with mHSPC better than **placebo** with **ADT** and **docetaxel**.

The researchers wanted to learn the answers to several questions to determine if combining **darolutamide** was working better than the **placebo**. To answer these questions, the researchers collected data from the trial patients until October 2021.

They compared the results of the patients who received **darolutamide** to the patients who received the **placebo**. The results below were similar in all race groups.

Below are the answers to these questions.

Compared to the **placebo**, did adding **darolutamide** to **ADT** and **docetaxel** help…

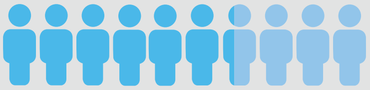
Risk reduction

After 4 years of receiving trial treatment

trial patients live longer?

Yes

Overall, treatment with **darolutamide** increased the chance of survival and reduced the risk of dying by **32.5%** compared to the **placebo**.



62.7% of patients in the **darolutamide group** were still alive

50.4% of patients in the **placebo group** were still alive

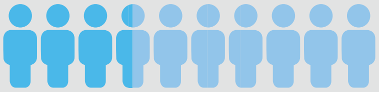
As of October 2021

delay castration-resistant cancer?

When prostate cancer becomes castration-resistant, it means it is no longer responding to treatment with ADT and the growth of cancer cells may increase.

Yes

Overall, treatment with **darolutamide** increased the length of time patients continued to respond to ADT and didn't require treatment change. It also reduced the risk of cancer becoming castration-resistant by **64%** compared to the **placebo**.



35% of patients in the **darolutamide group** had castration-resistant cancer

60% of patients in the **placebo group** had castration-resistant cancer

delay worsening pain?

Severity of pain was measured using a survey called the Brief Pain Inventory (Short Form) that was completed by trial patients.

Yes

Overall, treatment with **darolutamide** increased the length of time patients remained alive without worsening of pain and reduced the risk of pain becoming worse by **21%** compared to the **placebo**.

34% of patients in the **darolutamide group** had worsening pain

38% of patients in the **placebo group** had worsening pain

delay cancer-related bone fractures or symptoms related to bone fractures?

Yes

Prostate cancer and treatment with ADT can be associated with bone thinning and increased risk of fractures because of changes in hormone levels.

Overall, treatment with **darolutamide** increased the length of time it took for patients to have cancer-related bone fractures and related symptoms. It also reduced the risk of fractures and related symptoms by **29%** compared to the **placebo**.

15% of patients in the **darolutamide group** had cancer-related bone fractures or symptoms related to bone fractures

17% of patients in the **placebo group** had cancer-related bone fractures or symptoms related to bone fractures

delay the need for additional therapies for cancer?

Yes

Overall, treatment with **darolutamide** increased the length of time it took for patients to need additional therapies for cancer and reduced the risk of needing additional therapies for cancer by **61%** compared to the **placebo**.

34% of patients in the **darolutamide group** needed additional therapies for cancer

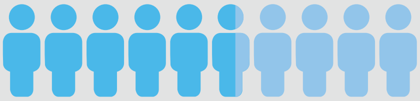
60% of patients in the **placebo group** needed additional therapies for cancer

delay worsening of cancer-related physical symptoms?

No

Severity of cancer-related symptoms was measured using a survey called the Functional Assessment of Cancer Therapy Prostate Cancer Symptom Index – 17 Item Version questionnaire that was completed by trial patients.

Overall, treatment with **darolutamide** did not increase the length of time it took for the patients' cancer-related physical symptoms to become worse and did not reduce the risk of worsening cancer-related physical symptoms compared to the **placebo**.



54% of patients in the **darolutamide group** had worsening cancer-related physical symptoms

47% of patients in the **placebo group** had worsening cancer-related physical symptoms

delay opioid use for 7 or more days in a row?

Opioid medication is used to control pain.

Not sure

The researchers could not answer this question because of the way they designed the trial. They designed the trial so that each question they wanted to answer was ranked by importance. If the researchers concluded that the answer to a question is "No" based on the trial results, then they did not analyze the results of the remaining ranked questions. Designing the trial this way helps make sure the results are as accurate as possible. This question was ranked the lowest, and the answer to the question ranked above it was "No." So, the researchers did not analyze the results for this question.

14% of patients in the **darolutamide group** had used opioids for 7 or more days in a row

18% of patients in the **placebo group** had used opioids for 7 or more days in a row

How many trial patients had adverse events?

In this summary, any medical problem that happened during the trial is referred to as an "adverse event". Adverse events are considered serious when they lead to death, put the patient's life at risk, require hospitalization, cause disability, or are medically important.

Adverse events **may or may not be related** to the trial treatments. This is why adverse events are not the same as "side effects". Side effects are known to be related to a treatment. It takes a lot of research to know for sure if an adverse event is related to a treatment.

Overall, the percentage of patients who had adverse events was similar between the **darolutamide group** and the **placebo group**. The combination of **darolutamide** with **ADT** and **docetaxel** did not result in more toxic effects than the combination of **placebo** with **ADT** and **docetaxel**. Many of the most common adverse events happened more often earlier on in the trial when patients were receiving **docetaxel**.

Percentage of trial patients who…	**Darolutamide group**	**Placebo group**
had an adverse event	99.5%	98.9%
had a serious adverse event	44.8%	42.3%
stopped receiving **darolutamide** or the **placebo** because of an adverse event	13.5%	10.6%
stopped receiving **docetaxel** because of an adverse event	8.0%	10.3%

What grade 3 or 4 adverse events did more than 2.0% of trial patients have?

Adverse events are categorized into 5 different groups based on severity:

Grade 1	**Grade 2**	**Grade 3**	**Grade 4**	**Grade 5**
adverse events are mild and will probably not impact daily activities	adverse events are not considered dangerous but may impact some daily activities	adverse events may impact more basic daily activities like eating or getting dressed and require medical attention	adverse events probably require hospitalization	adverse events cause death

The table below shows the grade **3** or **4** adverse events that happened in **more than 2.0%** of patients during the trial.

Adverse event	**Darolutamide group**	**Placebo group**
Low levels of neutrophils, a type of white blood cell that helps the body fight infections (neutropenia)	33.7%	34.2%
A fever and low levels of neutrophils (febrile neutropenia)	7.8%	7.4%
High blood pressure (hypertension)	6.4%	3.2%
Not having enough healthy red blood cells (anemia)	4.8%	5.1%
An infection in the lungs called pneumonia	3.2%	3.1%
Diabetes and high blood sugar levels (hyperglycemia)	2.8%	3.7%
Increased levels of alanine aminotransferase (ALT), a sign of liver inflammation	2.8%	1.7%
Increased levels of aspartate aminotransferase (AST), a sign of liver damage	2.6%	1.1%
Weight gain	2.1%	1.2%
Urinary tract infection	2.0%	1.8%

What adverse events of interest did the trial patients have?

Previous research has shown that treatment with **ADT** can be associated with specific adverse events. The researchers wanted to learn if the patients in this trial also had similar adverse events when **darolutamide** was taken with **ADT**. These are called "adverse events of interest".

The table below shows the **adverse events of interest** that happened during the trial.

Adverse event of interest	**Darolutamide group**	**Placebo group**
Feeling more tired than usual (fatigue)	33.1%	32.9%
Hot flushes	20.4%	21.7%
Rash	16.6%	13.5%
Diabetes and high blood sugar levels (hyperglycemia)	15.2%	14.3%
High blood pressure (hypertension)	13.7%	9.2%
Heart disorders (cardiac arrhythmia, coronary artery disorder, or heart failure)	10.9%	11.7%
Bone fracture	7.5%	5.1%
Falls	6.6%	4.6%
Mental fatigue, also called brain fog (mental impairment disorder)	3.5%	2.3%
Weight loss	3.4%	5.4%
Depression	3.2%	3.7%
Swollen breast tissue (gynecomastia)	3.2%	1.5%
Brain does not get enough blood (cerebral ischemia)	1.2%	1.2%
Seizure	0.6%	0.2%

What do the results mean?

In this trial, combining **darolutamide** with **ADT** and **docetaxel** helped treat trial patients with mHSPC better than **placebo** with **ADT** and **docetaxel**.

Trial patients in the **darolutamide group** lived longer than those in the **placebo group**. **Darolutamide** helped trial patients live longer than those who received the **placebo**, even though trial patients who received the **placebo** often had life-prolonging treatments later on once their cancer got worse.

Trial patients in the **darolutamide group** had a delay in their cancer becoming castration-resistant, worsening pain, having cancer-related bone fractures or related symptoms, and needing additional therapies for cancer compared to those in the **placebo group**.

The percentage of trial patients who had adverse events was similar between the darolutamide group and the **placebo group**. The combination of **darolutamide** with **ADT** and **docetaxel** did not result in more toxic effects than the combination of **placebo** with **ADT** and **docetaxel**.

Darolutamide in combination with **ADT** and **docetaxel** could be a treatment option for patients with mHSPC. Patients should always talk to their doctors and nurses before making any decisions about their treatment.

What does the ARASENS trial mean for the patient community?

"Prostate cancer (PC) patients need treatment options, especially patients who are metastatic (prostate cancer outside the prostate). The ARASENS study offers yet one more potential option for patients who are metastatic, yet still 'hormone sensitive' (responsive to ADT/hormone treatments).

As an advocate for 20 years, I'd like to take this time to encourage patients to stay involved in their care, especially if they are metastatic. Shared Decision Making is a valid term in medicine, and it means you share the decisions with your doctors and nurses – and they share the decisions with you. I speak from personal experience, with my husband's diagnosis of metastatic PC in the year 2000, and a PSA of 7,096. He lived for 13 years, greatly because of our involvement in his treatment decisions. I wrote an article about this in 2013, titled "Understanding Survival Statistics".

Remember that every man's prostate cancer is different, but Antonov, *et al.*, published a case study in 2019 titled "Unexpected Long-Term Survival in an Adult Patient with Metastatic Prostate Cancer". I would encourage everyone to read this article as it illustrates a case study of long-term survival in a metastatic PC patient, age 87 at last report.

Remember that new treatment options are still on the horizon, because many clinical studies are still underway as we speak. New treatment options are something we cannot measure today, so we cannot factor them into any current data, including survival. The ARASENS study offers one more treatment option, and patients, caregivers, and advocates will continue to watch for more options over time.

Stay involved in your care. Look up the phrase "Shared Decision Making" and see what inspires you. Even the best data will never measure everything, including the power you may have in your own cancer journey."

– J Manarite, Prostate cancer patient caregiver

"The results of the ARASENS study bring a number of significant benefits to patients with metastatic, hormone-sensitive prostate cancer when compared to the existing standard treatments. Patients at this stage of their prostate cancer journey are most interested in treatments that will extend their lives with minimal impact on their quality of life.

Darolutamide, as demonstrated by the ARASENS study, provides a 32.5% decrease in the risk of dying and increases the length of time for the cancer to become castration-resistant by 64%. These are real benefits that all patients can celebrate. While the decrease in the risk of dying is most appealing, delaying castration-resistant disease prolongs the time when patients will have to transition to harsher treatments and the associated reductions in their quality of life. We as patients would like to see prostate cancer become a chronic disease as opposed to one that we die from, and these two factors from the successful ARASENS study provides another step towards achieving this goal.

Today, the incidence of patients being initially diagnosed with metastatic disease has increased rapidly, making the ARASENS study very timely for all prostate cancer patients. African American men who are most impacted by prostate cancer, with higher incidence and death rates and historically with more advanced disease, could potentially benefit significantly from darolutamide treatment for metastatic, hormone-sensitive prostate cancer."

– T Farrington, Prostate cancer patient

"I was diagnosed in March of 2017 with a Gleason score of 4+3 and was blindsided with the news. Did not know who to turn to for guidance and I was scared. I was overwhelmed trying to get educated on the internet. I was fortunate enough to find www.ANCAN.org who helped me and other men in the same position navigate our disease and teach us how to be our own best advocates. Once I calmed down, I was able to understand the research and how much progress has been made with respect to cutting edge treatments. The more information (especially written in layman's terms) I have the more confident I feel I can live a normal life without fear."

– D Muslin, Prostate cancer patient

Who sponsored the ARASENS trial?

The ARASENS trial was funded Bayer and Orion Pharma.

Where can readers find more information on this trial?

The original publication discussed in this summary called: "Darolutamide and Survival in Metastatic, Hormone-Sensitive Prostate Cancer" was published in the *New England Journal of Medicine* in February 2022. You can read the original article at: https://www.nejm.org/doi/full/10.1056/NEJMoa2119115

The full name of the ARASENS trial is: A Randomized, Double-blind, Placebo Controlled Phase III Study of Darolutamide (ODM-201) Versus Placebo in Addition to Standard Androgen Deprivation Therapy and Docetaxel in Patients with Metastatic Hormone Sensitive Prostate Cancer.

You can read more about the ARASENS trial on the following websites:
- Enter the trial number **NCT02799602** into the "Other terms" search field at www.clinicaltrials.gov.
- Enter the EudraCT identifier **2015-002590-38** into the search field at www.clinicaltrialsregister.eu. Click "Home & Search" to find the search option.

If you were a trial patient and have questions about the results of this trial and darolutamide, please speak with the doctor or staff at your trial site.

An Animated Video describing this study is available online alongside this article. Scan this QR code to watch the video.

Educational resources

- Read more about prostate cancer on the Prostate Cancer Foundation website at: https://www.pcf.org/guide/prostate-cancer-patient-guide/
- Most countries throughout the world have dedicated national prostate cancer agencies and foundations. These organizations provide explanations, treatment options, educational resources, and support for people interested in maintaining prostate health and assistance following a prostate cancer diagnosis. Ask your doctors and nurses or community support group to direct you to these organizations.

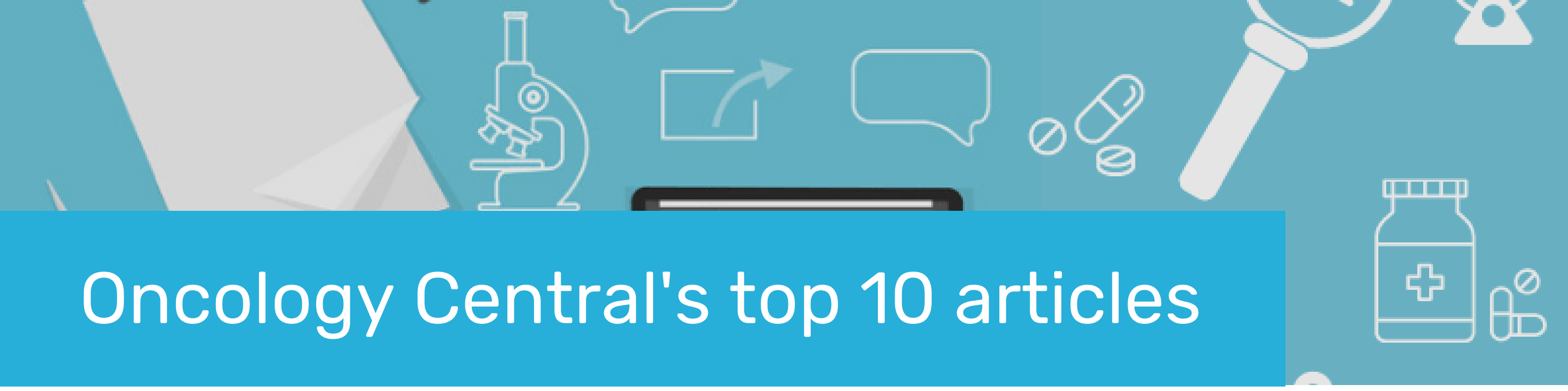
Acknowledgments

The authors would like to thank the patients in the ARASENS trial and their family members and caregivers. They would also like to thank the trial staff who cared for and supported the patients in the trial. Without all of these people working together, clinical studies could not move forward.

Medical writing and editorial assistance in the development of this summary were provided by Kimbra Edwards, PhD and Scott Finger of the Center for Information & Study on Clinical Research Participation (CISCRP), a non-profit organization focused on educating and informing the public about clinical research participation. Medical writing and editorial assistance was supported by Bayer.

Financial & competing interests disclosure

MR Smith reports receiving consulting fees from Amgen, Astellas Pharma, Bayer, Eli Lilly and Company, Janssen Biotech, and Pfizer. M Hussain reports receiving consulting fees from Bayer, Daiichi Sankyo Company, Janssen Global Services, LLC, and Novartis, as well as honorarium from AstraZeneca and travel support from Bayer. F Saad reports receiving honoraria from Astellas Pharma, AstraZeneca, Bayer, Bristol-Myers Squibb, Janssen Global Services, LLC, Merck, Myovant sciences, Pfizer, and Sanofi Pasteur Inc. K Fizazi reports receiving consulting fees paid to his institution from Amgen, Astellas Pharma, AstraZeneca, Bayer, Clovis Oncology, Inc., Janssen Biotech, MSD, Novartis, Pfizer, and Sanofi-Aventis U.S. LLC, as well as consulting fees from Orion Corporation and CureVac. CN Sternberg reports receiving consulting fees from Astellas Pharma, AstraZeneca, Bayer HealthCare Pharmaceuticals Inc., Bristol Myers Squibb Company, Genentech, Incyte Corporation, Medscape Oncology, Merck, Merck Sharp & Dohme Corporation, Pfizer, Sanofi, and Genzyme US Companies, and Uro Today. ED Crawford reports receiving consulting fees from Astellas Pharma, Carden Jennings, Janssen Biotech Inc., MDx, and TOLMAR Pharmaceuticals, Inc., as well as for data and safety monitoring for Bayer HealthCare Pharmaceuticals Inc., and has optical biopsy intellectual property. B Tombal reports receiving consulting fees from Bayer HealthCare Pharmaceuticals Inc. The authors have no other relevant affiliations or financial involvement with any organization or entity with a financial interest in or financial conflict with the subject matter or materials discussed in the manuscript apart from those disclosed.



Oncology Central's top 10 articles

1

Plain language summary of the final results from the DESTINY-Breast01 study

This is a summary of the article discussing the results of the DESTINY-Breast01 study originally published in the New England Journal of Medicine. The DESTINY-Breast01 study is a clinical study in participants with a type of breast cancer called HER2-positive breast cancer.

View full article here

2

An oncologist's perspective of COVID-19: "I wish I could hug you"

"Over the last three weeks, we have seen how medicine is changing in the USA. Last week my clinic went from face-to-face visits to >90% telemedicine encounters. We are facing a pandemic, the burden is growing and at times it feels unbearable."

Read the full article here

3

What's next for the DESTINY-Breast04 trial? An interview with Toshinari Yamashita

One of the most talked about studies from this year's American Society of Clinical Oncology Annual Meeting (ASCO, 3–7 June 2022, IL, USA) was the DESTINY-Breast04 trial. In this interview, we speak with a principal investigator of the trial Toshinari Yamashita (Kanagawa Cancer Center, Japan) to explore the trial further and to find out what the next steps are.

View full interview here

4

Top 5 Plain Language Summaries of clinical trial results

Plain Language Summaries of Publications (PLSPs) summarize the contents of a specialist research article(s) for non-specialist audiences and are therefore a very useful tool to help in sharing complex information like clinical trial results, particularly with your patients and their support network.

Read the full article here

5

What does the US FDA approval of trilaciclib mean for oncologists and their patients?

In this interview we speak with Jared Weiss from UNC's Lineberger Comprehensive Cancer Center (NC, USA) about challenges associated with treating small cell lung cancer (SCLC) and his thoughts on what the recent US FDA approval of trilaciclib, for the treatment of extensive SCLC patients to reduce chemotherapy-induced bone marrow suppression, could mean for SCLC patients.

View full interview here

6

Coffee Chat: mental health in the oncology clinic

For World Mental Health Day 2021, Oncology Central and Future Science Group facilitated a roundtable discussion between oncologists and patients to explore the challenges, and consider ways to improve mental healthcare in the oncology clinic.

Catch up now on-demand

7

Plain Language Summary: race and ethnicity representation in Phase I clinical trials

This article summarizes a Review published in Future Oncology that carried out a rapid evidence assessment (REA) of recently published Phase I clinical trials in clinical oncology. The primary objective of the REA was to conduct a descriptive assessment of published literature on the demographic representation in Phase I clinical trials of biopharmaceutical oncology agents.

View full article here

8

Panel discussion: how I treat non-metastatic castration-resistant prostate cancer (CRPC)

Gain an understanding of how oncologists are treating non-metastatic castration-resistant prostate cancer (CRPC) in our latest panel discussion, featuring experts insights from Catherine Marshall and Channing Paller (Johns Hopkins School of Medicine, MD, USA) and Judd Moul (Duke University Medical Center, NC, USA).

Read full panel discussion here

9

Panel discussion: how I treat metastatic HER2-positive breast cancer

Gain an understanding of how oncologists are treating metastatic HER2-positive breast cancer in Oncology Central's latest panel discussion, featuring experts from international institutions including Hans-Christian Kolberg (Marienhospital Bottrop, Germany), Franklin Castillero (National Oncology Institute of Panama) and Max Mano (Hospital Sírio-Libanês, São Paulo, Brazil).

View full panel discussion here

10

The Patient Perspective on…the aftermath of treatment

Many patients speak of their "cancerversary" as the day they either were diagnosed with, completed treatment for, or were declared without any evidence of cancer. Simply finishing a therapy may be all that is needed to remove malignant cells from our bodies. However, it does not eradicate all of cancer's ripple effects. Here is a reminder from patients to their medical care team about what lingers when we leave your facilities and re-enter the "normal world."

Read full article here

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