

What is ENGAGe?

Who is ENGAGe?

And what do we do?

ENGAGe Executive Committee 2016-2019

Murat Gultekin (Co-Chair, Clinicien)

Esra Urkmez (Co-Chair, Patient Advocacy)

Birthe Lemley (Denmark)

Michaela Simona Ene (Romania)

Elisabeth Avall Lundqvist (Sweden)

Rene Laky (Austria)

Cristiana Sessa (Switzerland)

<https://engage.esgo.org/discover/about-engage/>



ABOUT US

What is ENGAGe?

Established in 2012, the European Network of Gynaecological Cancer Advocacy Groups is a network of European patient advocacy groups established by ESGO representing all gynaecological cancers particularly (ovary, endometrial, cervix, vulva and rare cancers).

Why is ENGAGe needed?

- There are wide variations in patient care across Europe
- Patients are not adequately informed about gynaecological cancer and their management
- Survivorship issues are not adequately addressed and psychosocial support in general is poor



ENGAGe Blog

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- [Patient Seminar 2017](#)
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ENGAGe News

Get notified on all news and

2012-2017 Achievements

We Run, We Spin Against Cancer, We organize yearly Patient Seminars



Fact Sheets for Patients, Patient recommendations, Guidelines:

Fact Sheets for Patients

What is Cervical Cancer (English, Spanish) - updated 2017

What is Ovarian Cancer (English, Spanish, Swedish) - updated 2017

What is Uterine Cancer (English) - 2018

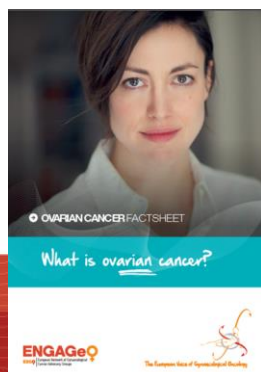
What is a Clinical Trial (English, Spanish, Swedish) -2018

Gynaecological Cancers in Europe Facts Sheets -2018

What is Vulvar Cancer - to be done from a scratch

ESGO Patient recommendations and Guidelines

Patient friendly version of different materials developed by ESGO for professionals will be designed to assist patients and their families



TITLE OF THE STUDY:	ENGAGe Patient Survey 2017 in Europe - What patients want to tell their doctors?
OBJECTIVE :	From the mouth of patients, tell their doctors and health care providers: What is being done good by their Health Care Team, What is missing in patient care and what areas need improvements?
TIMING:	Data collection was in field during August and September of 2017.
LOCATION:	The survey was conducted and finalized across Czech Republic, Denmark, Germany, Great Britain, Greece, Hungary, Poland, Serbia, Spain and Turkey.
SAMPLE:	The target group was Gynecologic Cancer Patients from 10 European Countries. Total of 1436 surveys were collected thru ENGAGe network. Survey has been translated into countries' mother languages
METHOD:	The survey was carried out as online web interviewing (CAWI) and as pdf in person format: it used a structured questionnaire (10 demographic + 25 question on awareness, prevention, diagnosis, treatment, clinical trial and conclusion) prepared by ENGAGe Team, reviewed by Executive Team, volunteer doctors and Non Profit Organization Members within ENGAGe network.

Special Thanks to our SPONSORS:

Priviledged Educational Partner



Supporter



AND to the TEAM who made it happen:

Murat Gultekin – ENGAGe CO-Chair,
Renata Brandtnerova - Executive Director, ESGO Office
David Cibula, ESGO President
ENGAGe Committee 2016-2019

Murat Gultekin (Co-Chair, Clinicien)
Esra Urkmez (Co-Chair, Patient Advocate)
Birthe Lemley (Denmark)
Michaela Simona Ene (Romania)
Elisabeth Avall Lundqvist (Sweden)
Rene Laky (Austria)
Cristiana Sessa (Switzerland)

ESGO Prag Team - especially Lucie Lamlova,
Quintiles IMS Team – Martin Vadura, Jiří Krýza
Elif Andac Jones, Research Consultant and Political Sociologist at Georgetown University
Luzia Travado, IPOS Board of Directors

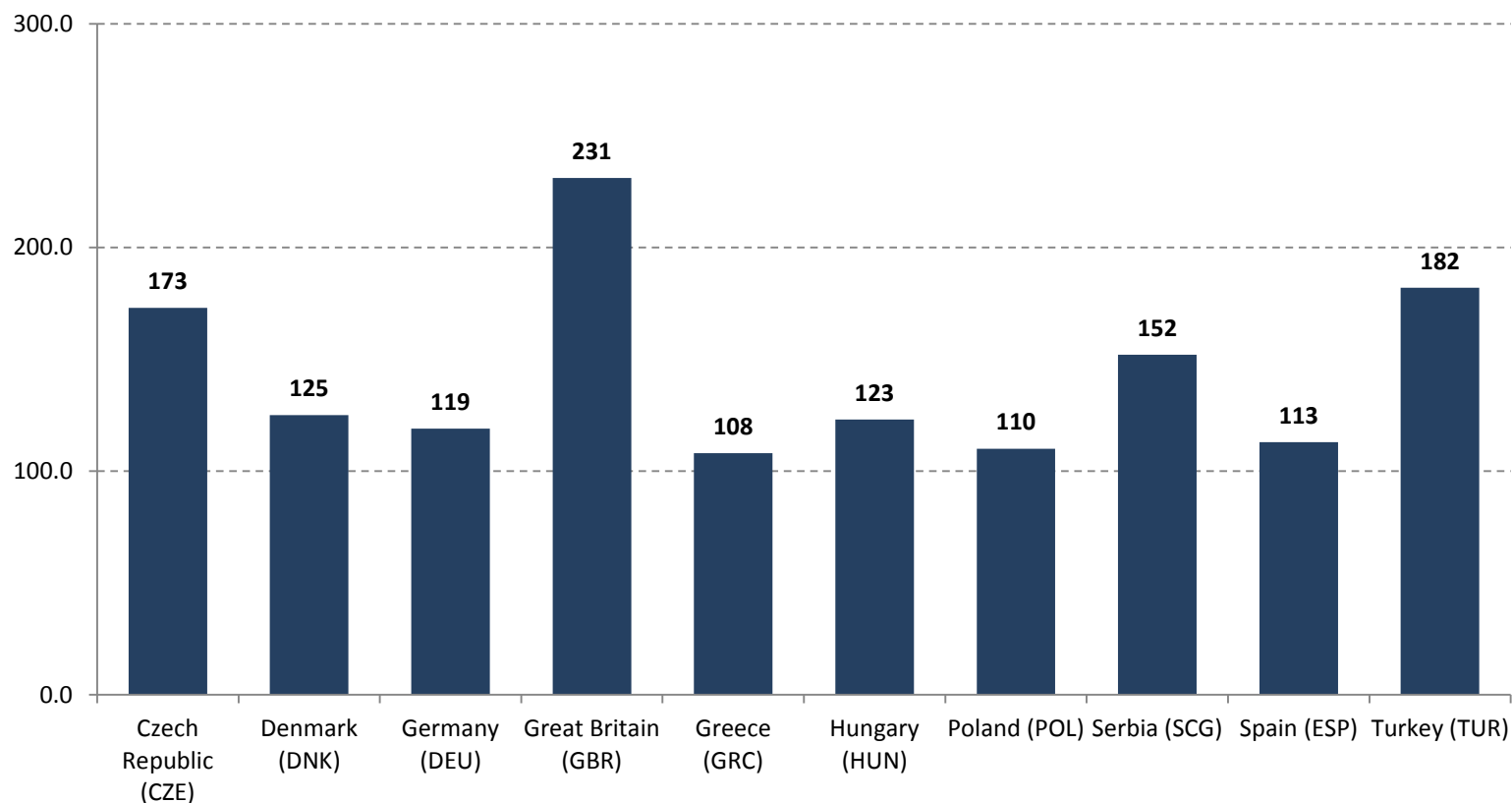
William S. Breitbart, Chair -Department of Psychiatry and Behavioral Sciences, Memorial Sloan Kettering



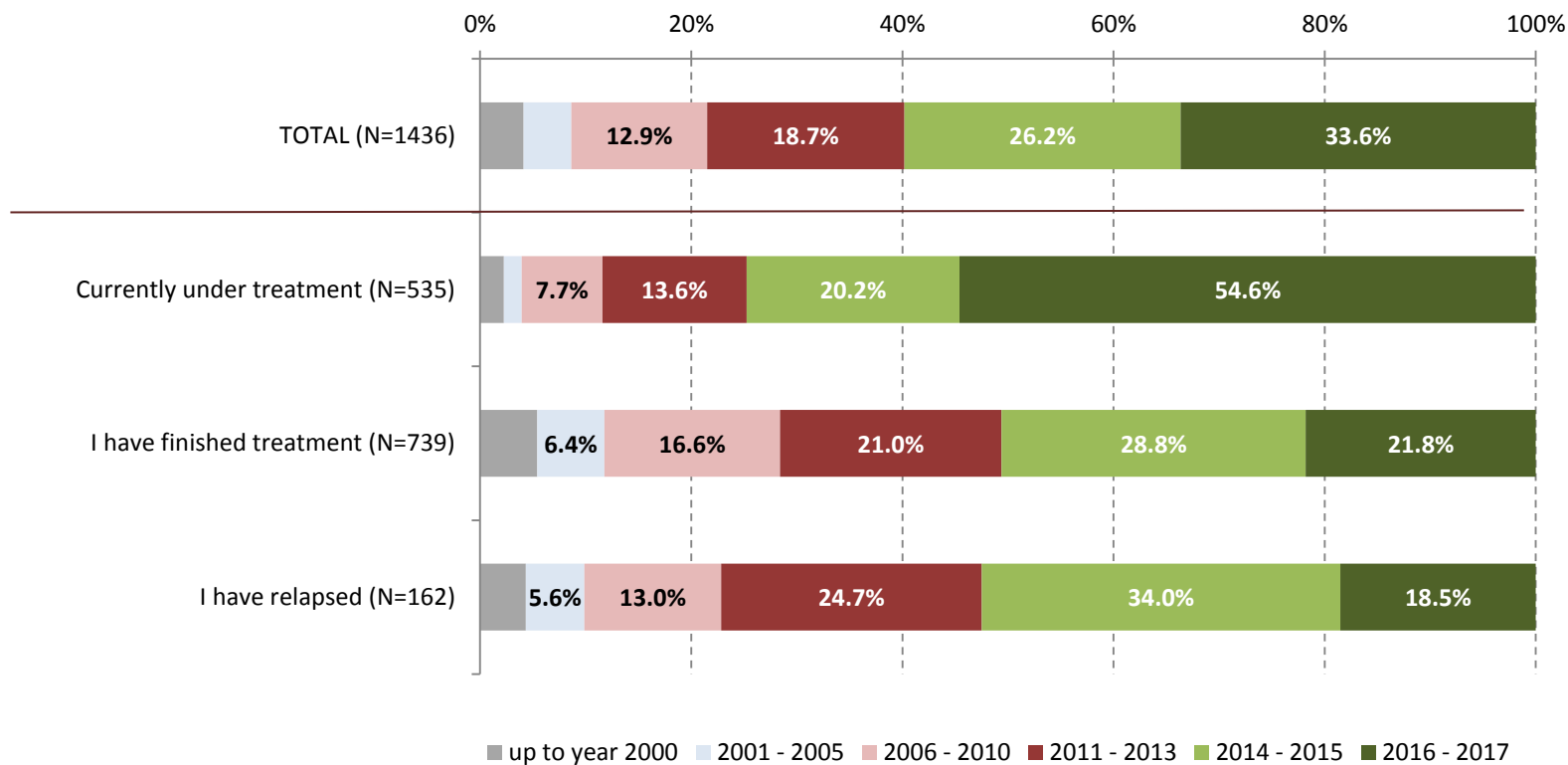
***AND to the Patient Organizations and our Volunteer Doctors
 who distributed the survey thru online and in pdf form:***

Country	Doctor / Patient Organization	Country	Doctor / Patient Organization
Czech Republic - 173		Poland - 110	
David Cibula	Doctor	Kamil Zalewski	Doctor & Blue Butterfly foundation
Veronika Cibulova	Volunteer	Serbia - 152	
Michael Halaska	Doctor	Vesna Bondzic	Women's Center Milica, Kraljevo Public Health institute
Daniel Driak	Doctor	Spain - 113	
Denmark - 125		Charo Hierro	ASACO
Birhte Lemley	KIU	Cristina Zorrero	Doctor
Germany - 119		Lucas Minig	Doctor
Jalid Sehouli	Stiftung Eierstock Krebs	Turkey - 182	
Susanne Fechner	Stiftung Eierstock Krebs	Muzaffer Sanci	Doctor
Jacek Grabowski	Doctor	Murat Alan	Doctor
Gulhan Inci	Doctor	Sevil Benli	Kanserle Dans Association
Greece - 108		Asli Ortakmac	Kanser Savascilari
Maria Papageorgiu	K.E.F.I. of Athens	UK - 231	
Hungary - 123		Christina Fotopoulou	Doctor
Ildiko Nagy-Toth	Mallow Flower Foundation	Jonathan Ledermann	Doctor
		Ross Little	Ovarian Cancer Action

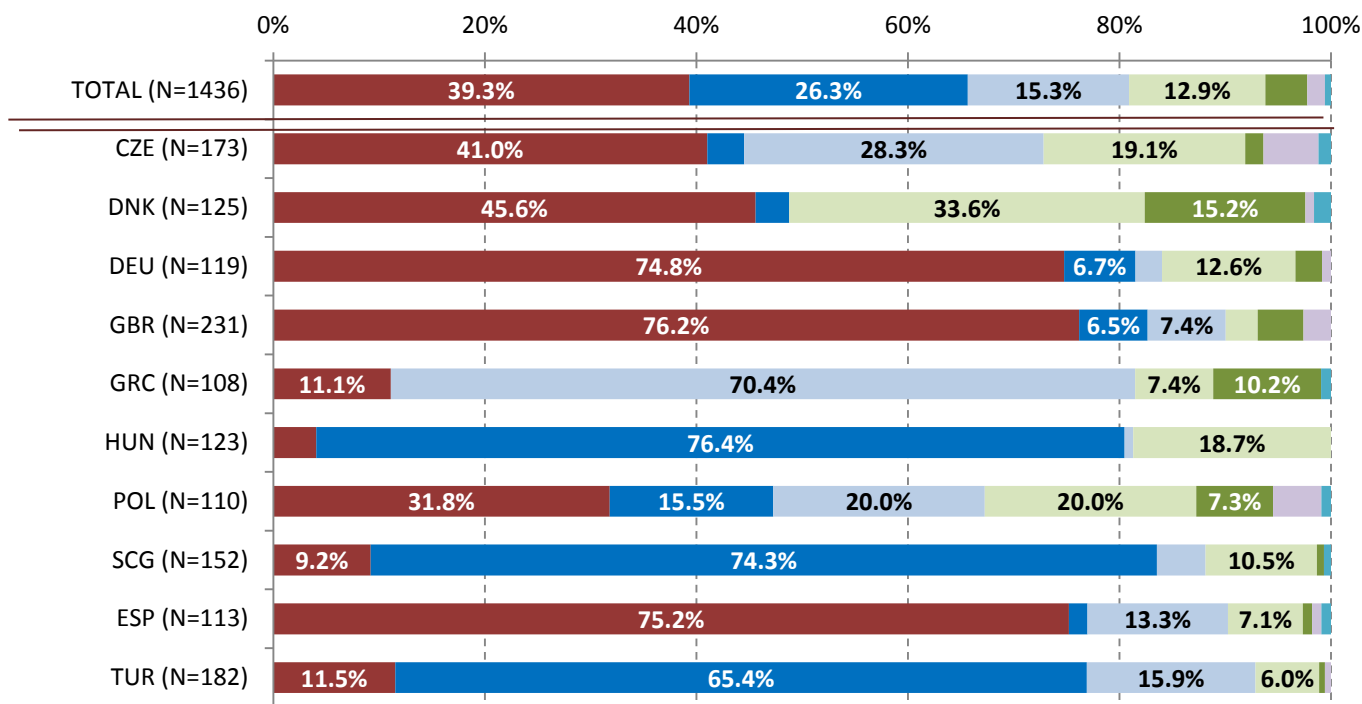
Number of respondents by country- 1436 total



Current health condition – SORTED BY YEAR OF DIAGNOSIS



What type of cancer do you have? *SORTED BY COUNTRY*

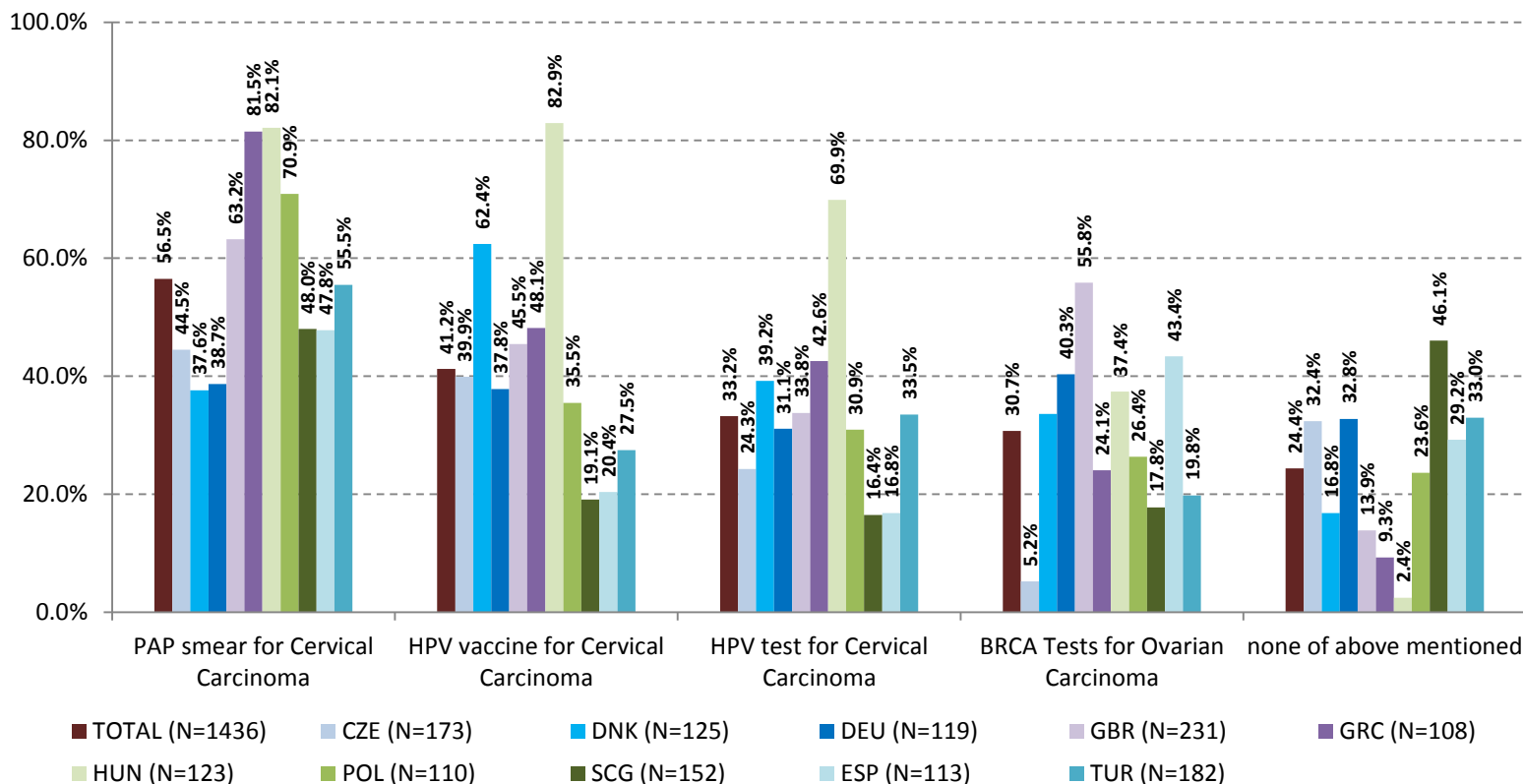


■ Ovarian cancer ■ Breast cancer ■ Uterine cancer ■ Cervical cancer ■ Fallopian tube cancer ■ Vulval cancer ■ Vaginal cancer

AWARENESS - Knowledge of screenings/methods

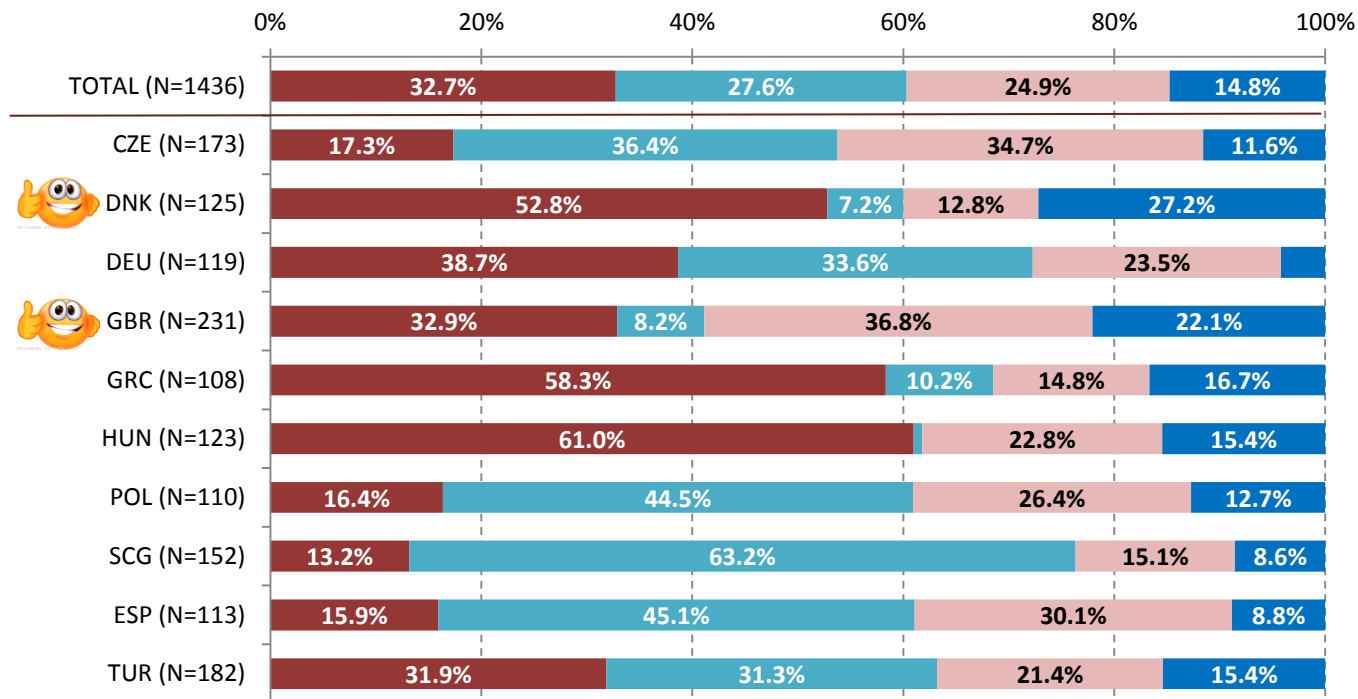
Have you heard of any of the following screenings or methods that might help prevent these gynaecological cancers? *SORTED BY COUNTRY*

The most frequently mentioned graphed – multiple choice question



PREVENTION – Which of the following screening tests do you regularly attend?

SORTED BY COUNTRY



■ cervical and breast cancer ■ never followed routine cervical nor breast cancer screenings ■ breast cancer ■ cervical cancer

SO US PATIENTS, WHAT DO WE WANT TO TELL OUR HEALTH CARE PROVIDERS?

- Many of us **did not know** about HPV vaccinations, PAP Smear Test, nor BRCA Tests for Ovarian Carcinoma -

WE WANT TO KNOW, WE NEED TO BE EDUCATED

- Even if we knew, many of us did not attend as we had **no access** to them, or **no finances** to get them done, or we did **not** find them **relevant** to us.

AGAIN, WE NEED TO BE EDUCATED, and WE NEED ACCESS TO THEM.

We need to find a way on how we can improve the prevention in these countries, together.

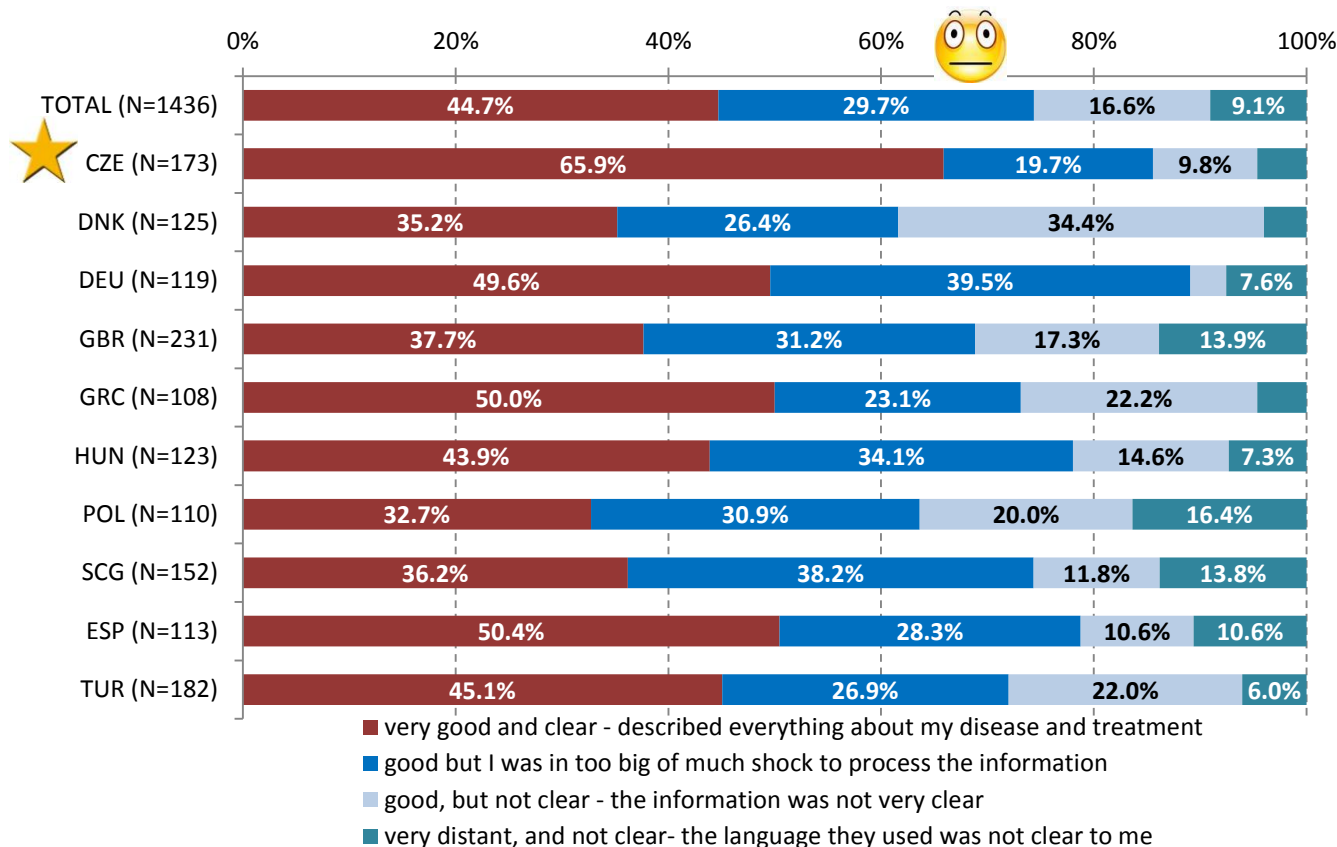
Don't forget, numbers and studies are meaningless unless we do something with them

DIAGNOSIS AND TREATMENT STAGE:

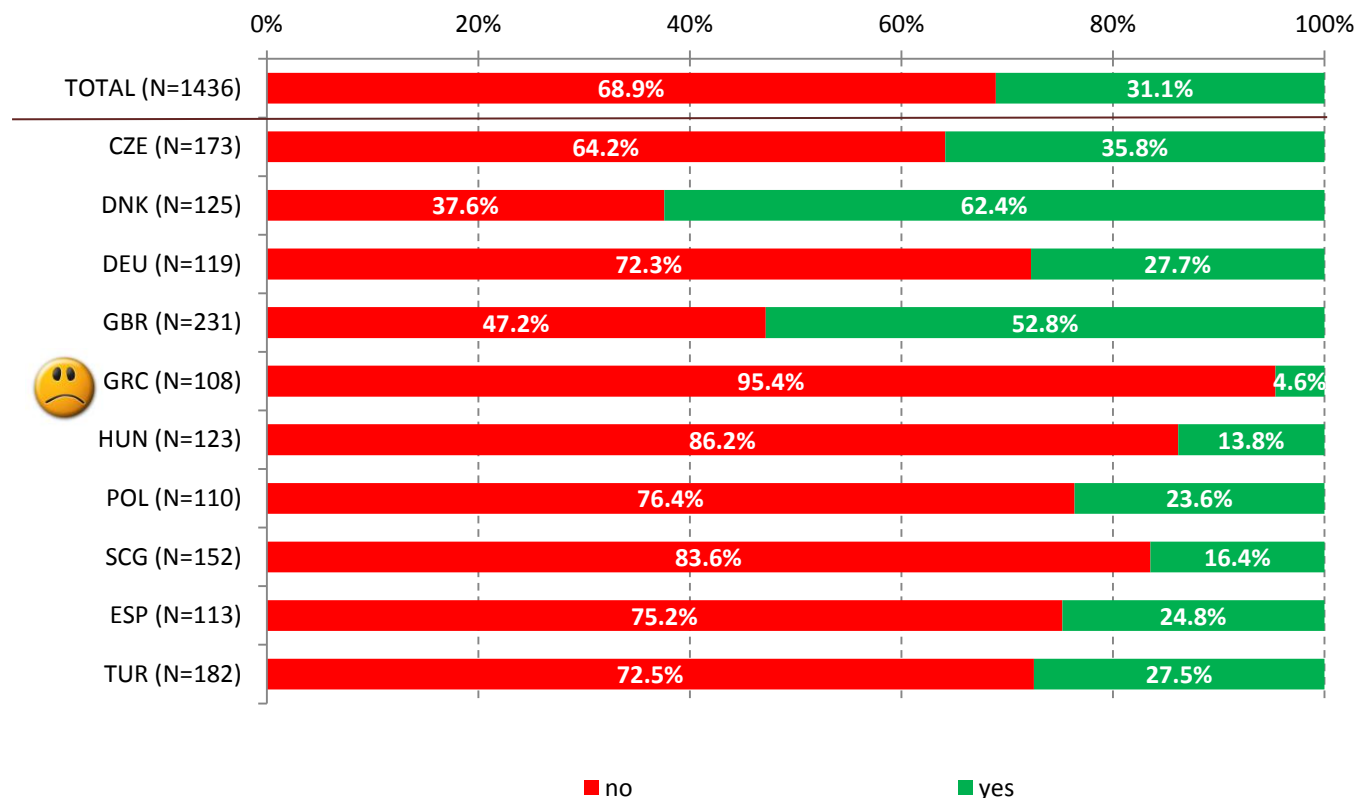
***First conversations,
First shocking moments,
First informative conversations with doctors***

A NEW LIFE FOR PATIENTS BEGINS...

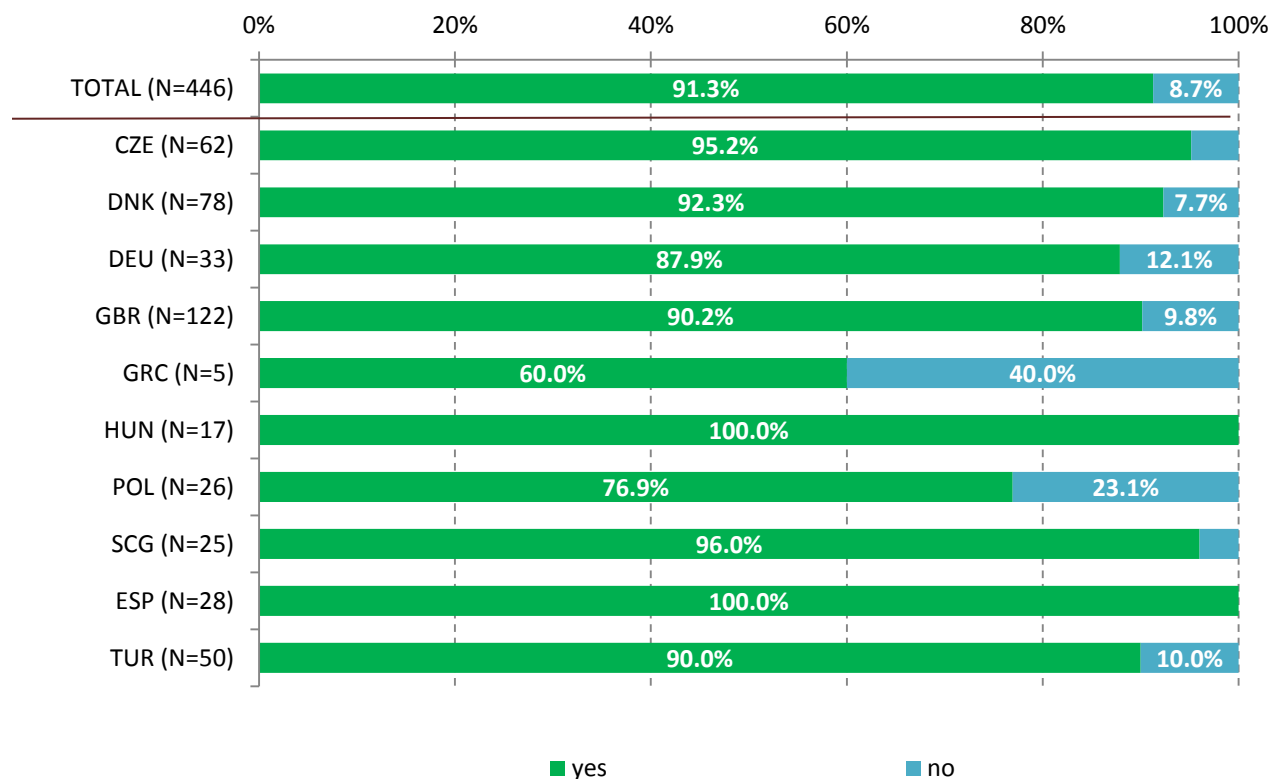
How would you describe your first conversation with your doctor/ nurse/ health care team? *SORTED BY COUNTRY*



Did you received printed educational materials from your health care provider after your first conversation? *SORTED BY COUNTRY*



Did you think these educational materials were helpful? *SORTED BY COUNTRY*



***SO US PATIENTS, WHAT DO WE WANT TO TELL OUR DOCTORS WHO
DIAGNOSE US FOR TREATMENT?***

- Many of us **did not get** printed informative material from you during first visits and we were too shocked to understand what you were telling us

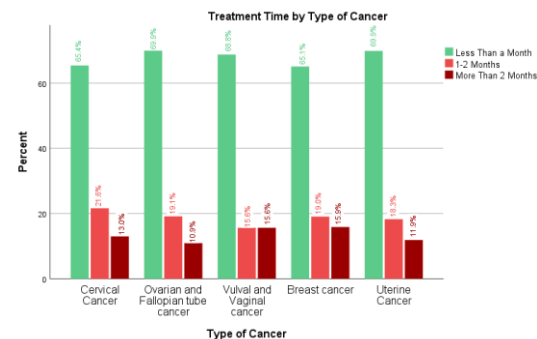
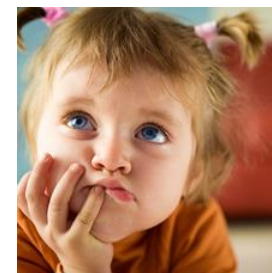
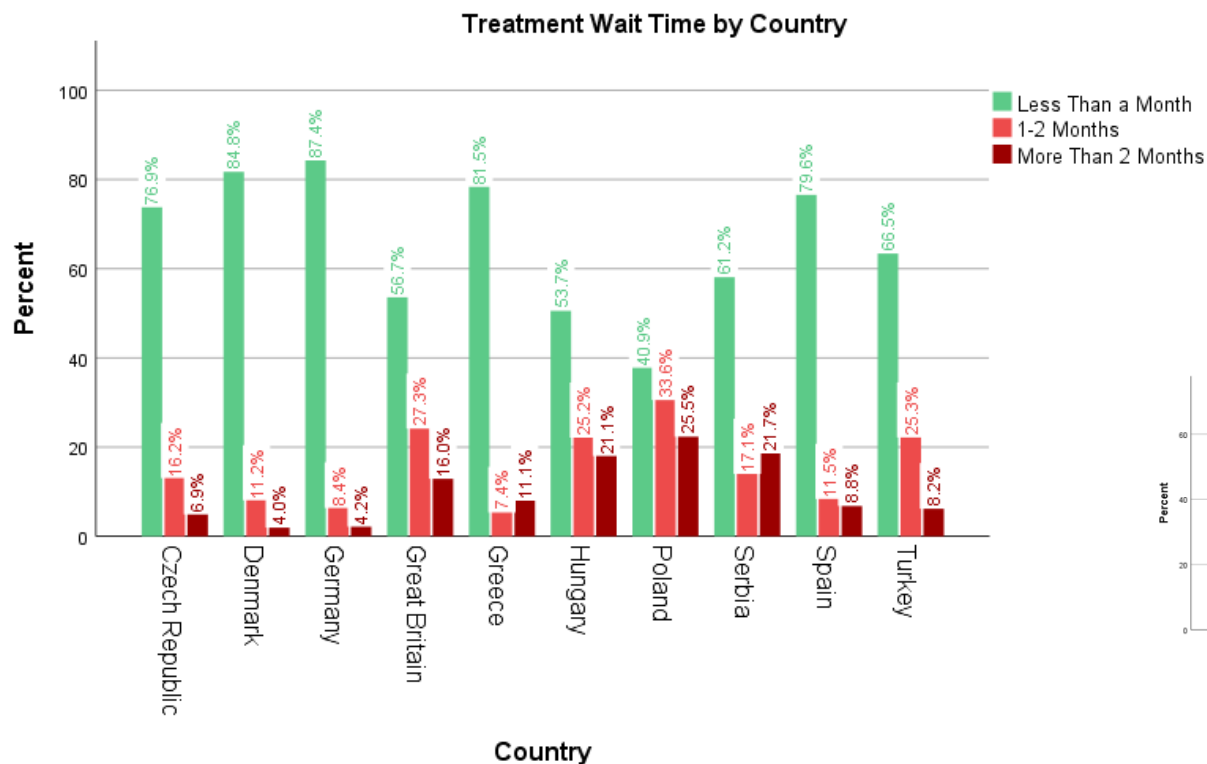
WE WANT PRINTED MATERIALS TO TAKE HOME, SO WHEN WE GET OVER THE SHOCK WE CAN EDUCATE OURSELVES AND OUR CAREGIVERS AT HOME

HOW: We need to find a way to work together to achieve this. Patient organizations should be working with doctors to provide the informative brochures, and we will need sponsors to do so.

AGAIN...

Don't forget, numbers and studies are meaningless unless we do something with them

Waiting Time - How long did you have to wait before treatment started?

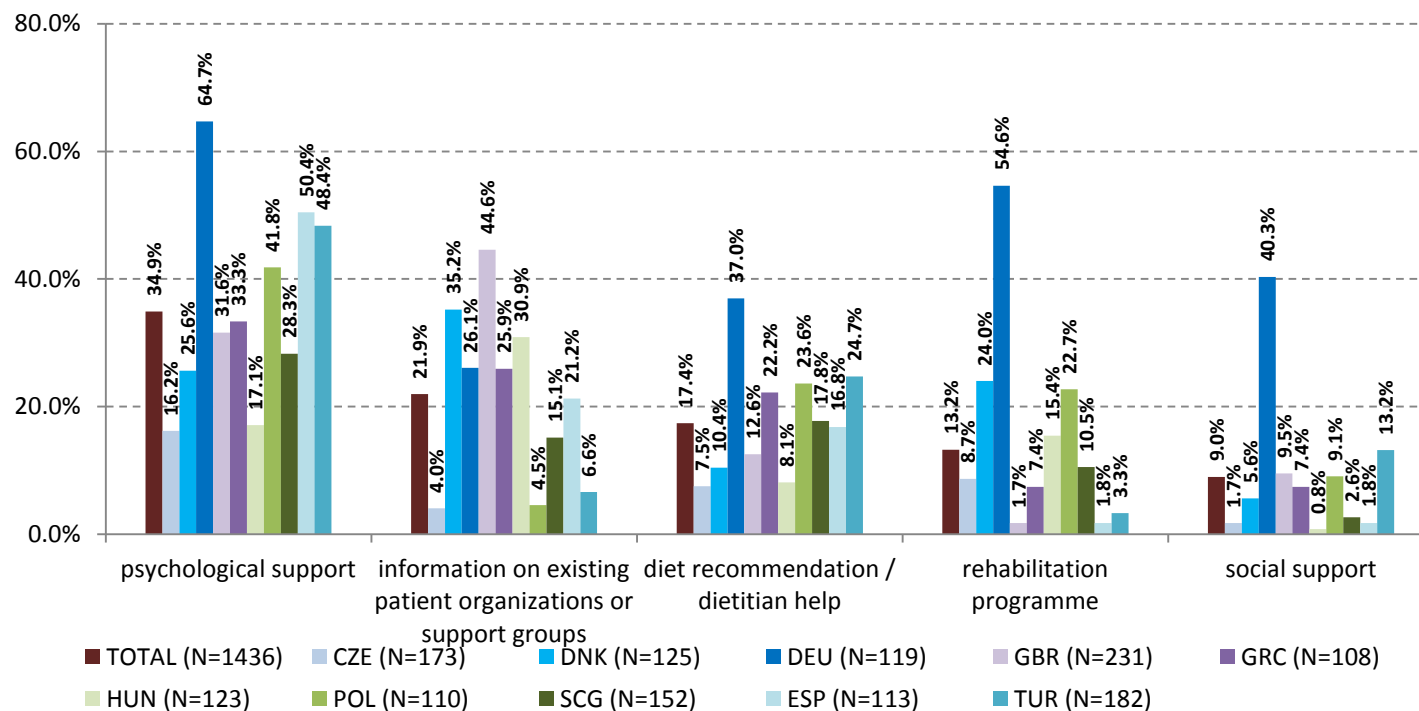


NOW, THE TREATMENT STARTS

PATIENTS MOSTLY DON'T KNOW:

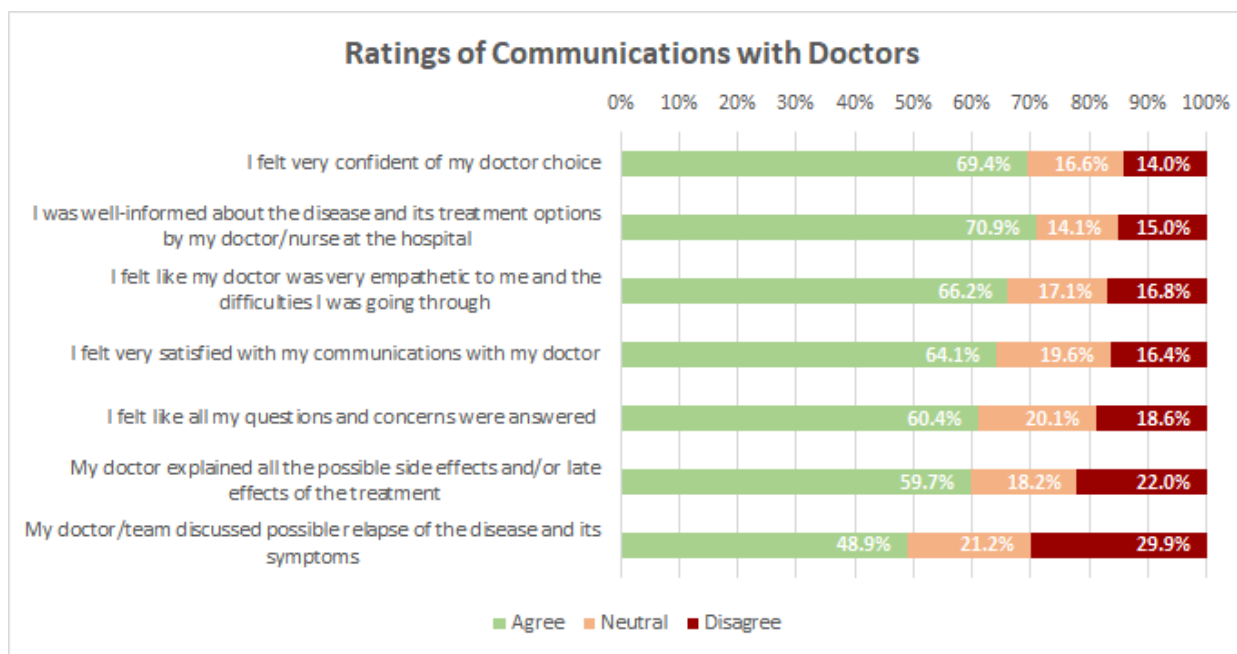
- ***WHAT TO EXPECT***
- ***WHAT TO EAT***
- ***HOW TO COPE***
- ***AND HOW TO LIVE WITH IT***

Were you offered any complimentary help? If yes, which of followings:
SORTED BY COUNTRY



Evaluations of Doctors and Nurses by Patients:

How strongly do you agree or disagree with the following statements?



WHAT DO WE WANT TO TELL OUR DOCTORS:

- ***We are here***
- ***We are a team: patients, caring families, patient organizations, doctors, nurses, other health care professionals***
- ***AND we SURELY want to do something with the numbers, with the results***
- ***AND we want to improve the care of the patients together***
- ***AND If you would like to be a part of our vision,***

ENGAGe needs your help !

