

## **Research behind the “Understanding Your Diagnosis of Ovarian Cancer” communication tool for providers to communicate better with patients during the initial diagnosis conversation**

Through primary and secondary research, the dandelionRX and Greater Good Studio team aimed to understand what happens in the communication process between healthcare providers and patients when a person is initially diagnosed with ovarian cancer. These findings informed the design of tools that can support improved communication during these foundational conversations.

### **Methodology**

- Desk research to uncover existing barriers and challenges for provider-patient communication.
- Semi-structured interviews, to learn about the behaviors, priorities, and actual experiences of patients with ovarian and/or endometrial cancer, their caregivers, and healthcare providers. (patients, n=6; caregivers, n=5; gynecological oncologists, n=2; nurses, n=2; social worker, n=1; oncological dietician, n=1)
- Insights from providers and patients were used to generate a range of ideas that could help solve common communication barriers (synthesis and ideation)
- Rapid prototyping incorporated content, visuals, and format ideas in a low fidelity communication tool. This tool was validated with providers and patients and caregivers in an online environment; feedback was incorporated into the next version, which was shared again with providers and patients for feedback (rapid prototyping)
- Final tool was developed from this process, along with an accredited continuing medical education (CME) module for oncology health care teams (implementation)

## Key insights from our secondary research that informed the development of our tools include:

- Comprehensive and clear communication appears to play a major role in well-being of patients and their families by reducing anxiety and depressive symptoms as well as increasing satisfaction<sup>1</sup>
- Most oncologists feel they need to give specific information to the patient about the status of her ovarian cancer and current treatment options<sup>2</sup>
  - Patients prefer brief, positive, personalized, and straightforward information without statistics
  - Patients want information about the purpose of testing, the implications for treatment decisions, and the time frame for results<sup>3</sup>
  - There is a gap between what patients and providers want to be communicating with each other, and what they are actually able to communicate, which causes problems
  - 34% of HCPs are unsure if, or do not feel that, they give their ovarian cancer patients all the information they need about ovarian cancer<sup>4</sup>
  - 49% of patients, in treatment or have been treated, admit they find not being sure of the path forward after diagnosis to be very or extremely challenging<sup>4</sup>
- Shared decision making often requires clinicians to not only master new skills but also to mentally shift roles from decider to partner<sup>5</sup>
  - Many clinicians need to break the habit of formulating treatment plans based solely on their training, clinical experience, and standard treatment protocols<sup>5</sup>
- Significantly influencing how oncologists give information is the oncologist's perception of the patient's vitality, comprehension of the information and their emotional well-being, along with the physical environment and schedule demands on the oncologist<sup>2</sup>
- Intercultural differences may affect how information is received
  - Latina cancer patients experience higher levels of perceived disrespect in the patient-provider relationship, higher perceived racial discrimination, and lower levels of patient-centeredness in care<sup>6</sup>
  - Medical mistrust, cancer fears, and concern for privacy have created communication challenges about cancer in the African American population<sup>7</sup>
- Published data suggest that at least one-third of patients have inadequate health literacy and struggle with everyday health and health care tasks<sup>8</sup>
- These gaps can be reduced, in part, by:
  - Using plain language, which includes limiting jargon, using an active voice and keeping sentences to 15 words or less<sup>9</sup>
  - Closely linking pictures to written or spoken text to increase attention to and recall of health information, improving adherence to health instructions
  - While all patients can benefit, particularly patients with low literacy skills
  - Patients with very low literacy skills can be helped by spoken directions plus pictures to take home as reminders or by pictures plus very simply worded captions<sup>9</sup>

## Key insights from our primary research that informed the development of our tools include:

- A patient's full and complete comprehension of a diagnosis and treatment plan is not a reasonable goal for the diagnosis visit
  - To make informed decisions about their health and to live well, patients need to learn the facts about their cancer and process the emotions that come with a serious diagnosis; It's impossible to do all of that in a single day, let alone a single appointment
- A reasonable goal for the diagnostic visit is to build trust, introduce information about the cancer, and empower the patient so they can share in the decision making about their treatment
- For providers to build trust with their patients, they need to:
  - Reassure patients they are the priority by creating enough time and space for the patient to feel heard
  - Communicate to patients that they deserve the very best care
- For providers to support the patient's comprehension pathway, it is important for providers to understand what patients understand

*When they're talking about the medicines, you're still thinking about is this something you even want to do. They get into the details real quick." – Caregiver*
- It is important providers introduce new concepts by covering the basics—what, why and how—using plain language and comprehensible images and metaphors

*She took out a plastic dummy and explained that to us, and she also used some diagrams. That made me feel confident." – Patient*
- Patients understand the provider can't see the future, but patients do want to understand what lies ahead

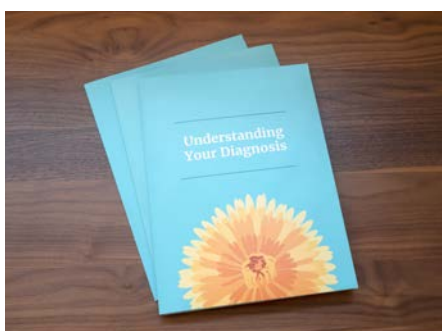
*Even if it's bad, share the information up front so they have realistic expectation. Don't sugarcoat it if the treatment is going to be bad, so that the people go home know what they're dealing with. Dealing with the unknown is not good. Dealing with the known you can handle." – Caregiver*
- Providers can help patients feel more in control by starting the empowerment process with encouraging patients to become an expert in their experience through tracking and sharing this with the healthcare team

*When you're at home and you think about something to ask the doctor about, I encourage [patients] to have a little notebook to write it down. Something like 'I noticed my heart beating a little fast.' Write it down, and you'll be able to bring*

*it up. Maybe they can adjust the medication. Often when you get into the doctor's office, the thing you needed to ask, you forgot.” – Nurse*

- Patients and caregivers can turn to practical matters for a sense of control in an uncertain situation, but not everyone knows where to start. Care teams can set patients up for success by pointing patients in the direction of their next step  
*I need to get my affairs in order—what kind of care I'll get, how I'm going to pay for it, what doctor I'm going to see, how good a surgeon he is. I build a barrier around the things I can control, and I do those things.”— Patient*

## How these insights informed the development of our ovarian cancer communication tools



*Patients need providers to communicate that they deserve the very best care.*

We designed tools that affirms for the patient that they deserve the best care and feel supported by their care team.



*Patients need their providers to reassure them that they are the priority by creating enough time and space for the patient to feel heard.*

Our tools are designed to help the providers create time and space in the diagnosis appointment for the patient to feel heard.



*To give patients a strong start on their cancer education, it's important for providers to understand what patients understand.*

To help the healthcare team communicate with the patient at the right level, our tools help providers assess what a patient understands.



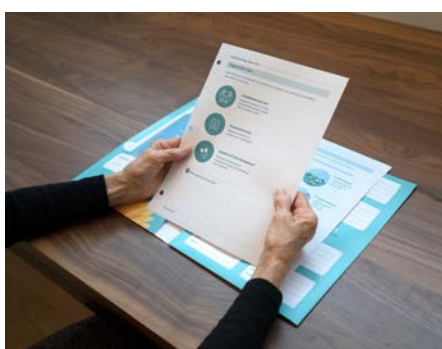
*When introducing new concepts, patients need providers to cover the basics—what, why, and how—using plain language and comprehensible images.*

Using plain language and familiar metaphors, our tools support providers to communicate the basics about the patient's diagnosis—cancer type and staging—as well as treatment options.



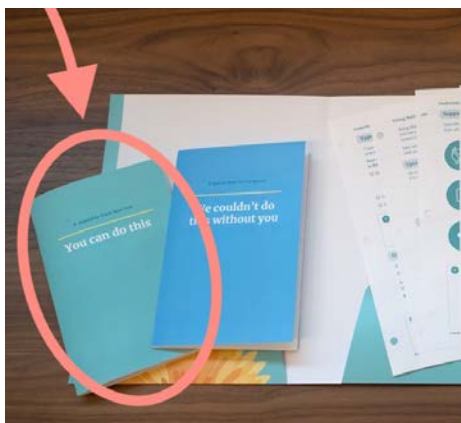
*Patients understand that the provider can't see into the future, but patients do want to understand what might lie ahead.*

Our tools include a journal with a calendar allows patients and caregivers to map upcoming appointments.



*"Being healthy" is about more than whether or not you have cancer. Providers can help patients take care of themselves as their diagnosis and treatment plans unfold by actively connecting them with complementary care resources.*

Our tools help providers to point patients in the direction of the next steps after diagnosis, so that they feel a sense of control in an uncertain situation.



So much of a patient's experience with cancer happens beyond the doctor's office: diet, exercise, side effects, quality-of-life conversations with family. All of this is a growing body of knowledge that can help them become a stronger advocate for themselves inside the office.

We created a journal with space for patients to record symptoms and side effects, encouraging them to recognize their own emerging expertise so that they can become stronger advocates for themselves.

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