The social challenge of ovarian cancer

January 2022

An initiative of

In collaboration with

And the support of

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Spanish Association for People Affected by Ovarian and
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Learning in the present continuous

We know that there are many types of cancer, but ovarian cancer in particular I had not considered. I hadn't even thought about it. Many people in our society do not know that it is possible to have ovarian cancer.

I had been feeling ill for some time and guessed that something was wrong but you assume it's just a digestive problem. Months before, I started to feel nauseous, my stomach was swollen, I lost my appetite, I felt like I was full despite eating very little, I struggled to sleep... but I justified it; I did not want to go to the doctor over something small. I'm not going to go just because my stomach is upset. The changes are so subtle and minute that we don't notice them. Ovarian cancer is often confused with a digestive problem and that is where we lose a lot of time. They call it the "silent killer" for a reason: it goes undetected, the symptoms are so non-specific... Maybe if I had known about it, I would have gone to the doctor sooner. I know the symptoms of breast cancer; I hear about it on TV. But I had no information about ovarian cancer.

I felt safe because I was going to the gynaecologist and they hadn't seen anything, but in oncology they told me that this type of ovarian cancer is not visible in check-ups. If I had known half of what I know now, it would have changed everything.

The surgery was very hard and one of the most difficult times of my life. At that point, it largely determines what is going to happen to you. The prognosis depends on the result of the operation. Therefore, the surgeon must be a specialist in this area because it affects not only the pelvic cavity but also the abdomen. You can't depend on luck or which hospital you go to. The problem is that patients don't know that. Patients trust what is said because they want it solved as soon as possible. Specialist surgery should be widely implemented because you are risking your life.

They remove our ovaries, uterus, lymph nodes... From then on, your life changes. It changes your sexuality, your body, it changes everything. You feel less womanly. It's a gynaecological cancer - that in itself tells you it only happens to women. It is a somewhat taboo cancer that people don't want to talk about, they don't want to think that women go through it... And yet we are still women, even with the disease. Society has no idea how we feel. We still have a lot to learn in Spain. Verbalising this kind of thing makes us feel ashamed and embarrassed, as if we have done something wrong.

It is difficult to accept your new sexuality in a society characterised by hyper-sexualisation. I had hot flushes, I went through the menopause... and the responses I expected from those around me... I didn't get them. I can't be the superwoman I used to be, that has now... gone. And I don't mind, but now I have to go to bed for several hours in the morning after taking my tablets, otherwise I have no energy. Suddenly you are an alien and some people don't understand because they are not patient.

The care team has always treated me with affection, I have felt a closeness and genuine human touch. However, I have missed a multidisciplinary team that covers not only the disease and treatment but also the consequences psychologically, physically, in other organs... And sometimes, they do a lot of things in a very automatic way and patients may not understand what is happening or may have questions. In medical school there should be a core part of the curriculum on managing emotions, with others and with oneself. There is a tendency to "behead" people, because they have to emotionally detach themselves in order to do their job, because they are overwhelmed, they are swamped.

Messages about ovarian cancer must also teach something. ***The message is ovarian cancer, but we have to show what we have learned; what life is like after diagnosis.*** *That is not normally spoken about, it is hidden.*

This testimony is by more than one person. It is a combination of the experiences of different women with ovarian cancer involved in this initiative. Different voices that show us a road along which society has a long way to go.

Ovarian cancer is much more than a health challenge. It is a social challenge that concerns the entire population and in which everybody has a leading role to play.

Your commitment is key to moving forward. So, thank you for reading this and welcome to this report, which we hope will help you to continue learning about ovarian cancer.

TABLE OF CONTENTS

1

PROJECT:
the social challenge
of ovarian cancer

“The social challenge of ovarian cancer” is an initiative that aims to inspire and generate ideas for possible actions and public initiatives aimed at promoting knowledge and **social awareness of ovarian cancer.**

It is an initiative led by the Spanish Association for People Affected by Ovarian and Gynaecological Cancer (ASACO) and the MÁS QUE IDEAS Foundation (MQI), with the aim of increasing the visibility of ovarian cancer and **encouraging reflection at a social and health level** on the challenges and difficulties faced by this group of patients. Many of them are invisible to the majority of the population and we believe it is a priority to make them known in order to build partnerships and support at a community level.

Through this project, we want to focus on everything that we, as a society, can do to achieve earlier diagnosis of ovarian cancer and better results in terms of survival and quality of life for women with this disease.

In addition, as shown in this report and as mentioned in ASACO’s ten goals[1], this project also aims to **promote a dialogue around self-care and recognition of gynaecological health,** urging women *“to make healthcare workers see that they are the ones who know their own bodies and their own needs best”.*

This report contains experiences, opinions and data that provide insight into the main demands of women affected by ovarian cancer. It also includes ideas for possible strategies and actions that can be taken to advance each of these challenges. We hope that this information will inspire more people and organisations to step forward and join the cause.

METHODOLOGY

a) Phase 1. Analysis of the challenges

The objective of the first phase was to explore the causes and impact of the main challenges in the field of diagnosis, social perception and awareness, and health and wellbeing of women with ovarian cancer. This analysis was based on a **review of different academic literature** that allowed us to define the most common difficulties experienced by women affected by this disease.

Based on the information gathered, ten interviews were conducted with women with ovarian cancer (2 by telephone and 8 by video call) during the month of October 2020. Each interview followed a semi-structured design with open-ended questions that were adapted to the stories of the women interviewed, in order to find out their perceptions and experiences of the challenges identified in the literature review*. This type of **qualitative interview** is ideal for facilitating the natural expression of opinions, avoiding the biases of other data collection techniques.

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*If you would like to see the interview questions and surveys used in this initiative, please contact:
lasideasde@fundacionmasqueideas.org

Participants were sought and selected through ASACO and MQI. All of the women had a pre-interview to ensure the suitability of their participation and signed a confidentiality and consent form. The interviews ranged in length from 30 to 60 minutes and were recorded for subsequent transcription.

All of the participants were ovarian cancer patients diagnosed with the most frequent subtype: epithelial carcinoma (which accounts for 85-90% of ovarian cancer cases). The following table shows the main characteristics of the participants (at the time of the interview).

Based on the results of this first phase, a **conclusion report** was drafted, which was reviewed and approved by the people interviewed. Annex I to this report contains a summary of the main findings.

Current age	Date of diagnosis	Stage of the disease	Genetic mutation	Current situation
30-40 years (1) **40-50 years (4)** **50-60 years (4)** **60-70 years (1)**	**Less than 1 (1)** **1-3 years (3)** **3-5 years (2)** **More than 5 years (4)**	**Stage I (1)** **Stage II (1)** **Stage III (5)** **Stage IV (3)**	**No (8)** **Yes (2)**	**In treatment (5)** **In remission (5)**

b) Phase 2. Reflection and search for solutions

The purpose of the second phase of the project was to further explore the challenges identified by the people interviewed and identify what kind of actions and good practices are advisable to make progress in overcoming these challenges.

To this end, a Working Group (WG) was created, comprising experts in different areas of health and social care so as to build a multidisciplinary group that would provide a diverse perspective as a result of their different levels of expertise in different (but complementary) fields such as: ovarian cancer, gynaecology, sexuality, youth, education, psychology and communication, among others. These individuals participated voluntarily, with no financial compensation.

Working Group members:

- **Óscar Allende Carreño.** Journalist. El Faradio.
- **Hugo Azcona Luis.** Family member of a person with ovarian cancer (son).
- **María Pilar Barretina Ginesta.** Medical oncologist. Healthcare Manager of the Medical Oncology Service. Catalan Institute of Oncology (Girona). Member of the Board of Directors of the Spanish Ovarian Cancer Research Group (GEICO).
- **Sofía Bauer Izquierdo.** Primary care physician Medical coordinator of the Quart de Poblet Health Center. Manises Hospital (Valencia).
- **Paloma Casado Durández.** Responsible for Humanization at the San Carlos Clinical University Hospital (Madrid).
- **Fátima Castaño Ferrero.** Psycho-oncologist and sexologist. Spanish Association for People Affected by Ovarian and Gynaecological Cancer (ASACO).
- **Marian Escolar Antúnez.** Patient.
- **Estíbaliz Gamboa Moreno.** Primary Care Nurse. Bidebieta Health Center (Donostia - San Sebastián).
- **Mercedes Herrero Conde.** Gynecologist. Sanchinarro University Hospital - Clara Campal Comprehensive Cancer Center (Madrid).
- **José Antonio Negrín de la Peña.** Family member of a person with ovarian cancer (husband).
- **Lucía Peralta Munguía.** Patient and Primary care physician.
- **Rosa María Plata Quintanilla.** Midwife. Marqués de Valdecilla University Hospital (Santander). President of the Spanish Association of Midwives (AEM).
- **Patricia Rodríguez Villalba.** Oncology nurse. Oncology Day Hospital of the Canary University Hospital (Tenerife). Member of the Spanish Society of Oncological Nursing (SEEO).
- **María Pilar Rodríguez Martínez.** Primary care physician La Milagrosa Health Center. Jerez Costa Health Management Area - Northwest and Sierra de Cádiz. Member of the Women's Care Group of the Spanish Society of Primary Care Physicians (SEMERGEN).
- **Esmeralda Romero Rodríguez.** Physiotherapist specialized in lymphatic drainage. Writer. Volunteer at MÁS QUE IDEAS Foundation.
- **Mercedes Ruiz Martínez.** Pharmaceutical. Member of the Health and Social Services Commission of the Spanish Confederation of Organizations of the Elderly (CEOMA).
- **María Sasía García.** Medical student. University of Cantabria. Member of the State Council of Medical Students (CEEM).
- **Carles Tomàs Cots.** Primary Education Teacher and International Cooperation and Humanitarian Aid Technician. EveryWhere Schools (EWS).
- **Rafael Vidaurreta Bernardino.** Social worker. San José Institute Foundation (Madrid).

The members of the WG signed a confidentiality agreement to give their consent for the data collected through different techniques to be processed and the virtual meetings recorded.

After reading the report on the conclusions of the first phase of the project, the WG members completed an **online questionnaire** in March 2021 in order to:

- share their opinion on the challenges identified by patients;
- assess the degree of priority of the same and the feasibility of taking action in these areas;
- exchange best practices, successful initiatives and recommendations for public campaigns.

This survey was completed by 18 of the 19 members of the WG and its results allowed us to collect data of interest and to design the structure and dynamics of the subsequent focus groups.

These **focus groups** consisted of three virtual meetings, the purposes of which were to:

- discuss the main questions from the interviews with women with ovarian cancer and the results of the online survey;
- accurately define each of the challenges identified;
- exchange ideas and suggestions for actions to be carried out to make progress in overcoming these challenges.

Due to the large number of participants, three separate groups were created with the aim of having an average number of 6-8 people per meeting in order to encourage participation and the exchange of ideas and opinions. Each meeting lasted 2 hours and they were moderated by two MQI professionals (Teresa Terrén and Diego Villalón) and attended by members of the WG (17 out of 19 people attended), as well as a different representative of ASACO each time (Soledad Bolea, Gemma Durán and Charo Hierro).

April 6th, 2021:

Sofía Bauer, Marian Escolar, Charo Hierro (ASACO), Lucía Peralta, Rosa María Plata, Mercedes Ruíz, María Sasía y Rafael Vidaurreta.

April 13th, 2021:

María Pilar Barretina, Soledad Bolea (ASACO), Paloma Casado, Estíbaliz Gamboa, Mercedes Herrero y José Antonio Negrín.

April 14th, 2021:

Fátima Castaño, Gemma Durán (ASACO), Patricia Rodríguez, María Pilar Rodríguez, Esmeralda Romero y Carles Tomàs.

The meetings were recorded and subsequently transcribed. The data collected was sorted into different categories according to the objectives of the project and used to build units and patterns of information, thus enabling the areas with the highest level of interest and consensus to be identified.

The analysis of the focus groups was used to design the **second online survey,** the purpose of which was to:

- explore some of the issues discussed in the virtual meetings in more depth;
- discover opinions on some areas that were not covered in enough detail in the virtual meetings;
- get ideas and suggestions that may have been thought of after participating in the focus groups.

This survey was completed in July 2021 by 15 of the 19 people included in the WG, as well as the three ASACO representatives who participated in the virtual meetings.

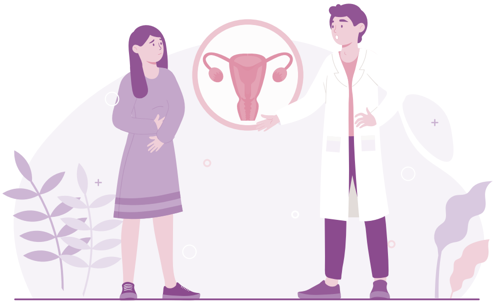
Finally, the data collected through the different data collection techniques was combined and analysed as one in order to **draft this report.** This draft was reviewed in October and November 2021 by the WG, the representatives of ASACO, the women interviewed in the first phase of the project and the organisations involved in the initiative.

2

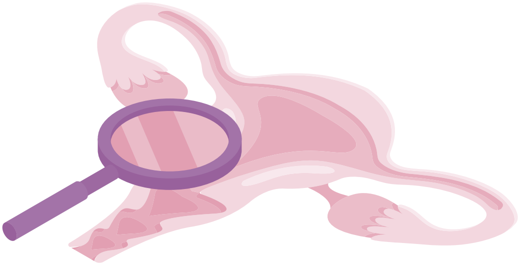
PRIORITIES

What to focus on?

Following the literature review, the semi-structured interviews with women with ovarian cancer and the assessments of the Working Group (WT), obtained through different data collection techniques, the following four priorities were identified as the ones that need to be addressed most urgently in the context of ovarian cancer.



Educate society and healthcare professionals on how to recognise the symptoms



Call to give women with ovarian cancer access to specialist surgery and a multidisciplinary approach

Promote education on gynaecological, sexual and reproductive health among the population

Train healthcare professionals in communication to improve their relationship with patients

2.1. EDUCATE SOCIETY AND HEALTHCARE PROFESSIONALS ON HOW TO RECOGNISE THE SYMPTOMS.

80% of ovarian cancer cases are diagnosed at an advanced stage, which has a decisive influence on the prognosis. **Diagnosing the disease at an earlier stage is a key priority.**

The majority of the women with ovarian cancer interviewed highlighted the speed of the diagnostic process once in hospital. Once the primary care, gynaecology or midwives' teams have identified potential clinical signs of the disease and referred the person to the hospital, the process is described as positive and smooth.

However, there is much room for improvement in recognising the symptoms that might be an indication of the disease. That is where the effects of the considerable lack of knowledge of ovarian cancer in society becomes evident.

6 of the 10 patients interviewed stated that they **had not heard of ovarian cancer before their diagnosis.** The consequence of this lack of knowledge is, according to them, **late recognition of symptoms.** 8 of the 10 people interviewed believe that their ovarian cancer could have been diagnosed earlier if they had known more about the symptoms of this disease.

The WG confirmed this reality and unanimously identified it as a challenge to be prioritised and addressed at a social level. It was not only ranked as the highest priority challenge in the context of ovarian cancer, but also the easiest to overcome.

The exchange of opinions and experiences in the focus groups allowed the name and scope of this priority to be expanded. At first, it was limited to self-recognition of ovarian cancer symptoms by the population. However, the WG unanimously noted the importance of looking at healthcare and addressing the significant lack of awareness of the symptoms among healthcare professionals. They pointed out that even if patients recognise the symptoms, if they hit a barrier when trying to access healthcare, the problem will not be resolved.

"If I had known half of what I know now about the symptoms, it would have changed everything" (patient interviewed).

"If I had known any of the symptoms... having now read the symptoms, I can say I had 90% of them" (patient interviewed).

"If I had known anything, I would not have self-diagnosed but gone to the doctor and asked: have you considered that this might be related to my ovaries?" (patient interviewed).

"You may be suspicious, but if the healthcare system doesn't move very fast... We need to shorten that waiting period" (Marian Escolar. Patient).

"There is still a delay in referrals, and it is difficult to recognise what might be a symptom of ovarian cancer" (María Pilar Rodríguez. Primary care physician).

This aspect was also echoed by the patients interviewed. The majority of them said that symptom recognition by medical teams is one of the biggest challenges in ovarian cancer, and it is especially related to the lack of familiarity with and non-specific nature of the symptoms.

"As a woman I can make a self-recognition of symptoms, but if I then go to my doctor with a series of symptoms and there is nothing to alert them to the possibility of ovarian cancer, they will start looking but they will not think about the ovary" (Patricia Rodríguez. Oncology nurse).

"Ovarian cancer is often confused with a digestive problem and that is where we lose a lot of time" (patient interviewed).

"I had a colonoscopy, X-rays, bone density scan... a lot of tests. Everyone said it was my back" (patient interviewed).

"The doctors look everywhere, but they don't look at the ovary. I don't know why, whether it is because there are fewer cases or because they are not used to it" (patient interviewed).

The **non-specific nature of the symptoms** is one of the main difficulties in making an early diagnosis. However, education about the symptoms helps both professionals and the public to consider the possibility that the discomfort they are experiencing may be due to a gynaecological problem. It also raises public awareness of the circumstances that should alert us to go to the doctor.

"It would be very good if the population were aware of the symptoms of gynaecological cancer in general, and ovarian cancer in particular, so that they are able to discriminate between what is important and what is not. Even if the symptoms are vague, we can differentiate between a normal stomach ache or bloating and something that is strange and persistent over time. That is what should alert us to go to the doctor" (Fátima Castaño. Psicooncóloga).

2.2. CALL TO GIVE WOMEN WITH OVARIAN CANCER ACCESS TO SPECIALIST SURGERY AND A MULTIDISCIPLINARY APPROACH.

A multidisciplinary approach is one of the major shortcomings of the healthcare system, according to the patients interviewed. By multidisciplinary, we mean the collaborative involvement of different healthcare specialists in responding to the needs of women with ovarian cancer. This approach is based on cooperation, with each professional contributing within their area of expertise.

The women with ovarian cancer interviewed referred to a **wide range of physical, emotional and social complications.** Aspects such as abdominal pain, physical changes, digestive problems, repercussions on their sex lives (around 50% experience some sexual dysfunction[2]), impact on finances and work, or emotional difficulties reduce their quality of life and **require coordinated assistance involving professionals from a range of disciplines.**

"They remove your ovary, uterus, lymph nodes... From then on, your life changes. Your body is not the same. It takes a lot of time to recover. Everything has to be put back into place with some organs missing" (patient interviewed).

"Regulating bowel habits is very complicated. Bowel control has limited my day-to-day life. I am self-employed, but there are days when, if I were an employee, I would not be able to go to work" (patient interviewed).

"The way you see yourself is very important because that is what you reflect to others, and I wondered if that was how people around me saw me. Will they be able to see how I feel? That crushes you..." (patient interviewed).

There is no response to these needs in the healthcare system. The WG noted that in this regard, multidisciplinary care is an important **pending issue** in our healthcare system:

"There are still gaps in healthcare. The psychosocial approach is practically non-existent in most of the specialist units, despite being one of the main requests of the patients and those around them" (Fátima Castaño. Psycho-oncologist).

"There is no obvious recognition of the implications of ovarian cancer, nor the psychological and social damage it may cause, even in interpersonal relationships" (Rafael Vidaurreta. Social worker).

"There is too much focus on diagnosis and treatment and not enough emotional and psychological support or information about the after-effects of the disease and surgery. You have to understand the patient, not only in terms of their illness but also as a person" (Patricia Rodríguez. Oncology nurse).

"The team must be made up of professionals from different areas, which is not possible in many hospitals, such as regional hospitals" (Rosa María Plata. Midwife).

Demanding a multidisciplinary approach requires greater awareness on the part of society, healthcare professionals and management. However, the WG highlighted the fact that this responsibility should not fall on those affected by ovarian cancer. Unlike in other cultures or healthcare systems, in Spain it is not common for people diagnosed to find out the experience of their medical teams or to request certain services or benefits. There is hardly any comprehensive and accessible information on the performance of each hospital compared with others.

Consequently, many people continue to rely on their healthcare teams without asking about other options or knowing that there are resources available to help them address the different needs they have as a result of the disease.

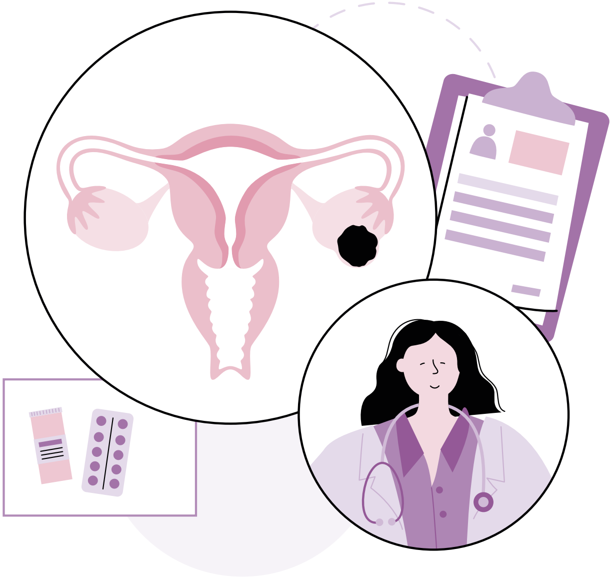
"When patients first enter the clinic, they are not aware of the need for a multidisciplinary team. This is normally identified during the course of the process" (José Antonio Negrín. Family member of a person with ovarian cancer).

"It is essential to have the support of oncology nurses for more personalised care, as well as to psycho-oncology services available in every hospital or a referral to patients' associations" (Soledad Bolea. Patient).

In addition to the importance of access to professionals in psychology, sexology, social work and rehabilitation, among other disciplines, the WG noted that the **main challenge** to achieving a suitable multidisciplinary approach to ovarian cancer is **effectively integrating gynaecological oncology.**

In this regard, it is worth mentioning that **access to specialist surgery** was different in the multidisciplinary approach suggested in the first survey completed by the WG, in that it was ranked as the lowest priority challenge by the respondents. However, in subsequent meetings, the WG showed that this assessment was biased by their own lack of knowledge about the need for gynaecological oncology and the risks of carrying out general surgery on women with ovarian cancer.

After reading the profiles of the WG participants, it was found that those living with the disease or professionally involved in ovarian cancer did identify this challenge as a priority. However, those who were more unfamiliar with ovarian cancer relegated it to a secondary position. By a qualified majority vote and with the unanimous support of the WG, access to specialist surgery was categorised as a priority challenge, along with a multidisciplinary approach.



"Part of the multidisciplinary approach must be to have specialist surgeons throughout the country. All women should have the right to specialist surgery, regardless of where they live, and the reality is that this is not the case. The delay between when you are referred by primary care to a gynaecologist is enough that a surgeon specialising in this disease may not to be able to attend you in an ideal way" (María del Pilar Rodríguez. Primary care physician).

"It was not identified as the highest priority challenge because of a lack of awareness of its importance" (Sofía Bauer. Primary care physician).

"The first person to reach out to an ovarian cancer patient must be a gynaecological oncologist. The surgical approach must be thorough from the start. Technically, ovarian cancer is so complex that the surgeon's skill and expertise makes a difference" (Mercedes Herrero. Gynaecologist).

Surgery in women with advanced ovarian cancer is called "cytoreductive" and aims to remove all visible tumour. Surgeons remove the uterus, ovaries, fat layer in front of the intestine and the largest amount of visible tumour possible in all affected areas. Specialist surgery is needed due to the **correlation between the quality of surgery and patient survival,** especially in ovarian cancer[3].

According to the European Society of Gynaecological Oncology (ESGO), if a service does not have gynaecological oncology certification, it is recommended that the surgeons devote **at least 50% of their clinical practice** to managing gynaecological cancer[4]. It is important, therefore, that certification and access to specialist surgery comes from within the healthcare system itself.

Until this is true for every case, it is advisable to raise awareness among healthcare professionals and to make this reality known at a social level. The public must know that **experience in ovarian cancer surgery is a fundamental factor** that can determine the prognosis of the disease and, therefore, that they have the right to ask questions and request access to specialist teams.

"It is very important for a patient to speak up and be able to ask 'Are you an expert in ovarian cancer operations?´ And if not, `where can I go?´. The prognosis will depend on the surgery. Healthcare professionals must be aware that this is key to treating the disease" (Charo Hierro. Patient).

"The problem is that patients don't know that. Patients trust what is said because they want it solved as soon as possible." (Gemma Durán. Patient).

"We must inform patients so that they know that there is a difference between being operated on by somebody who does it once a year and by somebody who does it regularly" (Mercedes Herrero. Gynaecologist).

2.3. PROMOTE EDUCATION ON GYNAECOLOGICAL, SEXUAL AND REPRODUCTIVE HEALTH AMONG THE POPULATION.

The need to promote sharing more information socially about gynaecological, sexual and reproductive health was unanimously recognised by the WG. Throughout the three meetings, the participants highlighted that these are different areas, but the majority of them stressed that they should be **addressed together,** as they are interrelated.

Looking after gynaecological, sexual and reproductive health is related to ovarian cancer in different ways. This self-care allows for closer contact with gynaecology or midwives´ professionals and for addressing these issues with primary care teams. It also promotes a positive relationship with your sexuality, facilitating better knowledge of your own body and helping to pay more attention to any changes that may occur, to know risk and protection factors and to know how to deal with problems that may occur in relation to sex and reproduction after being diagnosed with ovarian cancer. Initially, this priority focused on gynaecological and sexual issues. However, over the course of the meetings with the WG, the importance of including reproductive issues was identified.

“It is difficult to accept your new sexuality in a society characterised by hyper sexualisation” (patient interviewed).

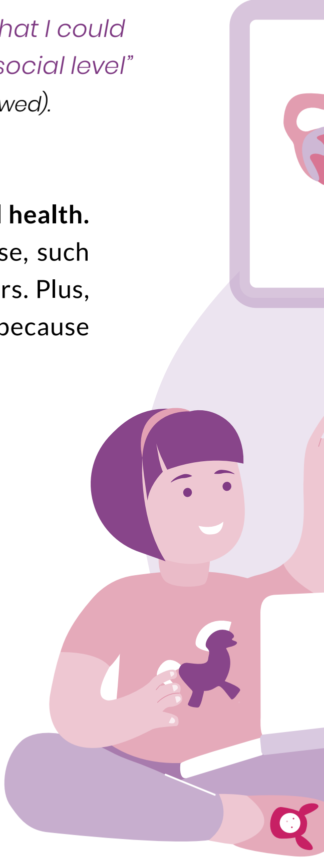
“I had ovarian cancer when I was 31 and it caused hot flushes, the menopause... and that didn’t go down well. The responses I expected from everyone around me... I didn’t get them. They said to me “What are you saying? How are you going through menopause? Are you crazy?” or “You mean you can’t be a mother? Don’t worry, you can adopt instead”. The answers I was expecting didn’t come... they were the complete opposite” (patient interviewed).

“Women with ovarian cancer have their ovaries removed, which are essential at a hormonal level and for bone balance. Not to mention pregnancy, which is a central part of our identity, and we must learn to manage it because in this society you are expected to have children. Children are a woman’s responsibility and daughters are expected to have children. I had to manage what I could not give at a social level” (patient interviewed).

The WG stated that there is still a major **lack of knowledge about gynaecological health.** This results in many people normalising certain pains which have a specific cause, such as suffering from painful menstruation, which they do not mention to their doctors. Plus, there is still a certain **taboo**, and some people avoid talking about possible changes because they are embarrassed or unaware.

“If someone is not aware that it is something important, there is no reason for them to pay attention to it” (Mercedes Herrero. Gynaecologist).

“There are many problems that we hardly talk about, and many people do not even know that there are treatments available for these gynaecological issues” (Estíbaliz Gamboa. Primary care nurse).

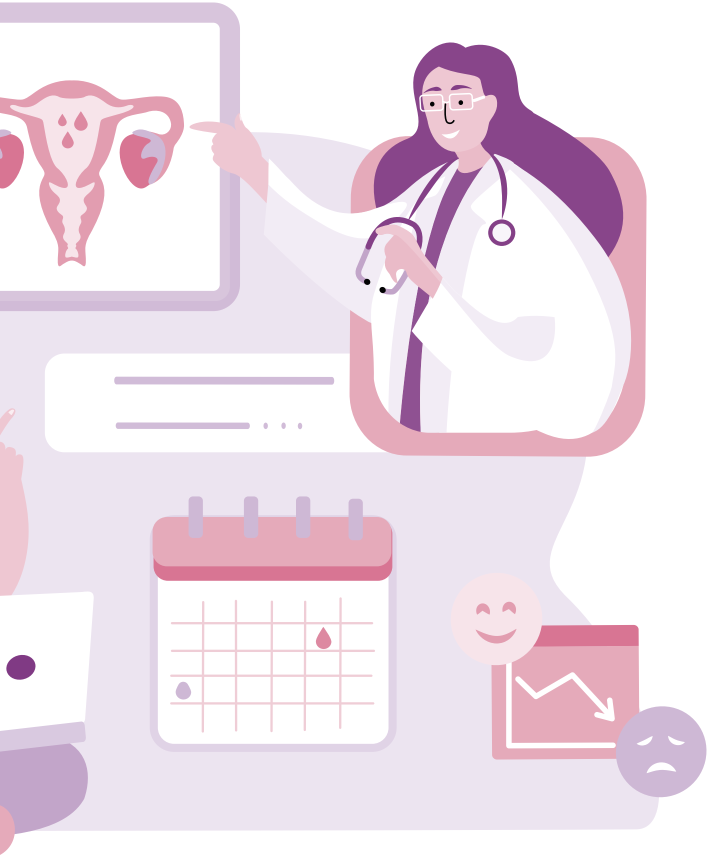


The women interviewed highlighted the importance of society being proactive and going to see the doctor if there is any sign of risk, which requires more education on sexual and gynaecological health.

"Ovarian cancer is not spoken about because it is a gynaecological cancer. We need to work on everything to do with gynaecology and women's bodies. There is very little visibility" (patient interviewed).

"We must give women's bodies a name and surname. We should plan and implement campaigns on looking after ourselves, starting with the most basic thing which is knowing our genitalia (what they are for, what they do) and what menstruation is from a young age…" (patient interviewed).

"We still have a lot to learn in Spain in terms of verbalising this type of thing; we feel ashamed and embarrassed to talk about it, as though we have done something wrong" (patient interviewed).



Gynaecological, sexual and reproductive health should be taught from childhood, at home and in school. However, the WG stressed the importance of **involving healthcare workers** in providing recommendations and guidance. Primary care teams provide healthcare throughout people's lives, so they are the professionals to ask about this.

"Women need to be more aware of how their body functions, so we can know ourselves and be able to examine ourselves. There is a lack of information from schools that enables us to detect any abnormal changes early on and have an idea of what may be happening" (Patricia Rodríguez. Oncology nurse).

In the context of women with **ovarian cancer,** the need to appropriately address the full **reproductive and sexual implications** was highlighted.

"Let's talk about all of the issues that affect ovarian cancer, not only those related to cancer - which should be talked about and normalised - but also those related to maternity, menopause and sexuality... these are the three important points" (patient interviewed).

"There is no information about the consequences of cancer and how to deal with them, such as the menopause. I was not informed of any after-effects. Nor anything to do with pregnancy. A little more training is needed. And the same with sexuality. Learning more about the collateral aspects of ovarian cancer" (patient interviewed).

2.4. TRAIN HEALTHCARE PROFESSIONALS IN COMMUNICATION TO IMPROVE THEIR RELATIONSHIP WITH PATIENTS.

The women with ovarian cancer interviewed rated their relationship with their healthcare teams very positively. 7 out of 9 rated it as outstanding and the remaining 2 said it was good. The aspects they valued most were communication, professionalism and knowledge, the ability to involve the patient and a proactive attitude in offering help.

Despite this, the participants mentioned that they were slightly uncomfortable with the way in which they received information.

"Women with ovarian cancer are put on medication but they don't know what they are taking. At most, they know the name of the medication" (patient interviewed).

"I want them to draw me a picture of what my body now looks like. There is a lack of explanation in that respect. And everything I don't know I have to learn myself. There is still a lot of work to be done by medicine to explain where we are" (patient interviewed).

"The medical team has been fantastic, apart from the day they gave me the diagnosis; they were very brusque" (patient interviewed).

"The relationship I have with my oncologist now is very different; at the start it was more strained. I understand that their position is very complicated because they lose patients, and they don't want to get emotionally attached" (patient interviewed).

The WG agrees on the need to improve ways of delivering information and communicating with patients and relatives. It is an intimate meeting that requires professionals to ensure quality and warmth. The WG references the fact that the method of communication used is even more important than the message itself, and that special care must be taken when conveying a diagnosis or bad news. The way information is received influences the emotional coping process and the group agrees that this is a very necessary and high priority challenge.

"When they put on the white coat, they lose a bit of that warmth, that clarity and that more human touch" (Soledad Bolea. Patient).

"More training and skills are needed for conveying information. There is a lot of disparity when doing it, depending on the professional" (María Pilar Rodríguez. Primary care physician).

The main difficulty reported is that there is no comprehensive training in communication skills in university. It is not included in the **curriculum of medical degrees** and, if it is offered, it is in the form of an optional course which is usually only four months long. Moreover, there is no provision for this training throughout a doctor's professional career.

Continuous training in communication skills is a priority. However, they note that there is a large group of professionals who do not seem to be interested in this type of training, so the challenge is not only to implement this type of course but also to find a way to convey to professionals the importance of building good relationships with patients and relatives.

Communication gaps do not help to create trusting and safe environments in which intimate issues, such as sexuality, can be discussed. It is not only a lack of confidence on the part of the patient but also a lack of training on how to address these issues in consultations, which hinders the multidisciplinary approach to women with ovarian cancer.

"Sometimes, when we ask about this topic, we don't even get answers" (Esmeralda Romero. Physiotherapist).

"Sex is a taboo subject. In nursing consultations, we assess all the functional changes and implications of the disease, but changes to sexual reproduction are not touched, they are not asked" (Patricia Rodríguez. Oncology nurse).

3

ACTIONS:
What can
we do?

The challenges surrounding ovarian cancer require a set of actions and measures aimed at detecting the disease early, promoting health and having access to a multidisciplinary approach in which communication is a key axis in the relationship between doctors and patients. The women with ovarian cancer interviewed, as well as the members of the WG, pinpointed three lines of work that would allow progress to be made on the main challenges identified:

Raise awareness and inform society.

Raise awareness and train healthcare professionals.

Raise awareness and demand action at an institutional level.

"The social challenge of ovarian cancer" is an initiative that looks at what we can do in the public sphere. Therefore, throughout this section, we discuss the reflections and recommendations made by the participants of this initiative as regards starting initiatives aimed at these three lines of work.

3.1. ACTIONS TO RAISE AWARENESS AND INFORM SOCIETY

There is a high level of agreement between both the women interviewed and the WG participants that there is a major lack of knowledge of ovarian cancer in society. Some of the reasons for this lack of knowledge include its low prevalence, poor prognosis (which does not help to draw attention to it), the fact that it cannot be prevented or that there are no screening programmes. These factors contribute to the fact that ovarian cancer is not very well known in society, while others are more normalised in public opinion.

> *"Targeting messages, preferably at those most at risk, women over 45, but without overlooking the fact that this message will also have benefits if we share it with other groups, such as young women and men, who could look out for it and encourage women to go to the doctor"* (Estíbaliz Gamboa. Primary Care Nurse).

Therefore, it is crucial to act on a social level in two ways: **raising awareness** (informing and capturing the attention of society) and **education** (sharing information to empower people). These actions will help to detect the disease early and help women with ovarian cancer feel a greater sense of social support that reduces stigma and improves support.

There is a consensus that people without ovarian cancer should be the target audience for any awareness-raising and/or education campaign about this disease. Within this population group, the majority of WG participants specify young women. However, the importance of reaching out to older women or even men is also mentioned.

As regards initiatives to increase gynaecological and sexual knowledge, the emphasis is that they should target all population groups, regardless of gender or age. The key is to **personalise information by age group**, as the demand is different.

> *"I believe it is essential to raise awareness in society, and especially among young women, of the symptoms of ovarian cancer"* (María Sasía. Medical student).

> *"Women should know what happens to men and vice versa. It should be personalised by age as the demand for information is different and the knowledge needs of each population group are different"* (Mercedes Herrero. Gynaecologist).

RAISING AWARENESS: How do we capture society's attention?

The following shows the degree of agreement on the most effective strategies for engaging society*:

CONSENSUS

- Promoting a message that creates empathy and identification, is concise and calls for action (95%)
- Speaking clearly, without fear or taboos (95%)
- Using a slogan, an easily identifiable logo (89%)
- Through young people with ovarian cancer sharing their experience on social media (89%)

MAJORITY

- Referencing traditional stigmas or false myths to debunk them (79%)
- Use attention-grabbing and surprising messages (79%)
- Through celebrities or acquaintances (74%)

NO AGREEMENT

- Conveying the seriousness of ovarian cancer (58%)
- Changing the message over time (58%)
- Focusing on men as well (53%)
- Relating it to the feminist cause (26%)

[*] Results obtained in the second online survey (WG participants and ASACO representatives).

The following pages discuss different strategies that help to capture the public's attention, as well as to encourage the process of raising awareness, focusing on the issues with an agreement of more than 66% (majority and consensus).

» Make people identify with the cause.

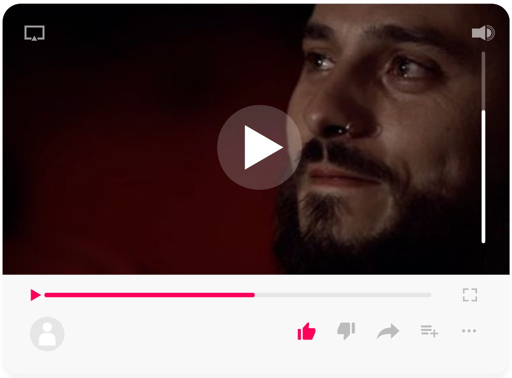
"This applies to you; you can get ovarian cancer too". Ovarian cancer is a disease that can occur in anyone, regardless of their age, affecting patients and their families, friends, etc. One way of attracting attention is to try to make the recipient of the message understand and agree that ovarian cancer is an issue of social interest because it affects people like them.

Therefore, **the key is not only to foster empathy, but also identification.** These types of actions allow people to think about themselves and how it might affect them personally. That is why this type of advertising is called "egoistic", as opposed to advertising that seeks to raise awareness of a particular issue affecting other people or communities ("altruistic" advertising)[5].

"It should include different stories that all women can relate to. Different ages and different symptoms, so that it is clear that any woman can suffer from it" (Paloma Casado. Head of Humanisation).

"You have to be aware that it can happen to you and, if you do have it, it doesn't have to be something dark that you cannot talk about; we must normalise it" (Gemma Durán. Patient).

"We need to correct the false belief that ovarian cancer only affects older women" (Fátima Castaño. Psycho-oncologist).



Watch video:
https://www.youtube.com/watch?v=BMfWF7z6TCE

One example of a successful identification-focused initiative is the campaign *"Todos tenemos familia. En la carretera, víctimas 0 [We all have a family. 0 victims on the road]"* by the Catalan Traffic Service (SCT). The campaign asks people how many deaths they think there should be in a year at most. Nobody answers zero. When a figure of three victims is proposed, they all consider it a success until some of their family members appear on screen who could be those three people.

Society has normalised the number of road traffic victims and this campaign makes the viewer realise that road accidents should be avoidable, and that they can affect anyone.

This same rationale could be used for ovarian cancer. There are 3500 new cases a year in Spain. That is considered low compared to other types of disease. But we or our mothers, sisters, daughters or friends may be in that number.

What if we told them that paying attention to the symptoms and knowing the importance of seeking specialist surgery **could save their lives?** Providing concise information, after having captured their attention, could ensure that many people are informed even before diagnosis. *"If it happens to you... this is what you need to know".*

> *"You become very conscious of it when you experience it first-hand. The message must convey that it can happen to you or your loved ones"* (María Pilar Barretina. Medical oncologist).

Watch video:
https://www.youtube.com/watch?v=RBQ-IoHfimQ

Another example of a campaign is the video *"Most Shocking Second a Day"* by the NGO Save the Children. This video raises awareness of the impact of war on children, appealing to our identity (it shows people and situations we can identify with) and empathy and successfully reaches a wider audience.

» Foster empathy and connect with emotions.

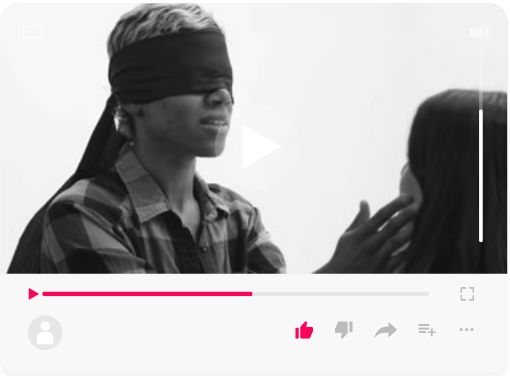
In addition to suggesting that awareness-raising actions should appeal to our identity, the WG suggests fostering empathy and connecting with emotions. The most effective way of achieving this is through the **involvement of people affected by ovarian cancer.** Speaking openly and naturally about their illness will help people connect with the message through emotion.

> *"It is advisable to use emotion to get the message across. The testimonies of patients and relatives who have experienced it are the most likely to attract people's attention and make them empathise with them and care about the issue"*
> (Estíbaliz Gamboa. Primary Care Nurse).

"It is essential that the message creates empathy and has an impact. Testimonies make this possible" (*Carles Tomàs. Teacher*).

Giving a voice to people with ovarian cancer helps to put a face to the disease and bring this hidden and invisible disease to light and understand it from a more human point of view. One idea put forward by the WG is to make **videos with short stories by patients and relatives (both women and men)** in which they talk about the main challenges in first person. Using colloquial language, a dialogue could be maintained with viewers to increase their connection with the protagonists of the videos.

One video that exemplifies the value of personal experiences in raising awareness in society is *"Quítate la venda [Remove your blindfold]")* by the "Psoriasis en Red" association. In it, we learn more about psoriasis through several people with the disease and reflect on the stigma attached to it and how it affects their daily lives.



Watch video:
https://www.youtube.com/watch?v=vcLVEC1khxc

A similar initiative could be used in ovarian cancer through the interaction of women with the disease and women without the disease. Or it could show men from your family (partners, sons, etc.) talking to other men about what they have experienced and why it is important to listen to them.

The emotional component helps to capture attention and process information. For initiatives that seek to improve social awareness of an issue, it is better to **connect with people's motivations,** rather than convey aseptic information that tends to be more easily forgotten.

» Speak clearly, without fear or taboos.

The WG noted the importance of speaking openly about the disease. The low visibility, false myths and stigma attached to women with ovarian cancer highlights the value of normalising and speaking openly about this disease.

> *"We have to speak openly about gynaecological cancer, without fear or taboos. Patients with this disease are opening an important line of visibility"* (Marian Escolar. Patient).

> *"The campaign must be direct and break taboos. It must call things by their name"* (Esmeralda Romero. Physiotherapist).

The **stigma** surrounding ovarian cancer stems from a lack of knowledge of the disease and the high degree of secrecy about its implications. There are still some beliefs that should be discarded such as everything related to being "empty", among others.

> *"The old idea that you now hear less and less... that you're hollow, that you've been emptied out. It is something that women with ovarian cancer find very repulsive because that is the image people have of them. There is a lot of misinformation about how you are left after a hysterectomy, even by women who have had the disease"* (Gemma Durán. Patient).

One way of dealing with beliefs that need to be challenged is to expressly mention them in order to promote a different meaning. It is a way to connect with people using traditional language and offer a different and more respectful interpretation for women affected by ovarian cancer. For example, the WG proposes some strategies such as using a play on words that suggests that **people who have had hysterectomies are full, not empty.**

Hysterectomies are less talked about by society than other types of surgery. It involves the removal of the uterus, an organ that is a symbol of femininity, sexuality, reproduction and motherhood[6]. As a result, it is linked to a series of meanings that influence how women cope with this surgery. This association of the uterus with these areas is rooted in the collective unconscious[7] and requires education and actions to raise awareness at a social level and to support people affected by this disease. The purpose should be to send a clear message: **not having a uterus is not synonymous with not being a woman.**

> *"That is not talked about, it is a somewhat taboo cancer because it stigmatises women and that may be why people don't want to talk about it, they don't want to think that women go through this... and yet we are still women, even with the disease. Society has no idea how women with this type of cancer feel. Just like with breast cancer they have done an excellent job, and everyone knows exactly how they feel, we are light-years ahead"* (patient interviewed).

“If you look at a picture of me before and after, I’m a completely different person. You go into menopause so... boom... early before your time. You feel less womanly, you don’t feel like a woman. It takes away so much of your womanhood that you don’t even process it in your head...” (patient interviewed).

“There is a lot of rejection of anything linked to gynaecological cancer. It is associated with sexual issues, losing the possibility of becoming a mother, losing part of your genitalia... and that, although it is not talked about, has many psychological implications. We don’t talk about it socially and what we don’t talk about doesn’t seem to exist” (Fátima Castaño. Psycho-oncologist).

The connotations associated with ovarian cancer have, therefore, a large social and cultural element. Changing these meanings means changing society’s attitudes and perceptions about sexuality and gynaecology in general, and ovarian cancer in particular.

The WG suggests carrying out actions based on the concept of sisterhood (solidarity among women) and to debunk false myths that are rooted in the position and social role traditionally assigned to women. The concepts of sexuality/gynaecology and ovarian cancer could be addressed in the same campaign, but it is recommended to identify whether the main purpose is to raise awareness of the former or the latter.

“It’s a gynaecological cancer, that already tells you that it only happens to women. Sometimes I have thought that it is a punishment for being a woman... it affects my quality of life psychologically” (patient interviewed).

“We must break the idea that a woman’s sole purpose is to be a mother. You are either a mother or you are nothing, which is why the campaign is so closely linked to feminism. However, a distinction should be made between an ovarian cancer campaign and a sexual health campaign. They are two different campaigns” (María del Pilar Rodríguez. Primary care physician).

The WG highlighted, as an example, how another social taboo, urinary incontinence, is becoming more and more normalised in the population. It remains a taboo and more than half of those who experience it admit to feeling embarrassed[8]. However, it is increasingly common to see advertisements about it starring Spanish celebrities and this has helped to further normalise urinary incontinence in society.

For example, the National Prostate Cancer Association promoted a campaign that looked at the urinary incontinence that some people with prostate cancer may experience. Under the slogan *"Ríe sin miedo" [Laugh without fear]*, they succeeded in creating a positive campaign to tackle a complication that is associated with feelings of shame and resignation.

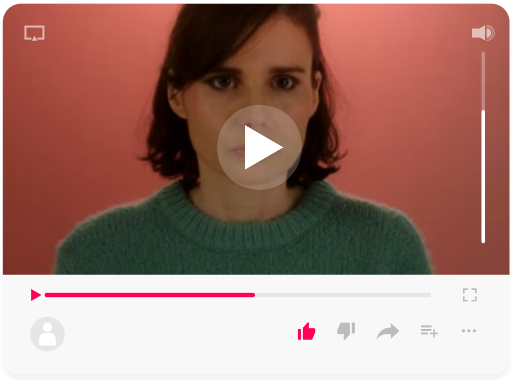
Stigma and taboos in ovarian cancer go beyond issues related to gender roles and the population's poor sexual and gynaecological knowledge. One of the most stigmatising aspects is associated with the poor prognosis of a high percentage of diagnoses. This fact led to it being known as the **"silent killer".**

The WG suggested **actions that refer to this stigmatising language,** as a way of reflecting on the implications of using certain words. Several people from the WG mentioned carrying out a campaign about the importance of language, which directly and openly addresses the stigmas associated with cancer.

> *"We must continue to work to raise awareness about ovarian cancer, as women still feel silenced, and banishing terms such as 'silent killer' will help to destroy stigmas related to the disease" (Fátima Castaño. Psycho-oncologist).*

The campaign *#nivencedorasnivencidas [neither beaters nor beaten]* was highlighted in relation to this, which points out the warlike and stigmatising language traditionally associated with breast cancer and suggests a new approach that is more suited to the reality of women with metastatic breast cancer.

Watch video:
https://www.youtube.com/watch?v=SZFaKC05Hqs



» Use a concise slogan and message that conveys a single concept.

We live in a world characterised by the vast amount of information that revolves around us. There is an increasing range of communication channels and a growing number of sources of information. This has given rise to a phenomenon known as "infoxication", which refers to the difficulty processing information we receive because of its volume.

Consequently, it is particularly important to use short and concise messages that capture people's attention and convey a single concept. By doing so, everybody who comes across the message will internalise the content, even if only a few of them do more research.

The WG referenced the following initiatives as examples of the value of such short messages:

- **Think outside the bra.** Using a play on words that resembles the popular phrase "Think outside the box", this campaign aims to raise awareness among women of the importance of knowing the symptoms of cancers other than breast cancer. Most women know the signs of breast cancer, but this campaign emphasises that other types of cancer exist, and it is important to be aware of them too. Within the scope of this slogan is another campaign to raise awareness of ovarian cancer.

- **I´m not ovary-acting.** This campaign promotes awareness of the need to seek medical advice if you experience symptoms. The ingenuity in this message is the play on words that links it to the phrase "I'm not overreacting". It is a way of stressing the importance of not taking symptoms lightly and seeing a doctor as soon as possible. Conversely, there have been campaigns called "I'm ovary-acting" to point out the importance of taking a stand against ovarian cancer.

A similar play on words is proposed in Spanish:

"We could use the word "obvio" [obviously] which has become very fashionable among young people" (Sofía Bauer. Primary care physician).

- **#EresJovenNoInmortal. [You are young not immortal].** Social media campaign promoted by the regional council of Madrid to raise awareness among young people of the risks of COVID-19 and the importance of their behaviour to tackle the pandemic. Through a hashtag with just four words, they managed to clearly convey the purpose of the message (in the relevant time period) and encourage people to reflect on their behaviour. It provides true information in a succinct and unbiased way that is easy to share and can be adapted to any additional information we may wish to add.

- **Póntelo, pónselo.** This campaign on condom use is now 30 years old and is still part of Spain's collective memory. It had a great social impact and helped raise awareness about using condoms to prevent the transmission of diseases. This slogan is one of the most famous in the history of advertising in Spain, managing to convey the importance of condom use in just two words.

Therefore, we propose finding a slogan that simplifies the message and connects with public opinion. Different slogans have been launched on World Ovarian Cancer Day (8 May) in recent years which could be used as a starting point to create a slogan to accompany the cause on an ongoing basis.

» Use a catchy and striking slogan or message.

In line with the previous point, we could look for a powerful message that is also sensitive to the cause. This type of message is usually more appropriate, in the context of a specific project.

For example, the slogan used by the Spanish Association Against Cancer to share the importance of colon cancer screening was a complete success story: "Esta mierda te puede salvar la vida" [This shit can save your life]. It was also accompanied by the 💩 emoticon to reach a wider audience and have a greater social impact

The impact of a slogan helps to capture people's attention and help them to remember the message. However, it also highlights the importance of considering your words carefully in order to **avoid offending people when dealing with sensitive topics.**

"We have to be careful...some of the slogans border on being crude. It is one thing to capture attention and another to attract attention" (José Antonio Negrín. Family member of a person with ovarian cancer).

"I agree with eye-catching messages, but I don't see the point of using rude words or gestures" (patient interviewed)

Another way to capture attention by surprising people is to **make the recipient of the message curious** and not explain it immediately. This is known as a “teaser campaign”. The objective is to arouse their curiosity by not revealing the background of the campaign but showing some of its characteristics. This could be a colour, question, image or music.

“Something that arouses people’s curiosity. For example, “What do these people have in common...” next to the names of famous people with ovarian cancer” (Lucía Peralta. Patient and Primary care physician).

» Use an easily identifiable logo.

Aside from words, there are other aspects that help to unify and internalise the concept. The WG highlights the importance of symbols and colours, around which a discourse can be built that is the gateway to capturing the attention of society. This is what has happened, for example, with the red and pink ribbons in the HIV and breast cancer campaigns. The same has happened with the colour purple to symbolise the fight against violence against women.

“If I say 016, everyone thinks of the colour purple. Just like pink with breast cancer. “It has to be something very specific, but it also has to mean something”* (Sofía Bauer. Primary care physician).

“In a campaign on the prevention of kidney failure in Andalusia organised by the Andalusian Foundation for the Fight against Kidney Disease (ALCER), we used an easily identifiable slogan and anagram. It made it easy for people to quickly relate any material to the campaign” (María del Pilar Rodríguez. Primary care physician).

Another example of a symbol that conveys a concept is the zebra to represent the cause of people with neuroendocrine tumours. This is a rare disease whose symptoms may go unnoticed. The image of a zebra was chosen due to its stripes for camouflage and the fact that it is rarer and wilder than other horses. As the NET-Spain association says: *“There is a Chinese saying that says ‘When you hear hoofbeats, think horses not zebras´*. However, a researcher of rare diseases and neuroendocrine tumours in particular once told his students ‘If you hear hoofbeats, think horses, but don’t forget that it could also be zebras’”. This allegory is intended to convey the importance of also suspecting possible rare diseases when faced with certain symptoms.

[*] 016 is the national helpline for domestic abuse in Spain.

The symbol for ovarian cancer is a **teal ribbon** and the WG stresses the importance of promoting it and increasing its visibility. It is widely used in actions promoted by patient associations internationally. However, there is still a long way to go for it to be recognised by society and for it to be identifiable.

"Ovarian cancer has a beautiful teal ribbon, we could simply take advantage of something that already exists and enhance it, increase its visibility" (Patricia Rodríguez. Oncology nurse).

"The image of the loop could be used as a letter A, by making some changes or adding extra detail. We are used to seeing a lot of ribbons, so maybe it would attract more attention if there was more detail" (patient interviewed).

In addition to this colour/ribbon, the WG proposed looking for new symbols that can represent the ovarian cancer patient group in a more visual and exclusive way:

"It is important to find a simple symbol. For example, a clearly recognisable V or a visual metaphor such as a cup can be connected to meanings and actions such as clinking glasses or other values associated with life" (Óscar Allende. Journalist).

» Involve influential people.

The WG referenced something which is increasingly common online: people sharing their experience with the disease with thousands of followers on social networks. For example, two people who standed out for having contributed to spreading the word about their illnesses through their social media presence were Olatz Vázquez (who shared her experience with gastric cancer) and Pablo Ráez (who promoted awareness campaigns about bone marrow donation).

"Testimonies work. It's good that young people speak out, so people don't assume it's something that only happens to older people" (Esmeralda Romero. Physiotherapist).

This type of experience is not part of a specific institutional campaign. However, the public and healthcare organisations involved in ovarian cancer could provide support and **advice to those who want to share their experience with the disease** in order to raise awareness. Staying in contact and offering assistance will help ensure the accuracy of the information and unify the messages that are to be shared with society. In addition, people can collaborate in **sharing these channels** to broaden the scope of its outreach work.

However, there is a challenge pointed out by several people in the WG. There are still many women who hide the fact that they have ovarian cancer because of stigma. This seems to be more persistent than that of other types of cancer and is due, in particular, to the lack of awareness of ovarian cancer. It is suggested that this may be why few celebrities have spoken openly about the disease.

The generosity of those who publicly share their lives with the disease is often well received by the public and attracts the attention of **famous and influential people** who can be a spokesperson for the cause. Many of the participants of the WG referred to the need for familiar faces in order for the message to reach a wider audience. People from cultural, sporting, entertainment or artistic backgrounds help to spread the message to large groups of the population.

However, several people draw attention to the fact that there are also certain risks to this strategy. The actions tend to be very specific and short-lived and, additionally, the narrative is not controlled as it depends on what the person wants to convey. Similarly, they mention that celebrities tend to go to private facilities, which runs the risk of giving a negative perception of the quality of care provided by public services.

"People who are not famous can become well-known or role models" (María del Pilar Rodríguez. Primary care physician).

"Raising awareness is most effective when people who have been through the disease take responsibility of telling the people around them" (Gemma Durán. Patient).

"The collaboration of famous people and the latest influencers would be ideal. Familiar faces supporting the cause" (Hugo Azcona. Family member of a person with ovarian cancer).

"It wouldn't hurt to involve well-known faces to support awareness campaigns. An impact advert with a well-known figure in the media" (José Antonio Negrín. Family member of a person with ovarian cancer).

"We have to be very careful with celebrities because they might go private" (Soledad Bolea. Patient).

The use of social media is also highly recommended **to promote gynaecological, sexual and reproductive health education.** Some taboos still persist, but more and more people are talking openly about these areas on social media. Especially those who work in the fields of sexology, gynaecology, psychology, fertility, etc. and dedicate themselves to sharing information on social media.

Examples of influential healthcare professionals on Instagram®:

@dra_herrero (gynecology and sexology)
@meduelelaregla (sexology and menstrual cycle)
@sexperimentando (sex education)
@dragarciagalvez (gynecology and sexology)
@mamacasquet (sexology)

A gynaecological, sexual or reproductive health education campaign should have a social media strategy that includes contact with these types of accounts, which will not only help to reach more people but also enrich the content.

Different materials can be created through infographics, live messages, reels, etc., that allow us to interact with these people and come into contact with other groups besides our own followers.

» Encourage participation.

Awareness-raising activities should in some way allow recipients to participate so that they can widen the audience of the message. This approach does more than inform people as it provides tools and resources for them to continue sharing the message, **raising awareness and mobilising** at the very least their immediate contacts[9].

“An interesting strategy could be to focus on participation. In other words, to make people active and not passive recipients, so they end up sharing the message themselves and continue raising awareness”
(María Sasía. Medical student).

This is something we see regularly on social media. Teenagers and young people in particular engage more if they can interact with content and share it with their followers. One success story was the *"Ice bucket challenge"* to raise awareness of ALS. It made it possible for more people to learn about the disease by encouraging them to throw a bucket of ice-cold water over themselves so they could put themselves in the shoes of people with ALS.

This initiative reached a wide audience because, among other things, it invited action. However, it did not allow participants to spread a message to those around them. As a result, the action became more important than the message it was intended to convey. That is why it is important for participation to go hand in hand with the possibility for people to become spokespersons and share the information that the initiative wants to convey.

In this regard, one of the ideas suggested by the WG is to encourage people to participate through a **dance that informs them of the symptoms of ovarian cancer.** This type of short video is widely shared on platforms such as TikTok® and Instagram®.

Through catchy music and different movements (e.g. crossing your legs to represent needing to go to the toilet more often and rubbing your hand on your belly or back to symbolise abdominal and lumbar pain), a fun initiative can be carried out that also has an educational component.

Using **games, challenges and memes,** among other things, will help to share the message with younger people, but it should be approached with caution so as not to detract or lose control of the message.

The WG indicates that this type of action can also be very effective at raising awareness about sexual and gynaecological health. They reference the considerable lack of knowledge of this topic in society, especially among men. Networking activities could help to inform them about issues such as the recommended age for gynaecological check-ups, other ways of understanding sexuality, or which activities are risky or protective to enjoy a full sex life.

» Build partnerships.

The more people who are involved in outreach and education programmes, the wider the audience will be. The participation of other individuals and organisations will help to develop the materials themselves and subsequently share them. These partnerships are particularly important in cases where there is a common interest, such as with other patient groups.

"Some of the symptoms overlap with other diseases. That is why there must be more unity between patient associations. There is strength in numbers. We cannot compartmentalise things in gynaecological health" (Lucía Peralta. Patient and Primary care physician).

"We can build partnerships with breast cancer organisations, calling for sisterhood and to use the large network they have created. It would allow us to think about actions: for example, imagine if there is a sporting competition in which we are both participating. We could also **partner up with the Movember network, aiming to collaborate with its events. We could also play with the concept of passing on the baton"**
(Óscar Allende. Journalist).

It is very important to join forces in relation to ovarian cancer. This requires prior work to **raise awareness among groups** that are directly affected but may not be aware of the problem.

Many of these groups have been involved in similar causes before, such as the work carried out by associations for women with breast cancer, which has raised awareness of this disease among very diverse groups of the population and can be used as an example and reference when building partnerships with other movements.

"Campaigns against breast cancer create empathy and call for companionship and unity in the face of the disease" (Carles Tomás. Teacher).

» Multi-channel strategy.

Campaigns aimed at society require multiple channels to be used, notably healthcare settings (through posters in hospitals, pharmacies and health centres), social networks, the media, public and health organisations (to be included in their communication channels) and public spaces (through publicity).

The following section deals specifically with the diverse range of communication channels and is also ideal for carrying out awareness-raising campaigns.

"Years ago, I worked on a project with the ALCER Foundation to raise awareness of chronic kidney disease, which was publicised in health centres and on the websites of various institutions. At the same time, it was presented to scientific societies, which provided support in sharing it with other people. Media campaigns were carried out and the slogan was shown on information panels in organisations such as local councils. The project had a major impact in Andalusia. The materials had a QR code that you could scan with your mobile to open the Association's website, which must have an information page" (María Pilar Rodríguez. Primary care physician).

EDUCATION: How do we teach it effectively?

Educational actions aimed at society are essential in the context of ovarian cancer. In addition to raising awareness, there is a need to equip the population with knowledge and resources for different purposes.

According to the WG, the priority at an educational level is to improve society's knowledge about ovarian cancer and its symptoms. The invisibility of the disease does not help with recognising the signs that should alert you to see a doctor. The following proposals are mainly directed towards this line of action.

» Provide concise and manageable information.

Sharing the symptoms of ovarian cancer does not imply giving a detailed explanation of all the signs that might imply somebody has the disease. According to the WG, it is better to **convey the most common symptoms,** as this will help the target audience to retain the information and not become overwhelmed.

It is therefore important that the information given aims to inform people of the presence and persistence of the following symptoms: abdominal pain or discomfort, feeling full, bloated and changes in bowel habits[10].

"It is better to mention only the most prominent symptoms. Almost all patients feel bloated (like they are pregnant) and suffer from incontinence, abdominal pain or have difficulty eating because of feeling full. Listing too many symptoms would be counterproductive" (Marian Escolar. Patient).

These common symptoms tend to be mistaken for digestive issues. Raising awareness that they could be symptoms of ovarian cancer will help people not to assume they are digestive issues and discuss them with their doctor.

"I had been feeling ill for some time and you do recognise that something is wrong. But you assume it's just a digestive problem; if I had known half of what I know now, it would have changed everything, I would have made different decisions, gone to accident and emergency earlier and had other types of assessments" (patient interviewed).

Specific messages also make it possible to reach younger age groups who, because of the communication channels they use, are more accustomed to receiving **concise information in the form of short messages.**

"The difficulty with information and awareness campaigns for young people that provide too much information is that they disconnect and it is not very productive" (María Sasía. Medical student).

As regards information about symptoms, one alternative is to make materials that draw attention to all gynaecological cancers and not specifically to ovarian cancer. This aspect was supported by the majority of participants (84%)*who stated that in addition to informing people about ovarian cancer, other complementary materials should aim to advise them of symptoms that could be signs of any gynaecological cancer.

"Many symptoms of ovarian cancer overlap with other gynaecological cancers, so it would be good to know what is normal and what is not normal. So that alarm bells start to ring when people feel that something is wrong. What matters is that the patient goes to the doctor because they notice that something is not right. You don't need to know what it is, just that it is not normal at a gynaecological level. Then we can put a name to it" (Lucía Peralta. Patient and Primary care physician).

If the aim is to provide gynaecological information to the general population, the WG proposes starting by sharing the **importance of check-ups** by answering the following questions:

- When should you start to go for gynaecological check-ups?
- What does a check-up consist of?
- How often do you need to go and why?

Moreover, the WG recommends giving specific information on **what is normal and what is not in relation to gynaecology.** A lack of gynaecological information and education has led to the normalisation of symptoms (e.g., painful menstruation) that could have a medical solution. Providing concise and practical information on when and why to seek gynaecological care could help improve the health of the population and prevent or detect a range of diseases early.

* Result obtained in the second online survey (WG participants and ASACO representatives).

The WG stressed the importance of using a **shared vocabulary** which is accessible to the population. Using colloquial words or expressions helps to connect with the target audience and helps them to understand the information. Sometimes there is a tendency to use technical terms or words that the public do not relate to, so it is advisable to test the information beforehand with a group of people outside of a healthcare context.

"It should provide a direct message with clear and simple language, explaining concepts but not dramatizing them" (María Pilar Rodríguez. Primary care physician).

Therefore, it is advisable to replace terms such as such as "symptomatology", "non-specific" or "distension" with others that are more common in our daily lives.

In addition, the WG proposes that information materials explain **why the information is useful** (e.g., early detection) and **what to do** (e.g., go to the doctor). It is also recommended to include a form of contact to request more information about the campaign.

» Use visual aids.

This type of material helps us to better understand the information and organise the ideas we see.

"It is recommended to use colours to identify symptoms, with a clear, concise and contextualised image to avoid hypochondria. Something very visual" (Esmeralda Romero. Physiotherapist).

"A picture is worth a thousand words. And it should be accompanied by a text with a brief description of what is possible, with a logical direction" (Rosa María Plata. Midwife).

One of the most commonly used strategies to raise awareness of the symptoms of ovarian cancer are **infographics,** as they help to explain the signs we should pay attention to in a simple way. There are several applications and websites that make it easy to create these infographics for free, allowing different visual aids to be created to accompany a communication strategy.

¿Cuáles son los síntomas que puede producir el **cáncer de ovario?**[1]

- Pérdida de apetito
- Sensación de cansancio no habitual
- Hinchazón abdominal
- Dificultad en la digestión
- Estreñimiento o diarrea
- Dolor pélvico o abdominal
- Sangrado vaginal anormal
- Necesidad frecuente de orinar

Si observas uno o más de estos **síntomas** mantenidos durante **más de 10 días, acude a tu médico**. Ten en cuenta que estos síntomas también pueden ser producidos por **otras enfermedades**.

El cáncer de ovario puede **no presentar síntomas** en sus primeros estadios. Esto **dificulta** enormemente **su diagnóstico**.

ASACO

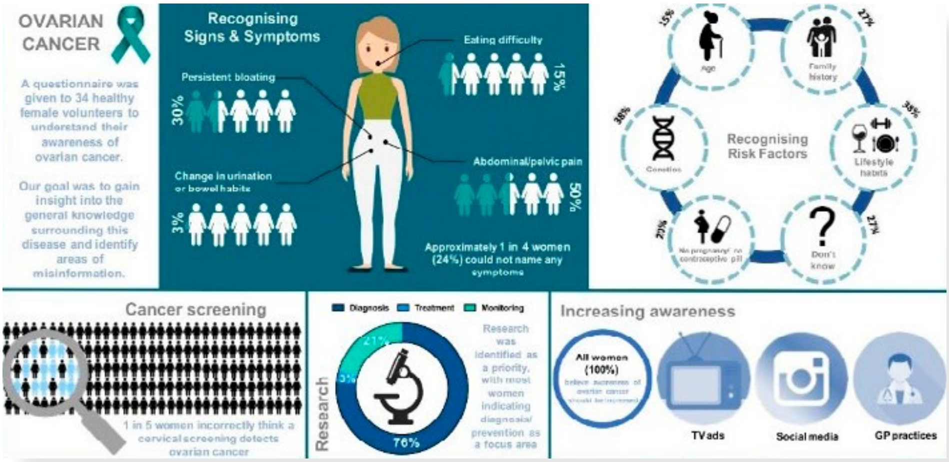
In this sense, several materials of this type have been produced in Spain that help to quickly learn about these symptoms and that could be used for campaigns in health centres, or as a basis for other infographics.

"People internalise information much better when it is conveyed visually. A simple infographic with an overview of the symptoms and information on where to go can be useful. And it is good for professionals too so they can see it schematically and be reminded when they suspect something is a digestive issue that it could be gynaecological" (Patricia Rodríguez. Oncology nurse).

This type of illustration is useful for advertising in health centres and on social networks for information purposes. The WG also suggested using this resource in a **smaller format,** so that it can be hand-delivered by health professionals.

"A pocket-sized card for monitoring gynaecological cancers with a description of the most common symptoms and how long they last would be ideal. When information is printed, women read it more closely and go to the doctor"
(Rosa María Plata. Midwife).

Infographics are resources that help to raise awareness of the symptoms and can also help to gather information of interest that you want to share with society. This type of material is ideal for targeting groups with a greater interest in the disease. However, they may not be recommended for the general public because of the diversity and quantity of information they contain.



Authors: Romina Silva and Adele Connor (Irish Cancer Society)

» Avoid alarming people.

Several WG members pointed out the importance of being cautious and responsible with information, especially when it relates to health, and mentioned that there is a fine line between providing truthful information that attracts attention and alarming people.

A badly worded message or information can lead to unfounded fears in the population, resulting in an unjustified increase in medical consultations. For this reason, **care should be taken when writing the message in order to avoid going into too much detail** regarding the information to be conveyed, as this can lead to interpretations that may scare some people.

"It is difficult to raise awareness without scaring people, without creating panic, fear... It is difficult to find the balance. You have to take care when writing a message in terms of words and tone" (María Pilar Barretina. Medical oncologist).

"If there is one thing that doctors are afraid of it is scaremongering that leads to frightened women wanting to see the gynaecologist, as that would place an enormous strain on resources that would be detrimental in terms of increasing the delay in seeing everyone" (María Pilar Rodríguez. Primary care physician).

"We have to stick to surface information and not go any deeper so as to avoid causing alarm" (Patricia Rodríguez. Oncology nurse)

The symptoms of ovarian cancer are non-specific. Therefore, we should not say that experiencing these signs is synonymous with having the disease. There would be no certainty and it would cause distress to many people in the target audience. It is possible to find a balance between raising awareness and not alarming people, and it is achieved through the correct use of words and messages.

¡Corre la voz! La detección temprana es vital y siendo los síntomas tan comúnes, si éstos persisten durante más de dos semanas acúde a tu médico.

Fuente: World Ovarian Cancer Day. What is Ovarian Cancer? Diponible en: http://ovariancancerday.org/what-is-ovarian-cancer/

In this regard, the WG highlights the importance of **contextualising information** and of consulting a gynaecologist or Primary care physician if suffering from more than one symptom for more than two weeks.

"We have sometimes been blocked by medical institutions that believe informing the public can cause panic. They say there is no need to make people panic because most of the time these symptoms are not going to be ovarian cancer, but... what if it is?" (Charo Hierro. Patient).

» Have evidence to legitimise the information.

Sharing information about health-related matters requires caution and accuracy. The participation of health professionals is therefore essential not only to elaborate on and/or validate the content, but also to legitimise the information. In addition to the involvement of individual professionals, the WG highlights the importance of inviting **professional associations and scientific societies** as a way of gaining institutional support for the information campaign.

Similarly, it is recommended to involve **Regional Health Departments** from the outset, as they will help to include information material in health centres and may even contribute to funding the campaign.

» Use a range of channels.

The actions with the greatest impact are those that combine different communication channels and are adapted to different population groups. There is a consensus that dissemination actions should be channelled through health centres, while at the same time using other channels outside healthcare settings that are used on a daily basis.

Health centres are an essential tool for any campaign and in addition to these, other channels for sharing health-related information are recommended, such as social networks, universities or public platforms. The language to be used should be adapted to the channel and target audience.

"It has to be multi-channel and encompass a large part of the population. Because it is such an unknown disease, we have to reach out to large groups of the population" (Sofía Bauer. Primary care physician).

"Although we are targeting society in general, when choosing the communication channel, we need to decide which audience we want to act on and which audience we want the campaign to have the most impact on" (María Sasía. Medical student).

Recommended information channels:

Health centres

"Health centres should be the mainstay because that's where patients go to. That's where they access the information and the resource"

(Mercedes Ruiz. Pharmacist)

Social networks

"Social networks are the main information tool, much more than other media"

(Sofía Bauer. General practitioner)

The media

"It is through the media that you reach the most people"

(Gemma Durán. Patient)

Universities

"Most of them have student organisations. You can use these to give talks at universities"

(María Sasía. Medical student).

Councils

"It is important to involve local councils. There are many people who get information through them"

(Rosa María Plata. Midwife).

Public associations (not health related)

"Talks in women's centres, neighbourhood centres, community centres, women's groups..."

(Estíbaliz Gamboa. Primary Care Nurse).

Public spaces

"Look for places where women are more likely to go and that allow advertising such as shopping centres"

(Rosa María Plata. Midwife).

The following three channels were mentioned by the WG the most:

a) Health centres

Health centres are ideal places to raise awareness according to the WG, and it mentions the usefulness of **posters** as a communication method. They can be displayed in waiting rooms as well as in the consulting rooms themselves. In the latter, they can also serve as a reminder for medical and nursing teams to consider it when faced with a particular set of symptoms.

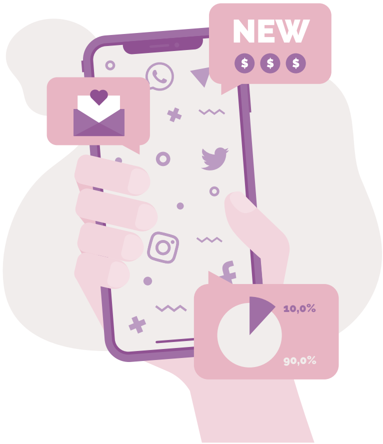
The difficulty with health centres is that they will appear next to other information posters and that younger age groups do not regularly visit these centres. That is why local pharmacies are suggested as a complementary channel:

"Pharmacy campaigns are financially cheaper and can be carried out through professional associations. There are more than 20,000 locations in Spain, so they reach 100% of the population and can never have too many posters" (Mercedes Ruiz. Pharmacist).

It is clear that the authorisation of these materials for display in healthcare facilities will require the involvement, from the outset, of Regional Health Departments (for health centres and hospitals) and pharmaceutical associations (for pharmacies), as well as the relevant scientific societies. These organisations can assist in the development and/or review of content, and their involvement will help in subsequent distribution.

b) Social networks

These channels, traditionally used only by young people, are now used by different population groups on a daily basis. Social networks can no longer be referred to as a single entity and the diverse range of platforms means that they use different methods of communication and therefore appeal to different age groups. For example, the social networks Facebook® and LinkedIn® are used mostly by adults while YouTube® and Instagram® are more popular with young people[11]. The use of images and videos is increasingly more common than written texts.



Social networks are the best way to connect with different population groups and especially with young people. **Information should be conveyed in a way that is visual, concise, adapted to the platform** and, as far as possible, participatory, so that it can reach a wider audience.

> *"In the age of technology, using social networks to publish small messages that are quickly disseminated to a large number of people is an effective way to have a social impact" (Patricia Rodríguez. Oncology nurse).*

Engaging with young influencers or youth movements from the start will help to build a larger network on social media and tailor the message to connect with their motivations and style of communication.

> *"Social media is what drives people the most, especially young people. It's what works the best" (Esmeralda Romero. Physiotherapist).*

c) The media

The WG highlights the importance of using traditional media (radio, press and television) to reach a wide group of the population. This channel is mentioned for different purposes: advertising, positioning, providing information of interest, etc. and it is particularly useful on the occasion of world or awareness days, as it is easier to include in your calendar.

» Awareness days.

Global or national awareness days are an opportunity to raise awareness in society of a specific cause that needs attention, in order to promote information and social support. Several people from the WG pointed out the importance of these awareness days as they give causes a public profile that is not usually achieved on other days of the year. However, it is important to note that only a minority highlighted the importance of these days in raising awareness of ovarian cancer.

World Ovarian Cancer Day is on 8 May and is organised in Spain by the Spanish Association for Women Affected by Ovarian and Gynaecological

WORLD
OVARIAN
CANCER
DAY

Cancer (ASACO). This association is part of the World Ovarian Cancer Coalition (WOCC), a coalition of 170 patient organisations around the world. According to the WOCC, the purpose of this day is to contribute to sharing knowledge of the symptoms and the need for more investment in research[12]. Thus, in addition to the specific slogans adopted each year, increasing awareness of the symptoms is always a priority in these global campaigns.

These global awareness days require the **support of society** to share the message so that it can reach large groups of the population. Achieving this requires wide-ranging mobilisation, which is more difficult in ovarian cancer because of its low prevalence and the scarcity of public organisations committed to this cause. This means that the desired visibility is not always achieved.

"Global awareness days are useful. Even in university we are given ribbons and reminders in classrooms. I have never had that with ovarian cancer" *(María Sasía. Medical student).*

"It is difficult to join forces with other public organisations. We are the only association. Some breast cancer associations have a small genital cancer section, but there are only a few of these. Social networks, word-of-mouth and the media attract the most attention" *(Charo Hierro. Patient).*

One of the WG's proposals revolves around building **partnerships with other awareness days** or causes, which could help to strengthen public support for these campaigns.

"The international day is very close to Mother's Day in Spain and that has a lot of impact. You could think about how to expand it and make references to it. I know it's not right to reduce femininity to motherhood, but it can help increase awareness. Moreover, you can build partnerships with other associations for "high-profile" cancers, such as breast cancer, calling for sisterhood and to use the large network they have created" *(Óscar Allende. Journalist).*

In this way, we can see how the different awareness days that are celebrated throughout the year can be used as communication milestones to share information on different issues related to ovarian cancer. For example, the International Day of Action for Women's Health (28 May), World Patient Safety Day (17 September) or World Mental Health Day (10 October) may be an ideal time to inform the public about issues related to these fields in the context of women with ovarian cancer.

02/04
CANCER DAY

03/08
WOMEN'S DAY

04/07
HEALTH DAY

04/18
PATIENTS' RIGHTS DAY

05/02
MOTHERS' DAY

05/08
OVARIAN CANCER DAY

05/28
ACTION FOR WOMEN'S HEALTH DAY

09/04
SEXUAL HEALTH DAY

09/17
PATIENT SAFETY DAY

09/24
CANCER RESEARCH DAY

10/10
MENTAL HEALTH DAY

11/05
CARERS' DAY

3.2. AWARENESS-RAISING AND TRAINING ACTIONS FOR HEALTHCARE PROFESSIONALS

It is essential to involve medical professionals in addressing the challenges of ovarian cancer. The WG stressed the need for specific actions aimed at these groups, as they have the power to change some of the issues raised by people affected by this disease.

In this regard, the areas requiring interventions aimed at these groups, according to the results of the first and second phases of the project, are:

- *Training in communicating with patients and relatives*
- *Knowing the symptoms of ovarian cancer*
- *Post-diagnostic planning and referral to specialist surgery*
- *Awareness and referral of patients and relatives to other support resources*
- *Inclusion of gynaecological, sexual and reproductive health education in consultations*

These challenges require structural solutions at management and decision-making levels. However, the outcome will depend to a large extent on the **attitude and willingness of the individual practitioner** and his or her involvement in bringing about these changes.

"We must make practitioners aware that these problems exist and involve professional associations in the fields of health, social care and psychology..."
(*Rafael Vidaurreta. Social worker*).

"We need to raise awareness among professionals who attempt to do an operation they shouldn't. There must be means to refer patients through healthcare management. It is a question of organisation and management, not of convincing a politician. Professionals would have to demand it"
(*Paloma Casado. Head of Humanisation*).

"It is very important that gynaecologists who do not specialise in ovarian cancer refer all cases they can diagnose themselves to their expert colleagues. The surgery is highly complex and the prognosis depends on it"
(*Charo Hierro. Patient*).

"It's not just the surgery, it's the approach, the diagnosis and the decision. Sometimes we are too hasty. It is essential to wait a few days to clarify what is the best option for the patient" (María Pilar Barretina. Medical oncologist).

One of the obstacles identified by the WG to raising awareness among health professionals on the different issues identified is egos, which can be addressed by educating healthcare professionals themselves and empowering the general public.

"Some professionals assume they are able to do everything. They don't cope well at all and that makes referral difficult. It is much more complicated because you are working with internal resistance" (Estíbaliz Gamboa. Primary care nurse).

"There is a vaccine against egos and that is patient information and demand. If patients have information on how many cases are being operated on per centre, egos will not matter, as the patient will ask for a referral" (Mercedes Herrero. Gynaecologist).

"Sometimes egos are very big, but they should be put aside. A good place to teach people this would be medical societies. They should be co-responsible for providing this information" (patient interviewed).

What should we focus our efforts on?

Training in communication skills to improve patient relations.

Communication with patients and relatives is one of the areas that needs to be improved in all healthcare professions, according to several members of the WG.

"We have a say in who has to operate on us and how, but we also need to influence how we are told this information. It is vital throughout the process. It is not just about knowledge; it is about communication skills" (Rafael Vidaurreta. Social worker).

These skills are lacking because they are not taught at university, so action must be taken to raise awareness of this and call for change. The WG agreed that **university** is the best place to train professionals in communication and bioethics. It is increasingly common to include subjects that train students in this area, but there is much room for improvement in making them compulsory (instead of being an optional subject) and offering them throughout the degree course (not as a one-off).

"In medical school there should be a core part of the curriculum on managing emotions, with others and with oneself. Because you do that every day. Doctors "behead" people, because they have to emotionally detach themselves in order to do their job, because they are overwhelmed, they are swamped" (patient interviewed).

The following actions could help to address this challenge within the framework of university[13]:

» Carry out more representative studies to highlight the lack of training in communication skills in health and social care studies and to raise awareness of the need for better academic and professional training.

» Produce a document requesting the inclusion of compulsory training in communication skills. The ideal situation would be to involve student groups, professional associations and scientific societies, as well as other relevant social organisations.

» Obtain the commitment of the Spanish Confederation of Rectors and Deans to include communication skills training in the faculties of health and social care.

» Contact regional health departments to include this training in the student residency period as part of a continuous training plan and to recognise its merits.

» Conduct courses and workshops on communication for health and social care students and professionals.

Furthermore, it is necessary to integrate this area in **continuous training for health professionals.** Communication and patient relations change over the years, so more training is needed to keep up with population trends and new ways of relating to care teams.

More and more people are interested in training in communication skills. However, the WG notes that there are still many people who are not receptive to this type of training. These training activities should encourage attendance and, to this end, three proposals are suggested, beginning with the need for a partnership with the heads of service.

Carry out these activities during working hours.

Make attendance compulsory.

Award formal certification.

The above points may help to increase the number of professionals interested in this type of training, but the WG recommends other actions that help to raise awareness of the value of communication among healthcare workers.

✓ Sending out invites to conferences and events that enable **contact with patients outside of consultations.**

"I notice the difference between when they're in their white coat in the consulting room and when you invite them to talks and conferences. You can talk to them and they become humanised. This closer relationship is very good for them. When you explain your concerns and feelings, they understand more that communication goes both ways" (Soledad Bolea. Patient).

✓ Create **materials they can display in their workspace:** infographics, posters or small cards that are accessible and act as a reminder, outlining the steps to be taken in certain situations. For example, the MÁS QUE IDEAS Foundation produced a pocket manual for health professionals entitled *"Connecting with breast cancer patients through communication"*, which offers simple keys and techniques to improve communication.

✓ Gather **evidence about the repercussions** of not taking care when communicating with patients. Collect data on the value of effective communication with patients and raise awareness among professionals and managers through statistics showing the value it provides for patients, professionals and managers.

"Use real cases to show what has happened to a patient who, despite several consultations, has not been able to follow the right pathway"
(María Pilar Barretina. Medical oncologist).

✓ Create **spaces where they can exchange experiences** and raise awareness of the importance of communication.

"Create spaces where professionals who have encountered situations that reveal a lack of knowledge can share their experiences, so as to raise awareness among their colleagues and to debate the potential consequences of this and how to mitigate them" (Carles Tomàs. Teacher).

✓ Carry out **specific awareness campaigns** aimed at the health professionals who are most reluctant to do this type of training.

"Awareness campaigns by recognised professionals and scientific societies on the need to improve communication skills"
(Fátima Castaño. Psycho-oncologist).

"Use testimonies by patients who were affected by professionals who did not treat them correctly. That will make them aware of the damage they can do"
(Esmeralda Romero. Physiotherapist).

The sometimes distant attitude of healthcare professionals reported by many patients seems to be related to them feeling a need to protect themselves. One of the ideas put forward by the WG is to organise **workshops and courses for professionals on how to manage emotions** that enable them to show empathy and warmth to patients and relatives without having an emotional impact on themselves.

"We are now doing a training course, to trial a new type of coaching. How to feel more comfortable in your relationship with patients to reduce your stress levels. When we are complaining about (limited) time, we do not have time to listen. We often say that we have no time for explanations, but what we lack is the patience to listen. We have to find a balance between what we need to say and what we need to listen to"
(María Pilar Barretina. Medical oncologist).

Knowing the symptoms of ovarian cancer

Raising awareness of the symptoms of ovarian cancer among healthcare professionals is one of the main priorities, according to the WG. This is also noted by the women interviewed, who identified this **lack of knowledge** as one of the factors that led to a delay in diagnosis.

"Ovarian cancer is often confused with a digestive problem and that is where we lose a lot of time" (patient interviewed).

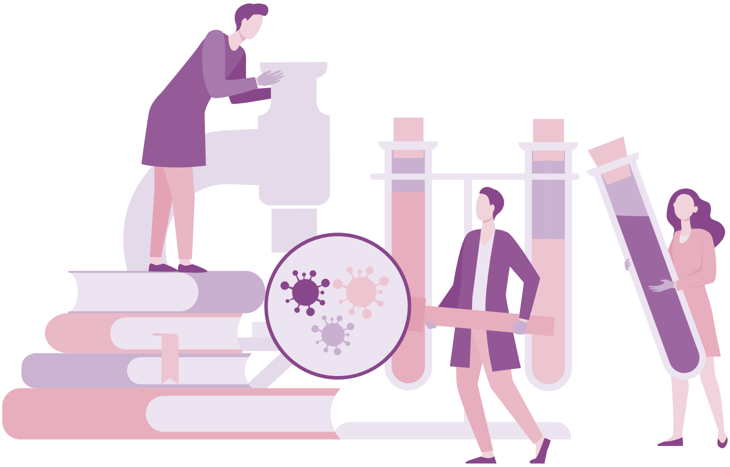
"Doctors don't look there, they look everywhere else, but not at the ovary. I don't know why, whether it is because there are fewer cases or because they are not used to it, but the truth is that is what happens. I was sent for so many tests" (patient interviewed).

"Education and awareness of the problem of ovarian cancer should be extended not only to society, but also to health professionals themselves, in order to facilitate an accurate and rapid diagnosis" (Fátima Castaño. Psycho-oncologist).

All healthcare professionals are the ideal target audience for an ovarian cancer symptom awareness campaign. However, the WG identified **raising awareness among primary care and gynaecology teams** as a priority.

"It is very important to train primary care and gynaecology professionals. When I was diagnosed, all of the women I knew asked me if I wasn't going to check-ups. This is one of the big misconceptions, ovarian cancer is not diagnosed in screening. Gynaecologists should tell us that themselves. And doctors. The professionals closest to us have very little knowledge of this subject" (Marian Escolar. Patient).

"I believe that pelvic examinations by doctors and/or gynaecologists when seeing a patient with generic symptoms can be a decisive way to detect worrying masses or lesions in that area" (patient interviewed).



This information should be shared through the channels usually used by healthcare professionals and four main types of actions are suggested:

CLINICAL MEETINGS

These are meetings to exchange views on a particular patient, in order to make decisions and update knowledge on a particular topic. They could, therefore, be used to share the symptoms and diagnostic process of ovarian cancer.

"Clinical meetings can be used to talk to your colleagues about ovarian cancer, but you have to be very careful about how you do it. The Regional Health Department offers training courses on different topics. I teach gender-based violence and healthy habits and I think it is important to introduce content related to women, roles, sexuality, reproduction..." (María del Pilar Rodríguez. Primary care physician).

"In primary care, each of the professionals could give short lessons in their consultation sessions" (Esmeralda Romero. Physiotherapist).

INFORMATION MATERIALS

The creation of posters or boards to be put up in consultation rooms would help to remind doctors of the symptoms and may even be informative for the patients themselves.

"I would give them an information board for their consultation room, so they don't forget them. Some doctors do not know the symptoms either. I went to the doctor twice and they didn't tell me anything" (patient interviewed).

"Sharing information with healthcare staff is difficult if you are not part of the system. If we make some resources, they can be presented to health departments and used to encourage dissemination in healthcare centres" (María Pilar Rodríguez. Primary care physician).

REFRESHER COURSES

These courses can be promoted by the centre itself or even by the Regional Health Department and allow professionals to further their knowledge on a specific subject.

"Almost no doctor suspects ovarian cancer when faced with symptoms. We have managed to get the Regional Health Department of Madrid to organise an annual course to remind them of the symptoms and explain the disease" (Charo Hierro. Patient).

PROFESSIONAL BODIES

The involvement of professional bodies and scientific societies is essential, and they can be the ideal means of disseminating information to thousands of professionals.

"One way to reach out is through scientific societies and professional bodies. If you make an agreement with them, they will send the information to their members. It is a quick and easy method of communication" (María Pilar Rodríguez. Primary Care Doctor).

Raising awareness of gynaecological, sexual and reproductive health education

The majority of the women interviewed and the WG pointed out that there is ample room for improvement in the level of sexual, gynaecological and reproductive education of the population. Families and educational institutions are ideal places to promote greater awareness of these subjects, which have traditionally been considered taboo.

"We must give women's bodies a name and surname. We should talk about and carry out campaigns on taking care of ourselves, starting with the most basic things such as knowing our genitalia (what they are for, what they do) and what menstruation is from a young age... Educate women about health to help them identify anything unusual and go to the doctors" (patient interviewed).

In addition, healthcare workers are identified as a key component through which to educate society in these important areas for maintaining their health and quality of life. Primary care teams are the ideal channel, but the WG argues that it is neither appropriate nor feasible for them to carry the entire burden and that it should be extended to all healthcare professionals.

This requires more **training and access to resources** that enable people to receive guidance and counselling in these areas. In addition, the WG stated that there is still a long way to go to eliminate the **sexuality and gynaecology taboos** that cause some professionals to avoid addressing them in consultations.

"It's a thorny issue that we sometimes tiptoe around and don't want to touch in case we get asked about it. There are still huge gaps, but we must be proactive in resolving them" (Mercedes Herrero. Gynaecologist).

Other reasons for this lack of support, according to other research, are limited consultation time, the professionals' belief that issues must be raised by the patient first and the lack of confidence on the part of the patient to mention problems in consultation[14].

Due to time constraints, this area was not discussed in detail in the virtual meetings. As we are conscious that the right approach would require a wider range of measures of different kinds, the following are some ideas that were suggested for improving gynaecological, sexual and reproductive healthcare.

1 » **Promote utilising screening consultations.** Gynaecology could be taught whenever there is an opportunity, especially when women first visit the service for other reasons (e.g., pregnancy). In addition, it is highly beneficial for primary care teams to incorporate some advice and guidance in their consultations to help educate the population in these areas.

2 » **Encourage the creation of peer groups.** Information about intimate areas is usually well received when it is shared by a peer. This is especially true for adolescents and young people. Health centres can encourage this type of community action by providing a space for it and helping to design and develop the groups correctly.

3 » **Explain the importance of gynaecological check-ups.** There is still a lack of knowledge about when to go for a gynaecological check-up, apart from when you first have sex. There is no continuity, so perhaps appointments could be sent in the post, like for breast or colon cancer screening.

4 » **Have information materials.** Having information materials could help to share information about gynaecological, sexual and reproductive health in any setting. In addition to the specialist areas that most commonly provide this information, it is important to approach these areas from the perspective of other disciplines such as nursing and community pharmacy. Having information materials would endorse explanations and help people to understand the information.

5 » **Raise awareness of how to approach the topics of sex and reproduction with women with ovarian cancer.** A multidisciplinary approach requires integrating these areas into the care plan, which could be achieved by increasing the awareness of the professionals involved, having a greater knowledge of existing resources and referring patients to the appropriate service.

3.3. ACTIONS TO RAISE AWARENESS AND CALL FOR CHANGE AT AN INSTITUTIONAL LEVEL

Actions within the framework of Social Action are characterised not only by empowering society but also by addressing situations of inequality or injustice[15]. This implies actively campaigning in political and institutional contexts in order to promote measures that solve these issues. According to the WG, effective advocacy requires the following steps:

Identify the problem and specify the message
What is happening? What do we want to change and why? How can we solve it? What do we want to achieve with our campaign?

Collect data that supports our arguments
What evidence supports the need for change?

Obtain the support of health and social care
What support do we have?

Approach the right people with our demands
Who has the capacity to bring about these changes? How are we going to contact and talk to those who have that capacity?

Continuity and perseverance
What steps will we continue to take in the longer term?

» Identify the problem and specify the message.

It is important that the problem is clearly and concisely defined, and that the exact words and rationale for the claims are given. Schematically, it is important to consider the following when conducting a campaign for action:

» What is the current situation?

Example: % of women with ovarian cancer who are operated on by general surgeons, who do not have the experience and expertise needed for such complicated operations involving multiple organs.

» Why do we want this change?

Example: because of the benefits it would bring in terms of prognosis and quality of life, as well as in terms of the financial cost to the system.

» What do we want to change?

Example: certify centres with gynaecological oncology services and refer women to them who do not have access to this specialist service in their local hospital.

» What do we hope to achieve?

Example: a plan for hospital certification and to include referral to oncology surgeons in clinical practice protocols for ovarian cancer.

Although the answer to each question is complex and nuanced, it is important to be concrete and **simplify the message** when conveying it. Sometimes there is only a short amount of time to present these approaches in meetings with managers or political parties or in media appearances. Providing clear and concise messages, regardless of the speaker, will help to improve understanding and make the speaker's position more coherent.

For example, it would be more effective to ask hospital management to include a nurse case manager in order to promote continuity and multidisciplinary care than to demand the need for a multidisciplinary approach. The message can be approached from the perspective of the definition of the problem or the result of the solution:

Definition of the problem. *Present the current situation that we identify as a problem.*	**Result of the solution.** *Present the improvement in results that would be obtained if the action demanded is taken into account.*
Example: Access to the best possible treatment for women with ovarian cancer is not equal.	**Example:** Access to specialist surgery would improve the prognosis of women with ovarian cancer.
Example: Many young women do not attend gynaecological check-ups.	**Example:** An information campaign on gynaecological check-ups will reduce disease transmission and unwanted pregnancies.

» Collect data that supports our arguments.

The demand for action should be accompanied by evidence. Presenting an issue requires data to endorse the claim. To do this, it is essential to provide information explaining the magnitude of the problem and the impact it has at different levels: health, economic, human, etc. It can be approached from the perspective of the disadvantages of the situation and/or the advantages of taking action.

Looking at the **financial aspect** is important as many of the decisions will be limited by this. In addition, it is advisable to provide a forecast of what would happen if our request was implemented.

"We must work with data on incidence, prevalence, mortality, after-effects and the financial, social and employment impact of the disease and appeal to the health, economic, social and employment benefits of early diagnosis and having specialist and multidisciplinary teams" (Estíbaliz Gamboa. Primary care nurse).

One of the main actions demanded is related to the challenge of **diagnosing the disease at an earlier stage.** Calling for more streamlined and efficient care procedures requires studying and showing the outcomes that would be achieved if a person follows an ideal care pathway compared to those achieved when there are delays in the process.

"We need to analyse the situation, the time between the onset of symptoms and diagnosis of the disease and the repercussions of this on healthcare costs (tests carried out, number of consultations, after-effects, treatment types, etc.). In short, the impact on the health system and every aspect of women's health. We must show the benefits of working towards early diagnosis and improving collaboration between different levels of care

(María del Pilar Rodríguez. Primary care physician).

"It is advisable to compare the results of a patient following the 'ideal' diagnosis and treatment pathway with the risks of complications and poor results of a case with a significant delay in diagnosis and treatment in a non-specialist centre

(María Pilar Barretina. Medical oncologist).

Additionally, calling for **access to specialist surgery and multidisciplinary teams** requires providing evidence of the positive results obtained when the team is more experienced and there are more professionals involved in the different needs of people affected by ovarian cancer. Some hospitals provide information on the results they obtain, and this can be a starting point to begin collecting evidence in this regard. However, the scarcity of this information can be a reason for demanding action in itself.

"Results can be published at different levels, within each hospital or comparing different doctors or hospitals. Managers are expected to organise care in such a way as to achieve the best results. It takes courage to show those results" (Paloma Casado. Head of Humanisation).

Some initiatives that could help collect data to substantiate calls for action include:

Conduct a survey of the general population on knowledge of ovarian cancer symptoms.

Ensure the position of medical societies and surgeons on the need for access to cancer surgery.

Conduct a survey of women with ovarian cancer on the sexual and reproductive repercussions of the disease and assess resources and care services.

Manifesto written by student groups supporting the introduction of a module on communication skills as a compulsory subject in every year of the degree course.

» Healthcare support.

Public actions to demand change should be accompanied by the support of healthcare professionals, which requires prior work to raise awareness among groups that are not so familiar with the problems.

Involving healthcare professionals is based, firstly, on the need for **legitimacy** as it will give arguments greater weight and validity. For example, the demand for access to specialist surgery for ovarian cancer would be more powerful if professional surgeons were to take a stand in favour of it.

"It would be fantastic if these organisations could issue a statement saying: 'Be careful, gynaecologists, do not operate when you have questions about ovarian cancer'" (Charo Hierro. Patient).

"We have to train professionals and understand that often the best thing for our patients is not for us to operate on them. And it is not an act of weakness, but of generosity and care, it is the very foundation of our work. Spread this message: You are a better doctor because you have known how to analyse and look for the best opportunity for your patient" (Mercedes Herrero. Gynaecologist).

This support is more likely to be given when there are already positions or evidence to justify the need for the changes requested. For example, the need to promote channels for referring patients to cancer surgery could be supported by individual practitioners or by relevant organisations.

In this regard, there is evidence backed by organisations such as the European Society for Medical Oncology (ESMO) that supports the need to make this surgery a specialist area: "It is a major and complex operation, but a surgeon in a specialist centre is sufficiently qualified to carry it out"[16-17].

"Ovarian cancer must be treated by a team of experts in this disease and surgery must be performed by a multidisciplinary team led by a gynaecological oncologist" (Charo Hierro. Patient).

Another document that can serve as a starting point is the Clinical Guidelines for Ovarian Cancer Surgery, produced by the European Society of Gynaecological Oncology (ESGO). This guide includes the following recommendations:

- Women with non-urgent clinical symptoms and suspected adnexal/peritoneal tumours should be referred to a specialist in gynaecological oncology.
- Surgery is discouraged in low-volume, low-quality centres. It is necessary to have an intermediate care unit and access to an intensive care unit.
- All patients should be reviewed after the operation by a multidisciplinary gynaecological oncology team.

The WG states that these recommendations should even be extended to allow the diagnosis to be assessed by a multidisciplinary gynaecological oncology team from the start, and to jointly plan the best strategy for combining surgical and systemic treatment (chemotherapy and biopharmaceuticals) personalised to each case. Sometimes, surgery is ruled out from the outset because of the patient's general condition or because of how much the disease has progressed, although it may be reconsidered after 3-4 cycles of neoadjuvant chemotherapy depending on the response obtained.

Centres of excellence in ovarian cancer[18] can help with this demand for action, either by sharing their results or by providing incentives to other centres.

"Look for centres of excellence so that they can share their experience and support other centres" (Paloma Casado. Head of Humanisation).

Additionally, partnerships and the support of healthcare professionals will multiply the **reach and dissemination** of the messages. The media, for example, tend to pay more attention if a campaign is supported by multiple groups of healthcare professionals.

"It is increasingly clear to me that we need greater commitment from medical institutions (ministry of health, regional health departments, hospitals...). We could make every effort in the world, but they have to believe in it" (José Antonio Negrín. Family member of a person with ovarian cancer).

"Campaigns must go hand in hand with patient associations and count on the support and dissemination of different scientific and professional societies" (Fátima Castaño. Psycho-oncologist).

Finally, it is important that they are involved as **their work may be affected by the changes or demands** made. It is advisable to work with these groups in advance to find out how care pathways and processes may be affected, their opinion on the changes requested and, subsequently, carry out awareness-raising and information activities in order to gain their support.

"It is of little use for patients to demand action if the professionals themselves do not see the need for changes to be made and incorporated into protocols. It is better for a need to be recognised than imposed by health departments. Campaigns should include all parties concerned: patients, relatives, healthcare professionals, managers... as one voice" (Lucía Peralta. Patient and Primary care physician).

"It would be a good idea to raise awareness among medical professionals of the need to refer patients to specialists. That is not always done..." (Fátima Castaño. Psycho-oncologist).

» Social support.

A key aspect of a successful campaign to demand action is to have the support of different social groups. This is one way to attract the interest of politicians and managers and, in addition, to raise awareness among other groups of the population.

To do this, the cause must be of interest not only to those affected or most involved in the disease, but also to other population groups. All community action must start by raising awareness prior to mobilisation[19]. This requires an **activity to raise awareness** in which people are personally informed of why what we are trying to change is of general interest or, at least, of interest to the sector of society we are addressing.

One example is the action of the **anti-smoking groups**, who have united and incorporated new movements to their cause. Besides the health element of smoking, they have known how to connect and encourage other areas to join forces, such as environmental movements (through data on the environmental impact of cigarette butts) or human rights (through impact analyses on vulnerable groups in developing countries).

Source: World Health Organization

In the case of ovarian cancer, an added difficulty is its low incidence compared to other diseases. It is therefore essential to build **partnerships with social movements and organisations that share the same challenges** as the cause. Women's groups, patient groups and groups for the elderly are potential partners in some ovarian cancer campaigns because they have overlapping objectives.

For example, people with pancreatic cancer have the same difficulty in identifying symptoms. And access to specialist surgery is equally important for people with gastric cancer. There is a possibility of forming partnerships to request care plans that take into account the issues shared by multiple patient groups.

"All social actors involved in this problem must join forces. The larger and more diverse these pressure groups are, the stronger they will be" (Estíbaliz Gamboa. Primary care nurse).

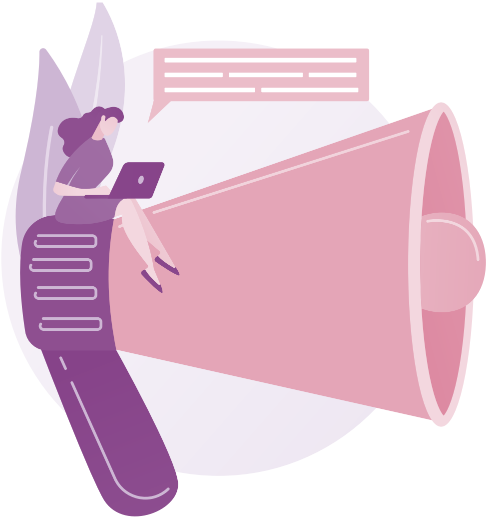
There are also other ways of seeking partnerships beyond having the same objectives. One of the most common is to **appeal to the injustice** experienced by a group of people, in this case, women with ovarian cancer. Thus, it was proposed to focus the messages on inequality or the lack of response from institutions.

"At an institutional level, what moves people the most is injustice and anger at things that are badly done. It gives them that sense of teaming up to achieve a common goal" (Esmeralda Romero. Physiotherapist).

"The hook can be the ministry's refusal, which can then be used to give a lot of leverage to what is happening with the treatment of women with ovarian cancer. And by doing so highlight the inequality" (*Mercedes Ruiz. Pharmacist*).

Practical examples of campaigns with a high social impact in Spain that have appealed to a situation of injustice and attracted many different kinds of support are the demand of people with hepatitis C for access to treatment, the case of "La manada" in relation to the need for changes to legislation to fight rape and sexual assault, or the case of Aylan Kurdi. The photograph of his body next to the sea highlighted the plight of migrants trying to flee war and the limited international protection they receive.

"The demand for access to hepatitis C treatments led to a great social debate in the media which generated the interest of politicians. Moreover, scientific evidence showed that, despite the cost of the treatments, the long-term savings were much greater"
(*Estíbaliz Gamboa. Primary care nurse*).



Raising social awareness of issues that call for justice is therefore essential. However, only 11% of the participants in the initiative identified raising social awareness of inequality in access to specialist surgery as a priority*.

Social support also requires a strong **communication strategy** to get the message to different population groups and institutions and to connect with their interests. Two types of communication actions should be distinguished. The first is aimed at the media and general public and the second at institutions, focusing on relations with organisations of interest.

"It should generate interest in the general population, not only in women who use the service or are affected, and be media-friendly" (*María Sasía. Medical student*).

"One part is public communication, with the media and society in general, and the other is private, on a one-to-one basis with institutions. The second is easier if it is already being discussed in the media"
(*Óscar Allende. Journalist*).

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* Result obtained in the second online survey (WG participants and ASACO representatives).

Therefore, this campaign must have a **roadmap** that covers contact with public bodies and movements and includes objectives at different times, different forms of collaboration/ participation and actions to be carried out throughout the campaign. The process proposed to seek community support is:

- Contact them to explain the cause specifically (inform).
- Explain why it is a cause that affects them (raise awareness).
- Provide details on how they can join and collaborate (call to action).

» Approach the right people with our demands.

All campaign activities must start with two key elements. Firstly, to know what the competent bodies are and, secondly, what proposal for improvement you want to put forward.

"I think the most important thing is to identify what actions each institution can take" (Charo Hierro. Patient).

"If my objective is to get funding for research, I need to know which institution to approach. Plus, we not only need to demonstrate the problem but also the proposal for improvement that the institution we are addressing can make" (Carles Tomàs. Teacher)

The WG proposes acting at different levels, depending on the demand and the objective:

- **Hospitals / Healthcare departments.** It is important to go to management to request the results obtained and, if this is not possible, ask for them to be published for transparency reasons. This data will help to gather evidence and justify areas for improvement in the care that women with ovarian cancer receive.

  In addition, reaching out to decision-makers in hospitals will help to bring about improvements in resources, services and care pathways. For example, this can be the way to call for psychology or social work professionals and to include case managers, who are the people to contact in order to guarantee coordinated and multidisciplinary care. They are the professionals who guide patients and organise all the care they receive, and their inclusion depends on the resources and will of each hospital. It is therefore advisable to provide data and arguments that make managers aware of the benefits of including them in their portfolio of services.

» **Health Departments.** The main demands for action in ovarian cancer (access to specialist surgery and a multidisciplinary approach) require changes in the care process, which is within the competencies of each autonomous region in Spain. Thus, the main efforts must be made at the level of regional health departments.

One proposal made by the WG is to act at a regional level so that, as is done with breast and colon cancer screening, **letters are sent to young people that inform them of the importance of attending gynaecological check-ups.**

"It would be wise to remind people of the need for regular check-ups, like for colon cancer" (Rafel Vidaurreta. Social worker).

» **Inter-regional Council:** Another way to demand action is through the Inter-regional Council of the National Health System. It is the cooperation and communication body between Spanish regional health services and between these and the state authorities. Its purpose is to unify the system and guarantee citizens' rights throughout Spain.

"In the case of childhood cancer, an agreement has been reached by the Inter-regional Council so that the autonomous regions align their healthcare model for childhood cancers and can share cases in a multidisciplinary team, despite being in different centres and the children receiving treatment in a centre closer to where they live. Or by pinpointing cases in which the surgeon's experience is key to survival" (Paloma Casado. Head of Humanisation).

» **Ministry of Health.** Competences are devolved to the autonomous regions, but it is important to make demands to state bodies so as to facilitate access to regional health services. Calls for action based on principles of equality and justice for women using the healthcare system should be conveyed in particular.

"Institutions need to be made aware. It would be beneficial for the Ministry of Health to issue a statement on the matter, although the autonomous regions make their own decisions" (Rosa María Plata. Midwife).

"You can't depend on luck or which hospital you go to. Access to specialist surgery should be implemented across the board because you are risking your life"
(Gemma Durán. Patient).

"Whether you are operated on by the right team depends on where you live. I never considered who was going to do the operation. When you are diagnosed, you enter a world of fear, shock and stress, and they say: "you need to have an operation". There are many patients who live in small towns and do not have access to a specialist team"
(Marian Escolar. Patient).

» Continuity and perseverance.

Consistency is valued as a fundamental aspect of institutional advocacy. Political and managerial processes are slow, and change tends to be achieved over the long term, so it is essential to define a strategy that enables consistency in the campaign and to continue building partnerships. The campaign must not stop until the objectives are met. If the person we are addressing sees that we are giving up, they will know that they just have to wait until we get tired, which is detrimental both to our future initiatives and those organised by others[9].

"The key is perseverance. If we want something, we have to persevere"
(Mercedes Ruiz. Pharmacist).

"Years ago, breast cancer was unknown to us and now, thanks to the perseverance and efforts of patient associations, the whole of society is aware of and knows about it"
(María Sasía. Medical student).

4

GOOD PRACTICE:

how do we do it?

SOCIAL AWARENESS

How do we capture society's attention?

Connecting with emotions through identification and empathy.

"You become very conscious of it when you experience it first-hand. The message must convey that it can happen to you or your loved ones".

Speak clearly, without fear or taboos.

"It must be direct and break taboos. Calling things by their name".

Use a concise and striking slogan and message.

"It is recommended to only share a very small amount of information. Once people have grasped the concept, then it can be expanded".

Use an easily identifiable logo.

"It has to be something very specific, but it also has to mean something".

Involve influential people.

"The collaboration of famous people and the latest influencers would be ideal".

Encourage the participation of the target audience.

"For them to end up sharing information themselves and continue raising awareness".

Build partnerships with public bodies and movements.

"There is strength in numbers. We cannot compartmentalise things in gynaecological health".

Multi-channel strategy.

"It should be on social media as well as on infographics in health centres, etc.".

EDUCATION

How do we teach it effectively?

Provide concise and manageable information.

"Is better to mention only the most common symptoms; listing too many symptoms would be counterproductive".

Use visual aids.

"People internalise information much better when it is conveyed visually".

Avoid alarming people

"We have to stick to surface information and not go any deeper so as to avoid causing alarm".

Have evidence to legitimise the information.

"It requires different scientific and professional societies to show their support and share information".

Use a range of communication channels.

"It has to be multi-channel and encompass a large part of the population".

Take advantage of awareness days.

"Global awareness days are useful. Even in university we are given ribbons and reminders in classrooms".

HEALTHCARE PROFESSIONALS Training in communication skills

Demand action at an academic/university level.

"Training is starting to take place, but it is not included in the university curriculum".

Integrate it in continuous professional development.

"If you are not personally interested, it is something you will keep leaving for the end".

Invitations to patient contact activities.

"This closer relationship is very good for them. They understand more that communication goes both ways".

Support materials in the workspace.

"Professionals take a lot for granted. They do a lot of things are done in a very automatic way".

Collect evidence on the importance of communication.

"Use real cases to show what has happened to a patient who, despite several consultations, has not been able to follow the right path".

Provide spaces where people can exchange experiences.

"Training to raise awareness among peers and to discuss the consequences and how to mitigate them".

Carry out awareness-raising campaigns.

"Awareness campaigns by recognised professionals on the need to improve communication skills".

Organise courses for professionals on how to manage

"How to become more comfortable in your relationship with patients to reduce your stress levels".

HEALTHCARE PROFESSIONALS Knowing the symptoms of ovarian cancer

Clinical meetings.

"Clinical meetings can be used to talk to your colleagues about ovarian cancer".

Refresher courses.

"We have managed to get the Regional Health Department of Madrid to organise an annual course to remind them of the symptoms".

Information materials for consultation rooms.

"I would give them an information board for their consultation room so they don't forget them".

Support from professional bodies.

"One way to reach out is through scientific societies and professional bodies".

HEALTHCARE PROFESSIONALS

Gynaecological, sexual and reproductive health education

Promote utilising screening consultations.

"We could teach women who have never been to gynaecology before and have come for another reason, such as pregnancy".

Encourage the creation of peer groups.

"The message must be shared among peers. One step above (parent, teacher) and we don't pay as much attention".

Explain the importance of gynaecological check-ups.

"It is not clear when to go for gynaecological check-ups. We talk about going when you first have sex, but after that there is no continuity".

Have information materials.

"A pocket-sized card for monitoring gynaecological cancers with a description of the most common symptoms and how long they last".

Raise awareness of the approach to sex and reproduction of women with ovarian cancer.

"Let's talk about all the issues that affect ovarian cancer, not only those related to cancer - which should be talked about and normalised - but also maternity, menopause and sexuality... these are the three important points".

DEMAND ACTION

How do we capture society’s attention?

Identify the problem and specify the message.

“We need to analyse the situation”.

Collect data to support arguments.

“Work with data and advertise the health, economic, social and employment benefits”.

Healthcare support.

“It is of little use for patients to demand action if the professionals themselves do not see the need for changes”.

Social support.

“All social actors involved in this problem must join forces”.

Approach the right people with our demands.

“The actions that each institution can take must be clearly identified”.

Consistency and perseverance.

“The key is perseverance. If we want something, we have to persevere”

Health is not everything, but without health, everything is nothing.

A. SCHOPENHAUER

5 ACKNOWLEDGMENTS

From the inception of this report, we came to realize that there were many actions to be undertaken by the society at large. All of these required an exercise of mutual understanding, and each contributor to this initiative has left his and her own personal contribution to that end. Their knowledge and personal experience have been critical in surmounting the challenges detailed in this report.

In the first place, we would like to thank the ten patients of ovarian cancer sharing their personal experiences and feelings in this report. Through your testimony we have been able to better understand the challenges this disease poses. Thank you for your generosity and your invaluable contribution to this project.

This report includes ideas, reflections and proposals compiled thanks to the participation of the nineteen members of the Working Group. These include people with different backgrounds and experiences, all bound by the same goal: to promote societal knowledge and understanding of ovarian cancer. We would like to thank Óscar Allende, Hugo Azcona, Mª Pilar Barretina, Sofía Bauer, Paloma Casado, Fátima Castaño, Marian Escolar, Estíbaliz Gamboa, Mercedes Herrero, José Antonio Negrín, Lucía Peralta, Rosa María Plata, Patricia Rodríguez, Mª Pilar Rodríguez, Esmeralda Romero, Mercedes Ruiz, María Sasía, Carles Tomàs and Rafael Vidaurreta.

This initiative is also indebted to the collective work of many organizations committed to the support of people with ovarian cancer. We would like to than the Spanish Midwife Association (AEM), the Spanish Association for Social Work in Healthcare (AETSyS), the Spanish Confederation of Organizations for the Elderly (CEOMA), the National Council of Medical Students (CEEM), the Spanish Ovarian Cancer Research Group (GEICO), the Spanish Society of Oncological Nursing (SEEO), and the Spanish Society of Primary Care Physicians (SEMERGEN).

We also want to thank CLOVIS Oncology, for their generous support in developing this project. Their contribution has been essential to make this initiative a reality.

Finally, we would like to thank you, the reader, for your interest in this report. We hope it has provided you with a new perspective on ovarian cancer. We can only hope this experience has served for increasing your commitment in this critical societal challenge. We'd love to have you at our side.

Remember: ***you have a key role against ovarian cancer.***

ASACO
Asociación de Afectados por Cáncer de Ovario y Ginecológico

Fundación
más que ideas
Juntos sumamos en salud

6

ANNEX I

PHASE I REPORT. SUMMARY OF RESULTS

SOCIETY — Widespread lack of knowledge about ovarian cancer

False sense of security

There is a misperception that gynaecological check-ups can detect any gynaecological disease.

Difficult to recognise symptoms

The symptoms are normalised or associated with other causes. It is common to live for months with multiple symptoms.

Contributes to stigma

Ovarian cancer is poorly understood and is directly associated with death. The "silent killer" label is a burden for diagnosed women.

GATEWAY TO THE HEALTH SYSTEM

Delay in clinical recognition

Multiple visits prior to recognition due to unfamiliarity and the non-specific nature of the symptoms.

Referral to a specialist service

HOSPITAL

DIAGNOSIS

WELLBEING

Satisfaction with the smoothness of the diagnostic process once referred to hospital

SUPPORT

Positive feedback from patient associations

The main values of patient associations are peer-to-peer contact and support, access to information and access to psychological support.

Positive evaluation of the support of those around them

The people around them have become a support bubble. However, they acknowledge disappointments in relation to their expectations of support from loved ones.

Positive opinion of the healthcare team after

They value the treatment received and the professionalism of the healthcare team, although they identify a lack of care in responding to several patient needs (management of consequences and side effects and psychological and social care).

PRIORITIES. WHAT TO WORK ON AT A SOCIAL LEVEL?

- Raise awareness that it can affect any woman.
- Inform people of the symptoms of the disease.
- Educate society about women's bodies.
- Normalise cancer in society to reduce stigma.
- Raise awareness that ovarian cancer does not mean death.
- Make the consequences of the disease visible.

Main difficulties

Recovery from surgery

Radical hysterectomy and adnexectomy is complex and one of the most difficult moments.

Fatigue

Day-to-day, the worst thing is the asthenia and not being able to do what they used to do physically.

Changes to the body

Life changes after their ovary, uterus, lymph nodes, etc. are removed.

Psychological impact

Uneasiness due to fear of death and repercussions on loved ones.

7

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The social challenge of ovarian cancer

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