



**23<sup>rd</sup> European Congress  
on Gynaecological Oncology**  
Oct 27-30, 2022 | Berlin, Germany

# **ENYGO-ENGAGe survey sexual health after gynaecological cancer Preliminary results + Workshop**



Launched in October 2021



Survey on  
Sexual Health after  
Gynaecological Cancer

Let's talk about it!

Flags of the United Kingdom, France, Poland, Hungary, Germany, Czech Republic, Italy, and Spain.



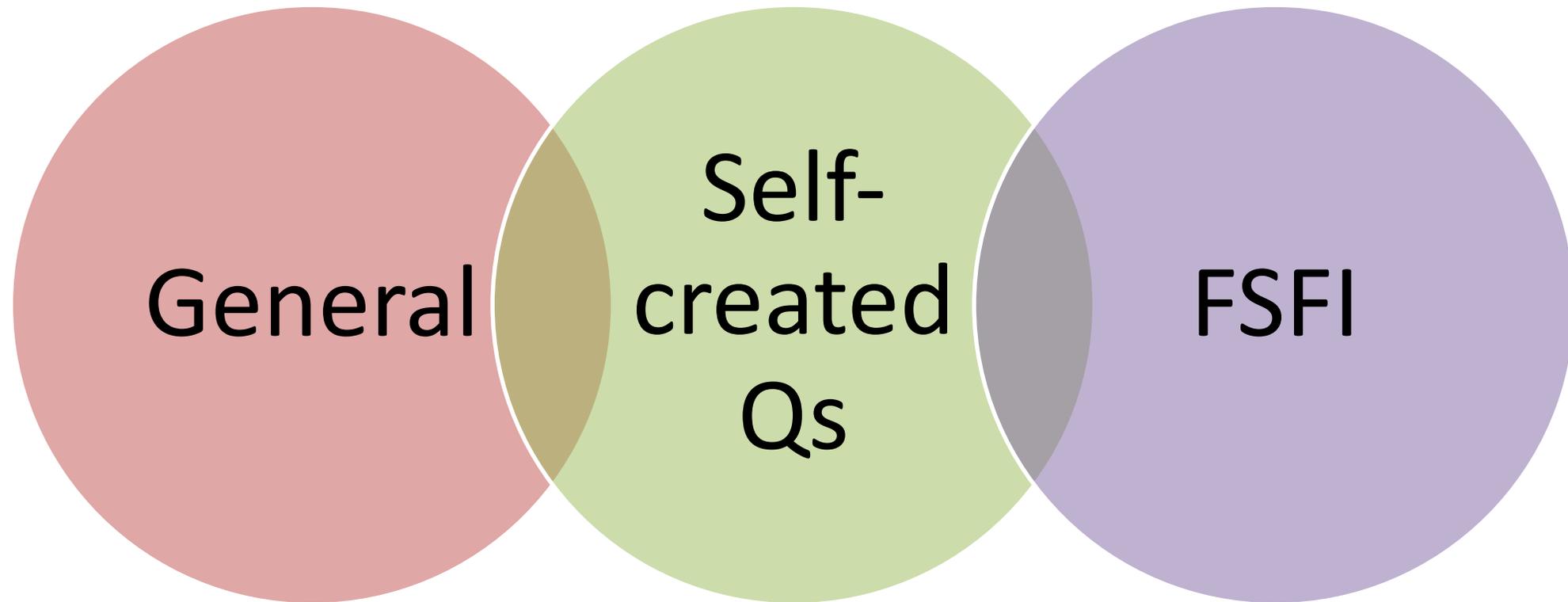
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# Facts to know about ENYGO-ENGAGE Questionnaire

- ✓ Patient-driven questions
- ✓ Developed with the help of the psycho-oncologist and clinical psychologist
- ✓ Translations into the **10 languages**

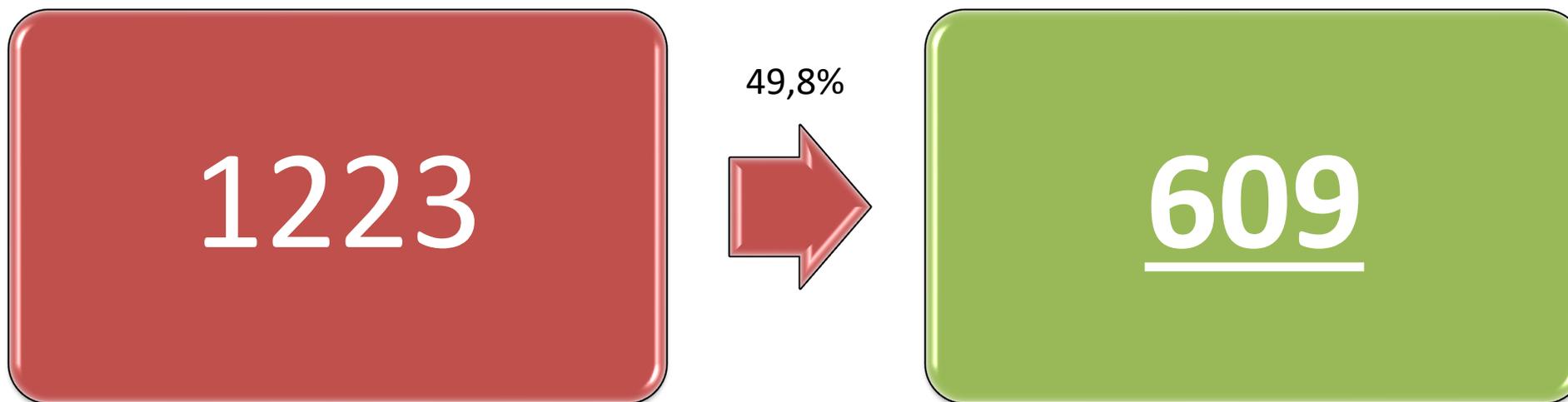


# Structure of questionnaire – 3 parts

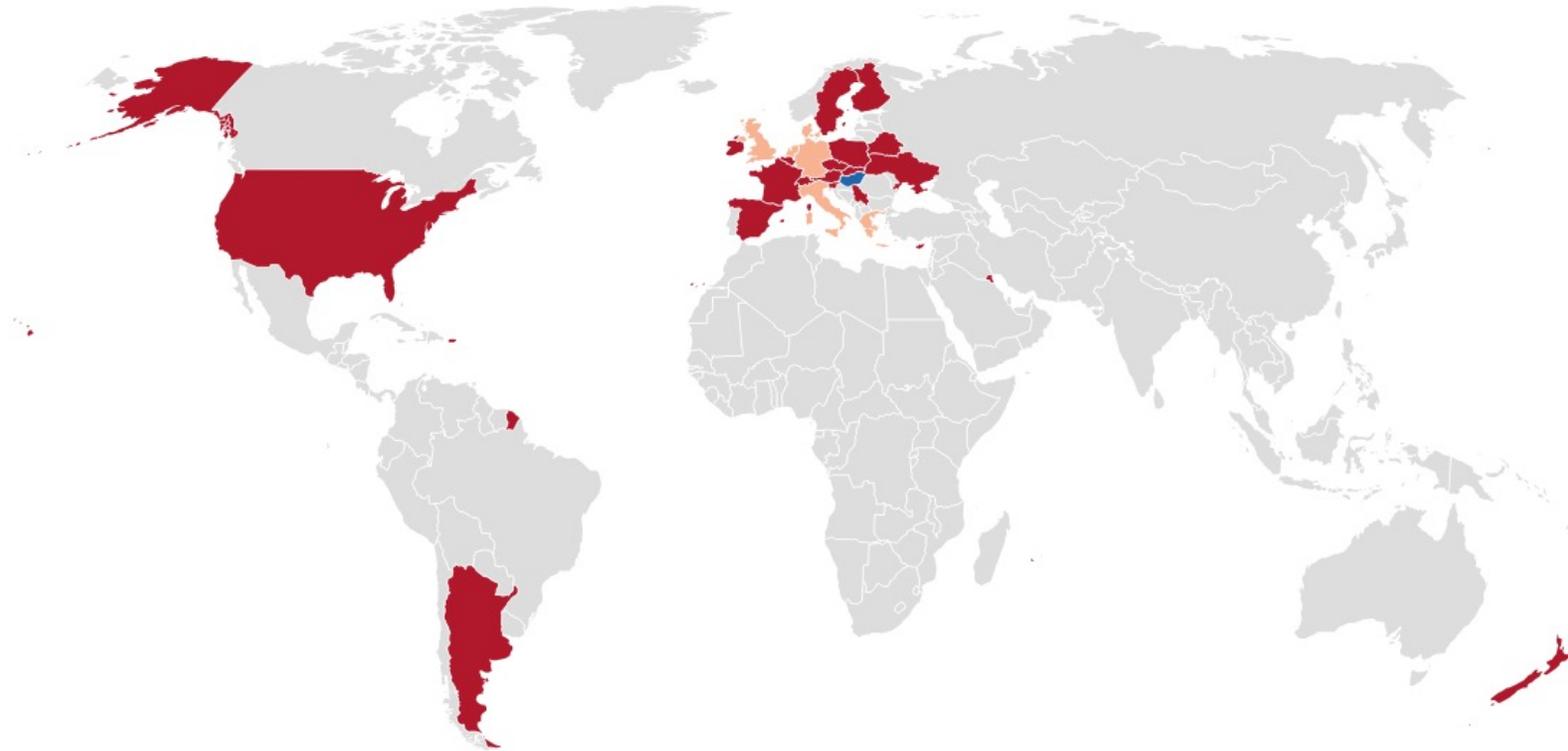
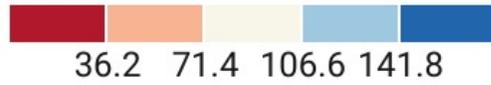


# Results

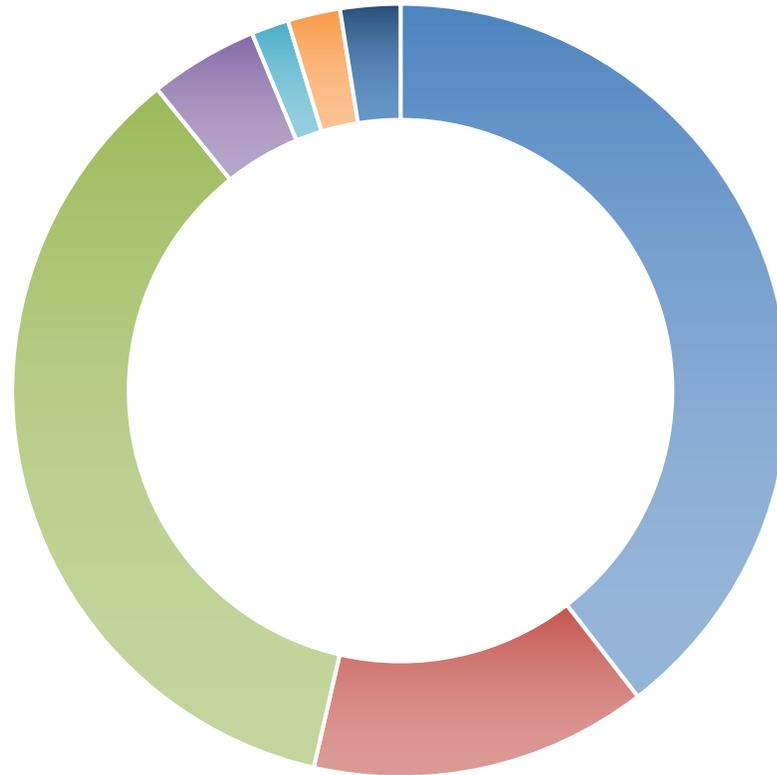
## Collected data - number of answers



# Countries

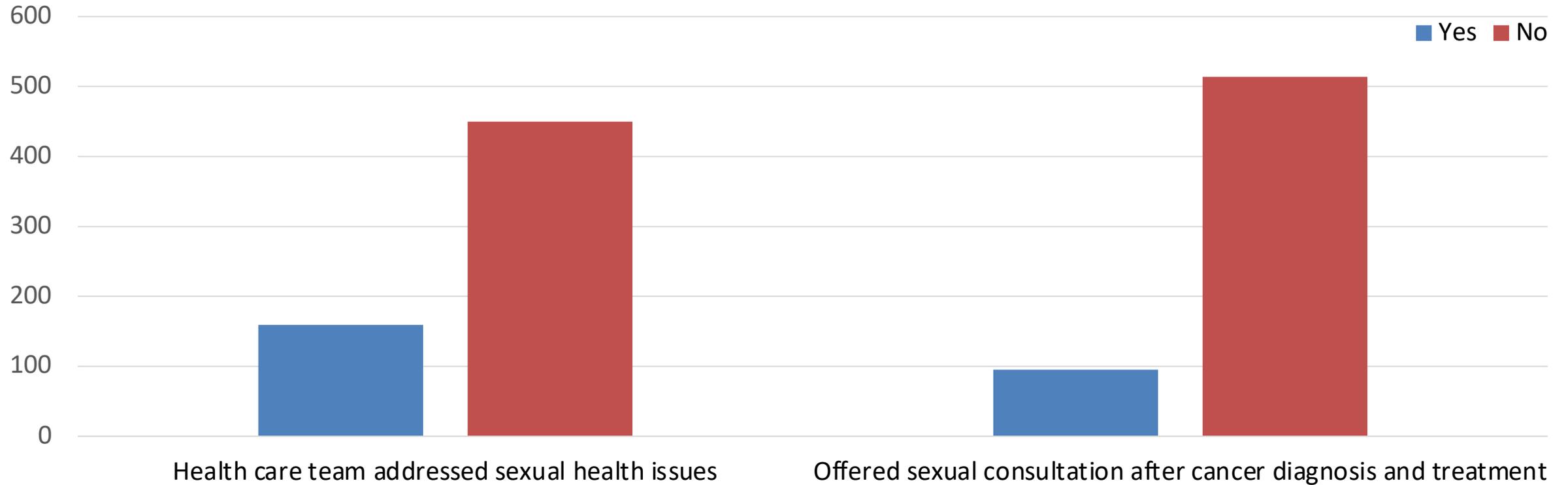


# Cancer type



- Ovarian Cancer
- Uterine cancer
- Cervical Cancer
- Vulvar Cancer
- Vaginal Cancer
- Rare Gynaecological Cancer
- Other (please specify)

# Sexual Health Counseling



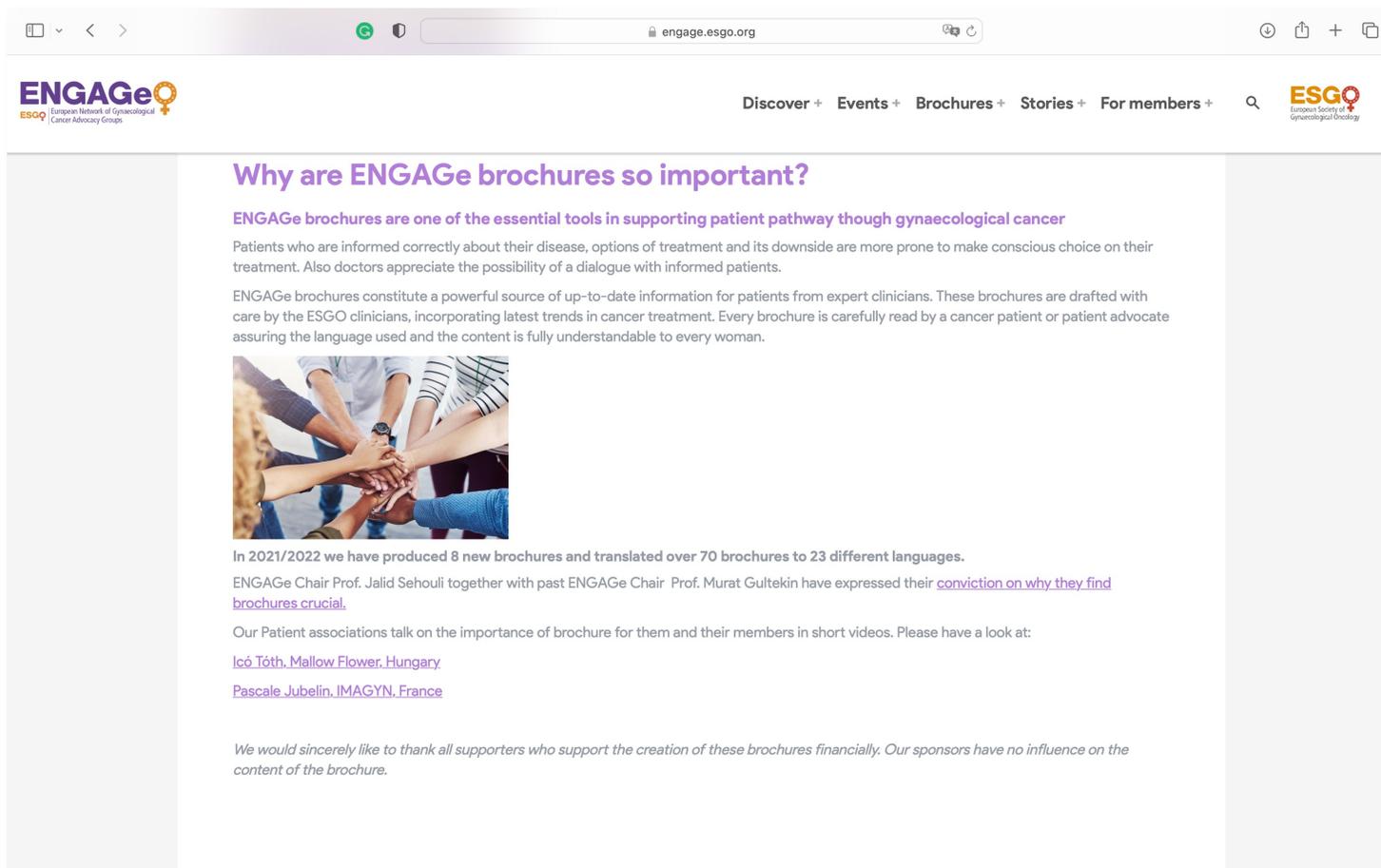
**60% of the patients accepted sexual  
counseling**

# How do you like to get information?

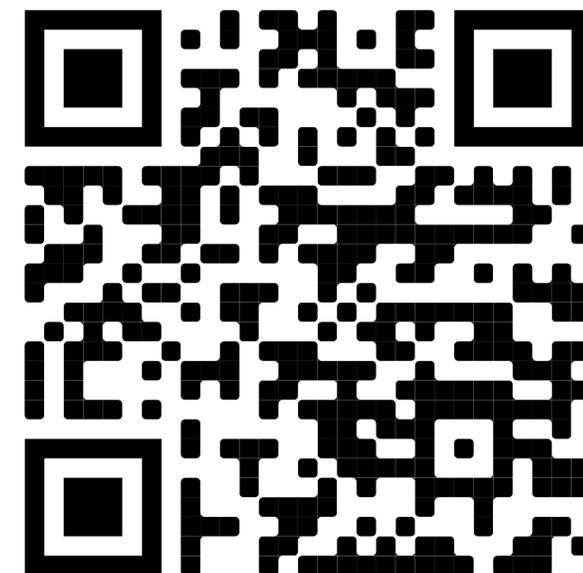
Source	Number (%)*
Medical doctors	321 (52,7)
Nurses	165 (27,1)
Other patients or a patient group	231 (37,9)
Sexual health specialist at the hospital	371 (60,9)
Sexual health specialist outside of the hospital	238 (39,1)
<u>Brochure</u>	<u>230 (37,8)</u>
Internet	180 (29,6)
I don't like wish to get information about sexual heath	20 (3,3)
Other (please specify)	19 (3,1)

\*Multiple answers were selected

# ENGAGe brochures



The screenshot shows a web browser window with the URL [engage.esgo.org](http://engage.esgo.org). The page features the ENGAGe logo (European Network of Gynaecological Cancer Advisory Groups) and the ESGO logo (European Society of Gynaecological Oncology). The main heading is "Why are ENGAGe brochures so important?". Below this, a sub-heading states: "ENGAGe brochures are one of the essential tools in supporting patient pathway though gynaecological cancer". The text explains that informed patients are more likely to make conscious choices and that brochures provide up-to-date information from expert clinicians. A photograph shows a group of people with their hands stacked in a circle, symbolizing support and teamwork. The text continues: "In 2021/2022 we have produced 8 new brochures and translated over 70 brochures to 23 different languages." It mentions that ENGAGe Chair Prof. Jalid Sehouli and past chair Prof. Murat Gultekin expressed their conviction on why brochures are crucial. It also lists two patient associations: "Ic6 T6th, Mallow Flower, Hungary" and "Pascale Jubelin, IMAGYN, France". A final note states: "We would sincerely like to thank all supporters who support the creation of these brochures financially. Our sponsors have no influence on the content of the brochure."

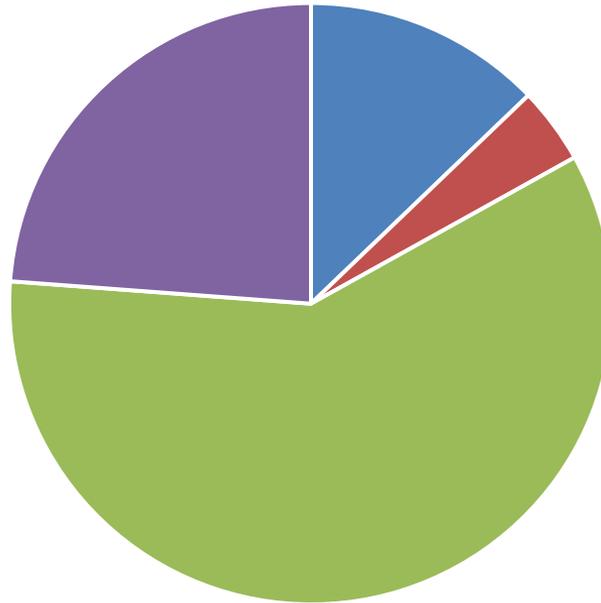


# With whom can you talk about your sexuality?

Source	Number (%)*
My partner	367 (60,3)
<u>My doctor</u>	<u>148 (24,3)</u>
My family member(s)	55 (9,0)
Other patients	168 (27,6)
Sexual health specialist at the hospital	92 (15,1)
Sexual health specialist outside of the hospital	66 (10,8)
Other (please specify)	31 (5,1)

\*Multiple answers were selected

# Has your sexual life changed after your cancer diagnosis or treatment?



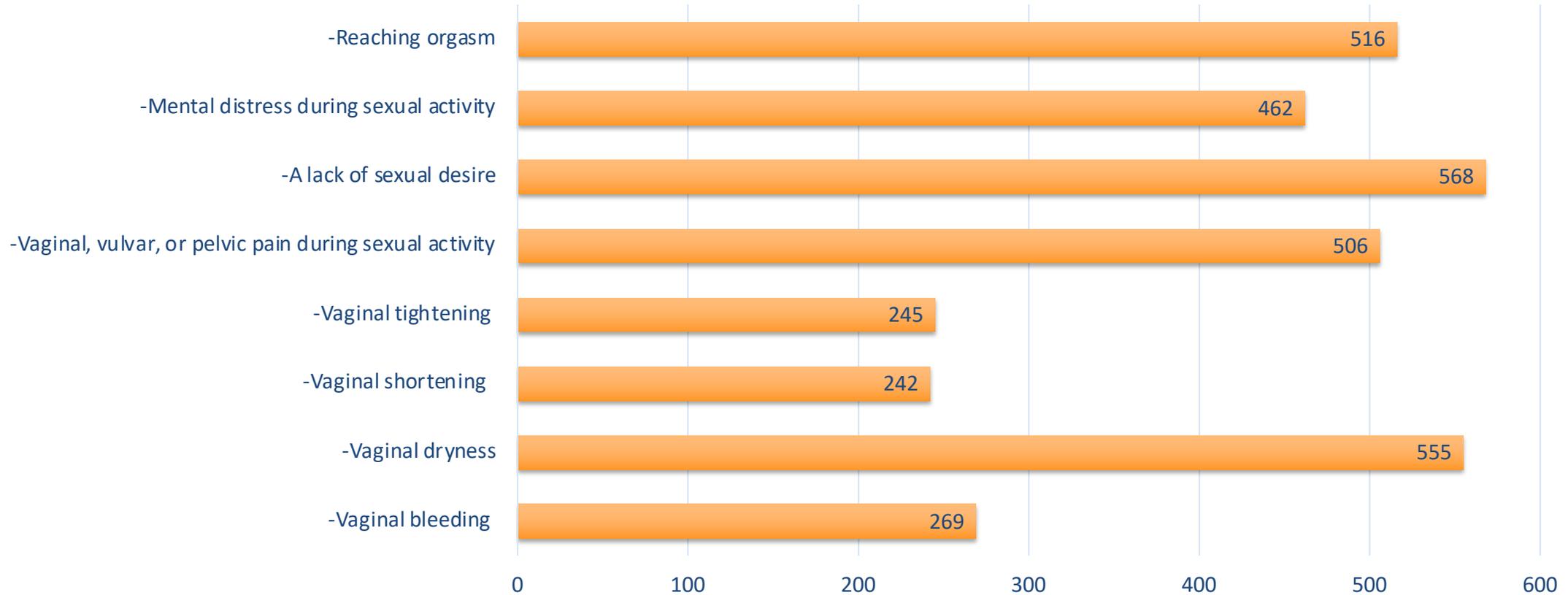
■ No, it did not change

■ Yes, it became worse

■ Yes, it became better

■ I am not sexually active any longer

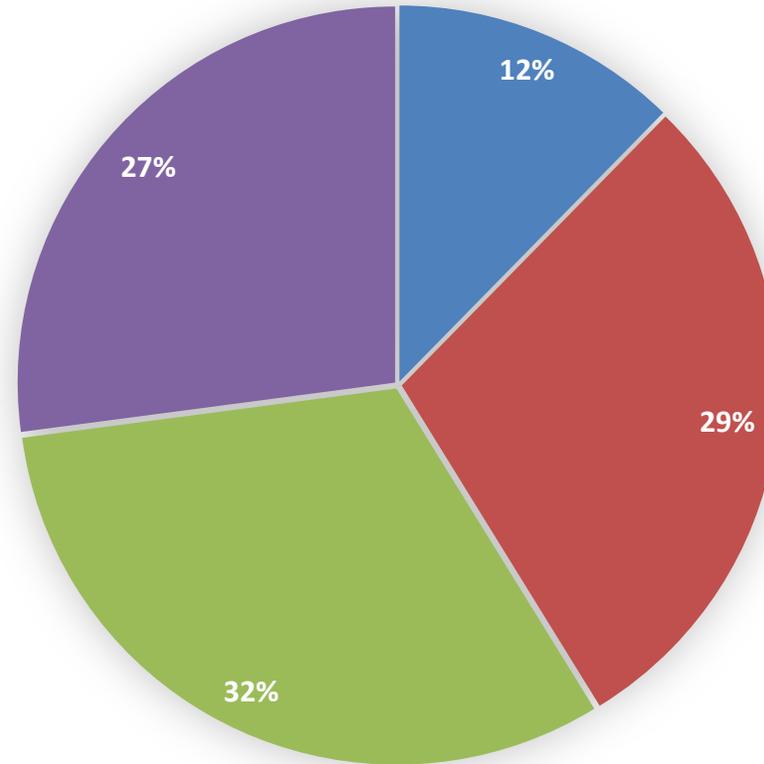
# Symptoms



# Change of the Type of Sexual Activity

Type of sexual activity	Before cancer diagnosis or treatment (%)	After cancer diagnosis or treatment (%)
<b>Vaginal intercourse</b>	562 (92,3)	291 (47,8)
<b>Sexual activities involving hands/fingers</b>	434 (71,3)	256 (42,0)
<b>Oral sex</b>	390 (64,0)	208 (34,2)
<b>Sexual activities involving sex toys</b>	171 (28,1)	86 (14,1)
<b>Anal sex</b>	67 (11,0)	21 (3,4)
<b>I was/am not sexually active</b>	18 (3,0)	155 (25,5)
<b>Other</b>	9 (1,5)	21 (3,4)

# How satisfied are you with your sexual health overall?



■ Very satisfied   ■ Somehow satisfied   ■ Somehow dissatisfied   ■ Dissatisfied

# Common sexual health problems and examples

## PHYSICAL

vaginal dryness,  
bleeding, vaginal  
shortening or tightening  
pain during intercourse

## PSYCHOLOGICAL

decreased sexual interest,  
distress during sex,  
body image problems,  
loss of femininity

## INTERPERSONAL

changes in sexual scripts,  
lack of physical closeness  
and intimacy,  
impact on relationship

Reese et al. 2017,  
Sadovsky et al. 2010,  
Panjari et al. 2011,2012

# It's not only about sex....

Many post-treatment health problems improve over time

Sexual dysfunctions tend to persist → risk for life-long sexual distress

Many cancer survivors report

- Impact on body-image, self-image, self confidence
- Impact on individual well-being and quality of life
- Impact on emotional closeness and intimacy
- Impact on relationship dynamics
- Impact on family structures

Ganz et al. J Natl Cancer Inst. 2002

Ganz et al. Breast Cancer Res Treat. 1996

Levin et al. Int J Gynecol Cancer. 2010

Reese et al. Support Care Cancer. 2010



# Sexual health discussion after diagnosis and treatment of cancer

## Prostate Cancer



Impact of treatment on...  
erectile dysfunction  
and urinary problems

Top topics routinely discussed  
Main outcome in majority of  
prostate scientific studies

## Gyn Cancer



Impact of treatment on...  
the vagina as one potential side  
effect beside many others

Sexual health rarely discussed  
Lack of scientific studies

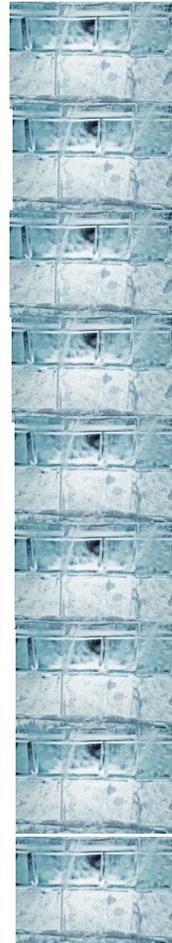
Discussing potential treatment effects on sexual function is twice as common in male patients (64 %) compared to female patients (28 %)  
→ Gender disparity! Systematic review, 11 studies: Reese et al. J Cancer Surviv. 2017

# Overall reluctance patients & clinicians

to talk about cancer- and treatment-related sexual difficulties

## Patients

- concerned about making the doctor feel uncomfortable
- feel embarrassed
- believe that it is the clinician's responsibility to raise the issue
- believe that their sexual health concerns are not valid
- believe they are an expected and untreatable complication



## Clinicians

- concerns about making patients feel uncomfortable
- feel insufficiently skilled
- lack of time and privacy
- not aware of effective interventions
- feel inadequately trained

Carter et al. JCO 2018



# The dilemma

Although oncology clinicians generally acknowledge the importance of addressing sexual health for female cancer survivors

Reese et al. Support Care Cancer. 2017, Traa et al. Support Care Cancer. 2014

and patients clearly state that they want their physicians to ask about these concerns

Sporn et al. Psychooncology. 2015, 48. Scanlon et al. J Cancer. 2012



Communication about sexual health is not part of routine care for most individuals diagnosed with cancer

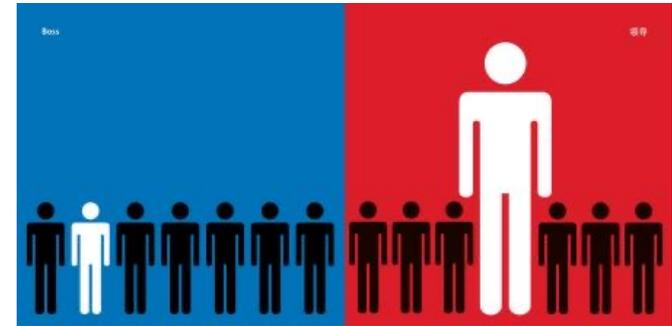
Reese et al. J Cancer Surviv. 2017, Flynn et al. Psychooncology. 2012



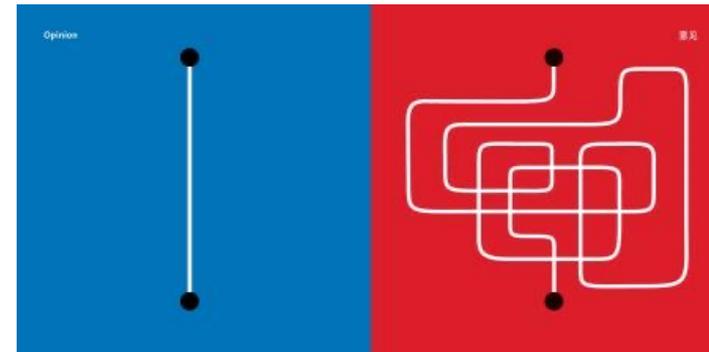
# Socio-cultural differences all around Europe

- Open-mindedness
- Pushing boundaries
- Taboos in addressing the topic

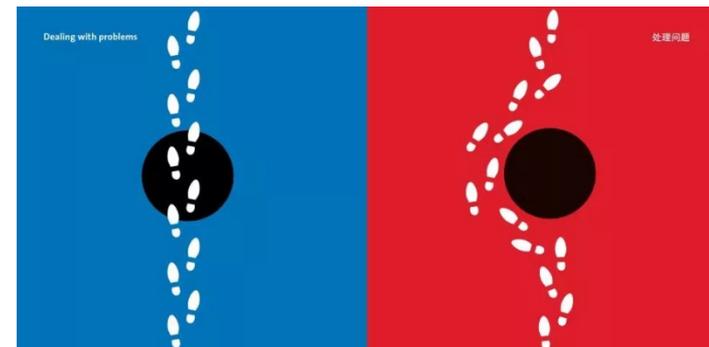
## Doctor status



## Expressing opinions



## Addressing problems



# What's the problem?

Female sexuality is multi-faceted  
→ no “magic bullet” treatment

Lack of universal pharmacologic solution  
→ no “blue pills”



male libido



female libido



Sexual health problems need expertise,  
time, and effort



**There are more important  
things in life....  
(I am grateful to be alive)**

**I deserve to find my way back  
to a happy and healthy intimate life!**



# Solutions

Patients need knowledge, resources and information for self-help

Plenty of effective aids available

- lubricants,
- dilators, vibrators,
- penis rings
- pelvic floor training
- and much more

Doctors need awareness and training for sexual health problems

Plenty of workshops available

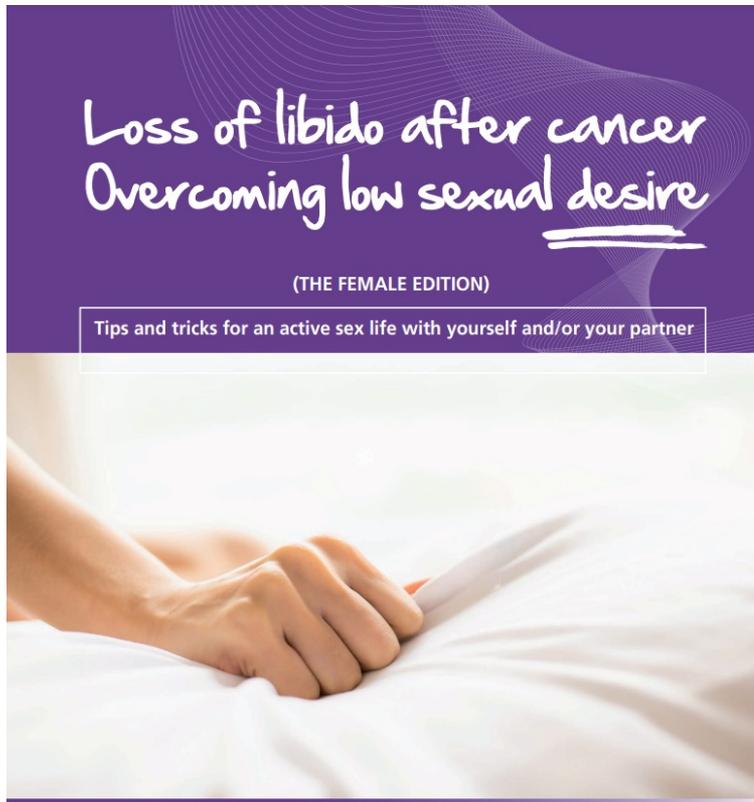
- To address the topic
- To offer low-level advice
- To refer to sexual health specialists if necessary

## Let's break the ice together!



# Overcoming low sexual desire

## A free self-help booklet for patients



**ESGO**   
European Society of  
Gynaecological Oncology

**ENGAGE**   
ESGO | European Network of Gynaecological  
Cancer Advocacy Groups

**ENYGO**   
ESGO | European Network of  
Young Gynae Oncologists



**ENGAGE**   
ESGO | European Network of Gynaecological  
Cancer Advocacy Groups

*Has your sex drive decreased  
or even disappeared since your cancer  
diagnosis and treatment?*



Kirchheiner 2022

<https://engage.esgo.org/resources/loss-libido-cancer/>  
9 translations available

# Workshop

## Time to work together!

- Brainstorming session
- Collecting ideas
- Sharing experiences

in a safe space

→ ensure confidentiality!



Joint reporting back to all of us

# #1 ... your perspective and wishes

- How do you want your doctor approach sexual health issues?
- When is the best time point to start this conversation?
- Should doctors consider gender, age and religious aspects?
- What are do's and don'ts in this conversation?
- What makes you feel comfortable / uncomfortable discussing sexual health with your doctor?

## #2 ....the doctors' perspective

- How do you address sexual health in your consultation?
- What is your favorite "opening line"?
- At which time point(s) do you address the topic?
- Do you consider age, health status and relationship status?
- If so, how is this background information guiding your conversation?
- What makes you feel comfortable / uncomfortable discussing sexual health with your patients?

## #3 ....how to make policy

- How can your patient advocacy group raise awareness for sexual health issues?
- How can your PAS break the ice within the community and with your collaborating doctors?
- Which campaigns or action points do you envision in your country?
- How can the socio-cultural background of your country be acknowledged appropriately?
- What barriers can you foresee?
- Are there facilitators in the progress?