CHOICE
BREAST CANCER LITERACY

Preliminary Insights into Health Literacy and Decision-Making among BRCA Mutation Carriers in Czech Republic

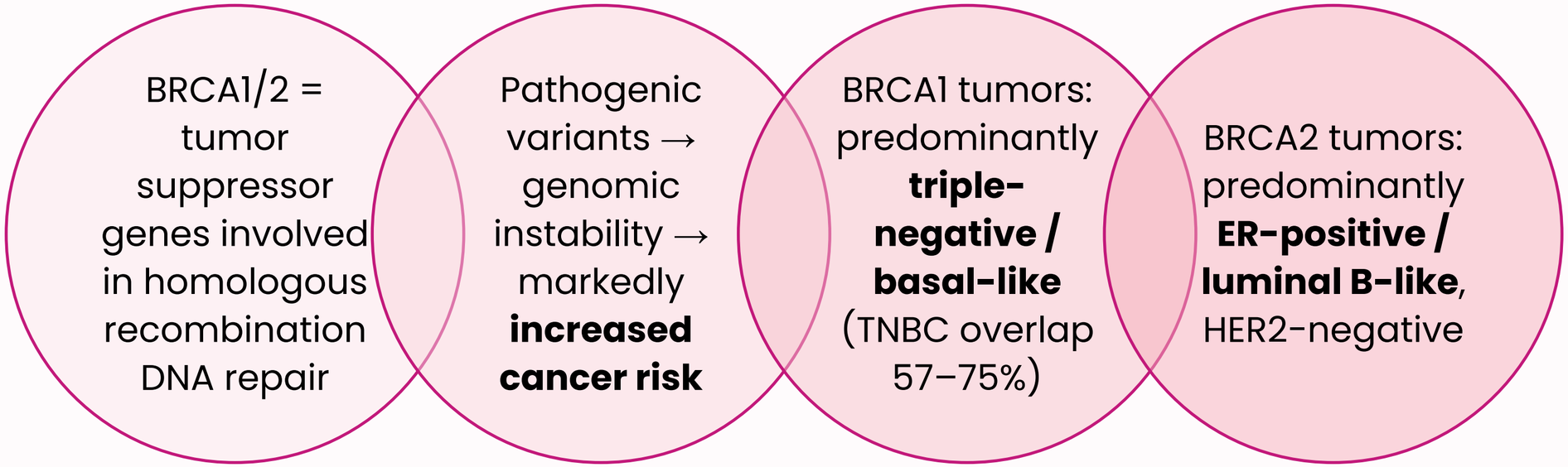
Pelzová A. [1,5] , Fialová L [1,5], Palácová M. [2,5], Zimovjanová M. [3], Mokrá L. [4], Schwarz D. [4,5], Pinto D. C. [6], Churová V. [4] , Streit L. [1,5]

1 Klinika popálenin a plastické chirurgie, FN Brno
2 Masarykův onkologický ústav Brno, Klinika komplexní onkologické péče
3 Onkologická klinika, VFN a 1. LF UK Praha
4 Institut biostatistiky a analýz, s.r.o. Brno
5 Masarykova Univerzita
6 NOVA IMS

Co-funded by the European Union

EPIDEMIOLOGY & PATHOPHYSIOLOGY

BRCA1/2 Mutations: Prevalence & Cancer Risk



EPIDEMIOLOGY & PATHOPHYSIOLOGY

BRCA1/2 Mutations: Prevalence & Cancer Risk

5-10 %	of all breast cancers are hereditary
20-60 %	of hereditary BC attribute to BRCA1/2
1 of 150-300	general population carrier frequency
72 %	BRCA 1 cumulative BC risk by age 80
69 %	BRCA 2 cumulative BC risk by age 80

BC = breast cancer

EPIDEMIOLOGY & PATHOPHYSIOLOGY

BRCA1/2 Mutations: Lifetime Cancer Risk

CANCER	BRCA1	BRCA2	GENERAL POPULATION
Breast	72 %	69 %	~12 %
Ovarian	39–58 %	13–29 %	~1.1 %
Pancreatic	~5 %	5–10 %	~1.7 %
Prostate (M)	7–26 %	19–61 %	~10.6 %

Note: Although pathogenic variants in BRCA1/2 increase cancer risk in both **women and men**. The CHOICE Project includes women only.

EPIDEMIOLOGY & PATHOPHYSIOLOGY

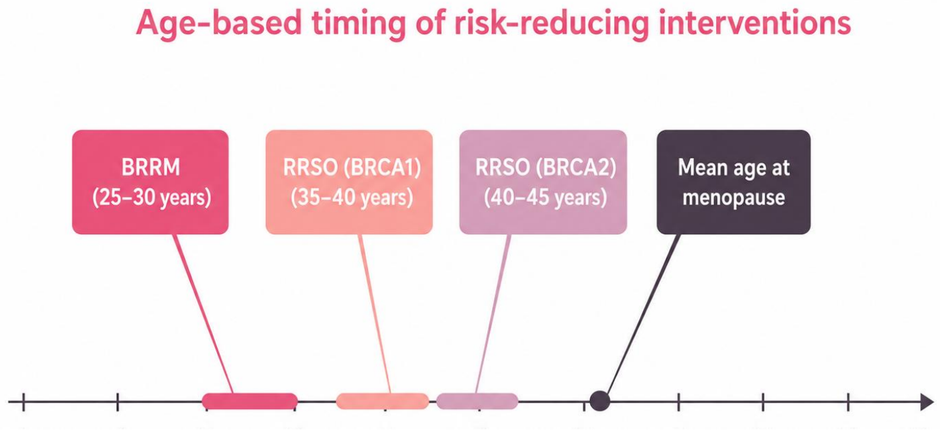
BRCA1/2 Mutations: Cancer Risk by Age

Risk increases rapidly in early adulthood, then plateaus:

- BRCA1: plateau reached at **31–40 years**
- BRCA2: plateau **5–10 years later** (41–50 years)

Peak BC incidence:

- BRCA1 **41–50 years** old
- BRCA2 **51–60 years** old



BRRM = Bilateral Risk-Reducing Mastectomy
RRSO = Risk-Reducing Salpingo-Oophorectomy

Key principle: Lifetime risk alone is insufficient - Focus on **residual risk from current age - Balance with morbidity, life expectancy, QoL**



⚠ Clinical trap: **lifetime ≠ remaining risk** - At 75, residual BC risk is much lower - Age >75: individualized counselling - Consider comorbidity, life expectancy, QoL;+9

KEY ONCOLOGIC POINTS

Risk-Reducing Mastectomy: Oncologic Rationale & Technique

>90%	BC risk reduction after bilateral RRM (BRRM)
91–93%	Contralateral BC risk reduction (CRRM, meta-analysis)
>11%	Prevalence of occult tumors in preventive specimens (negative pre-op imaging)

EPIDEMIOLOGY & PATHOPHYSIOLOGY

BRCA1/2 Mutations: Prevalence & Cancer Risk

- ≥3 relatives with BC *(bilateral BC = 2 tumors)*
- ≥2 relatives with BC *(≥1 before 50, or both before 60)*
- BC before 50 + 1st-degree relative with HBOC cancer *(esp. pancreatic/prostate)*

Familial forms

- Bilateral BC *(≥1 before 50, or both before 60)*
- Ovarian / tubal / peritoneal cancer at any age
- Double primary BC + ovarian/pancreatic cancer
- Breast cancer before 45 *(or before 50 without family history)*
- Male breast cancer
- Triple-negative BC before 60

Sporadic forms

CZ Strategy: Genetic testing criteria

NON-SURGICAL MANAGEMENT

BRCA1/2 Carriers: Surveillance Protocol & Chemoprevention

CZECH REPUBLIC

SURVEILLANCE SCHEDULE

- Start: **25 y** or **10 y before youngest family BC**
- Self-exam monthly
- Clinical exam every **6 months**
- **25–29 y:** MRI ± US; baseline MLO mammogram
- **≥30 y:** alternating MRI/mammography every 6 months
- US mainly before 30; later individualized

POST-RRM SURVEILLANCE

• After prophylactic subcutaneous mastectomy: MRI

• If residual glandular tissue present → surveillance must continue

• Final strategy: individualized per geneticist + oncologist

NON-SURGICAL MANAGEMENT

BRCA1/2 Carriers: Surveillance Protocol & Chemoprevention

CZECH REPUBLIC

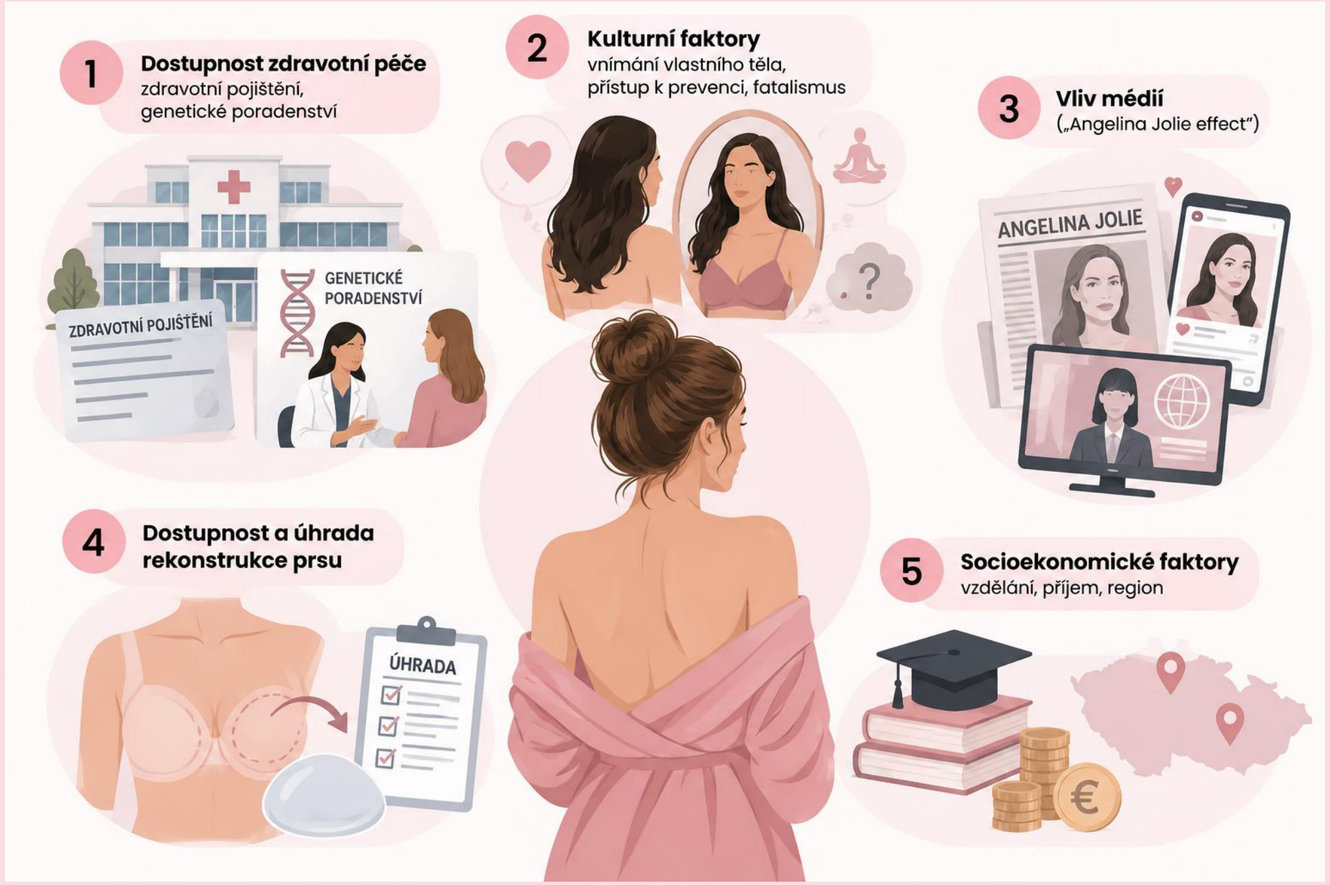
CHEMOPREVENTION — KEY AGENTS

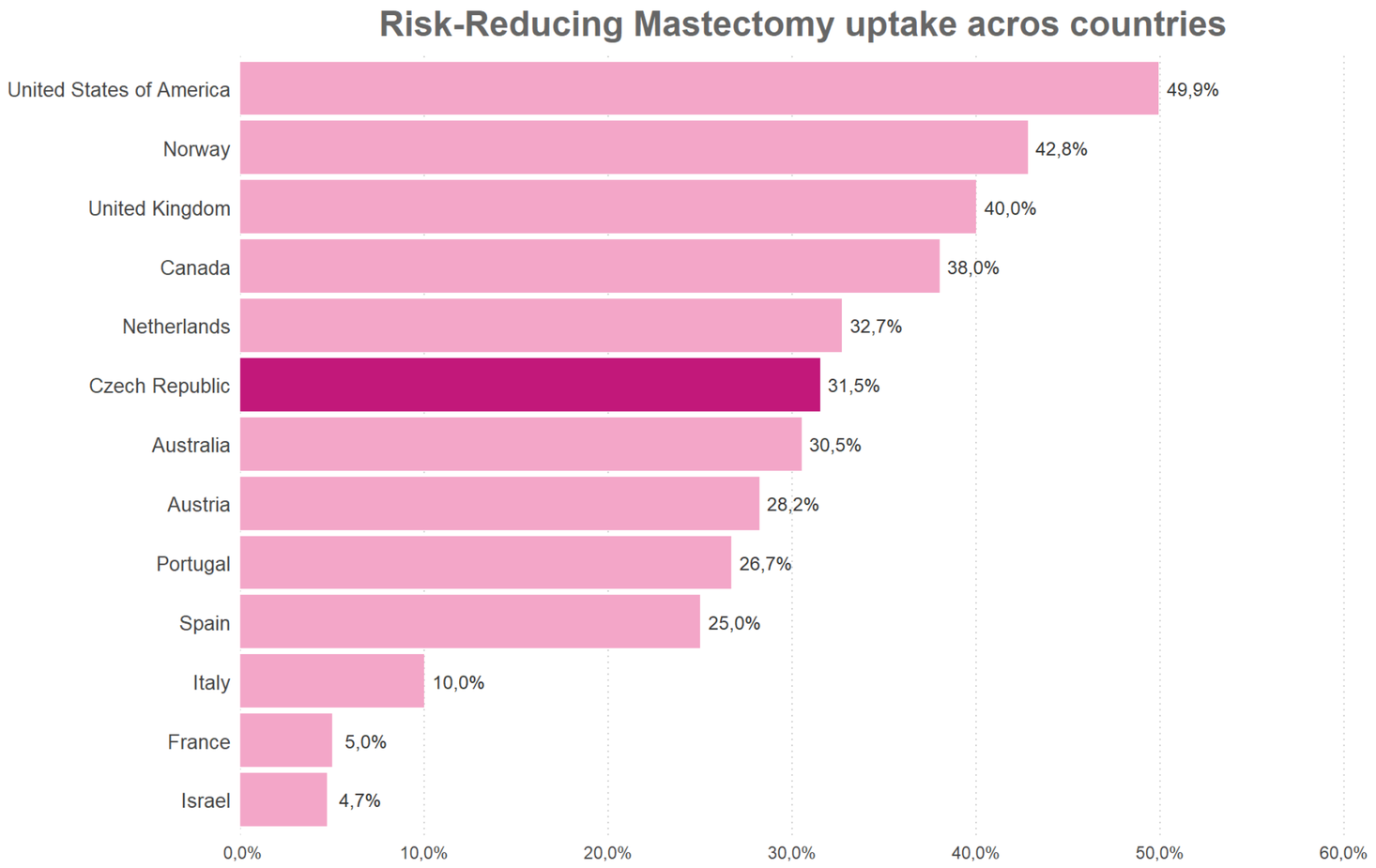
Agent	Population	Risk reduction	Key note
Tamoxifen	Pre- & postmenopausal	49% overall; ~62% BRCA2; unclear BRCA1	VTE, endometrial cancer risk
Exemestane	Postmenopausal only	~65% (MAP.3)	Monitor bone density
Anastrozole	Postmenopausal only	~53% (IBIS-II)	Arthralgia, osteoporosis
Raloxifene	Postmenopausal only	Less effective long-term	Less endometrial toxicity

⚠ CZ context: Tamoxifen not routinely used as standard chemoprevention in healthy BRCA carriers in Czech Republic. May be considered individually — particularly in BRCA2 carriers or where ER-positive BC risk is elevated.

INTERNATIONAL COMPARISM

RRM Uptake in BRCA1/2 Carriers Across Countries





CZECH REPUBLIC CONTEXT

RRM CZ uptake: **31.5%** → upper-middle globally

Similar: Netherlands, Australia

Mean age PM: **41.8** years (BRCA1 40.7; BRCA2 42.4)

≥60 years: **3.4% only**

CHOICE

BREAST CANCER LITERACY

4	36	3	155
participating countries	months of duration	participating CZ centers	CZ women patients

NOVA IMS INFORMATION MANAGEMENT SCHOOL

iba Institute of Biostatistics and Analyses

MUNI MED

ARISTOTLE UNIVERSITY OF THESSALONIKI

CHOICE PROJECT — CZECH COHORT

Data source (N=155)

Age

18-33 years	34 (22%)
34-50 years	82 (53%)
51+ years	39 (25%)

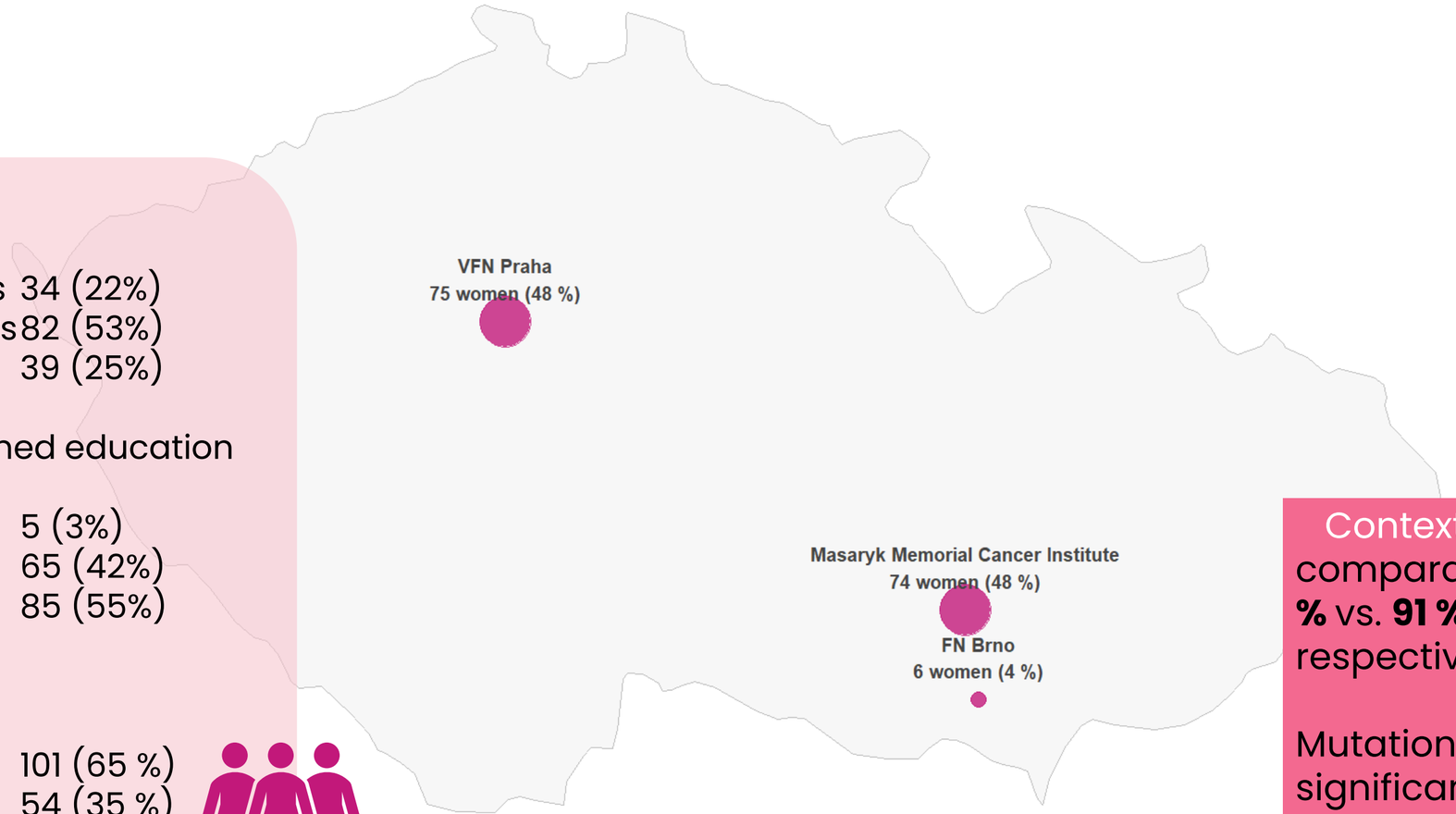
Highest attained education

Primary	5 (3%)
Secondary	65 (42%)
University	85 (55%)

Mutation

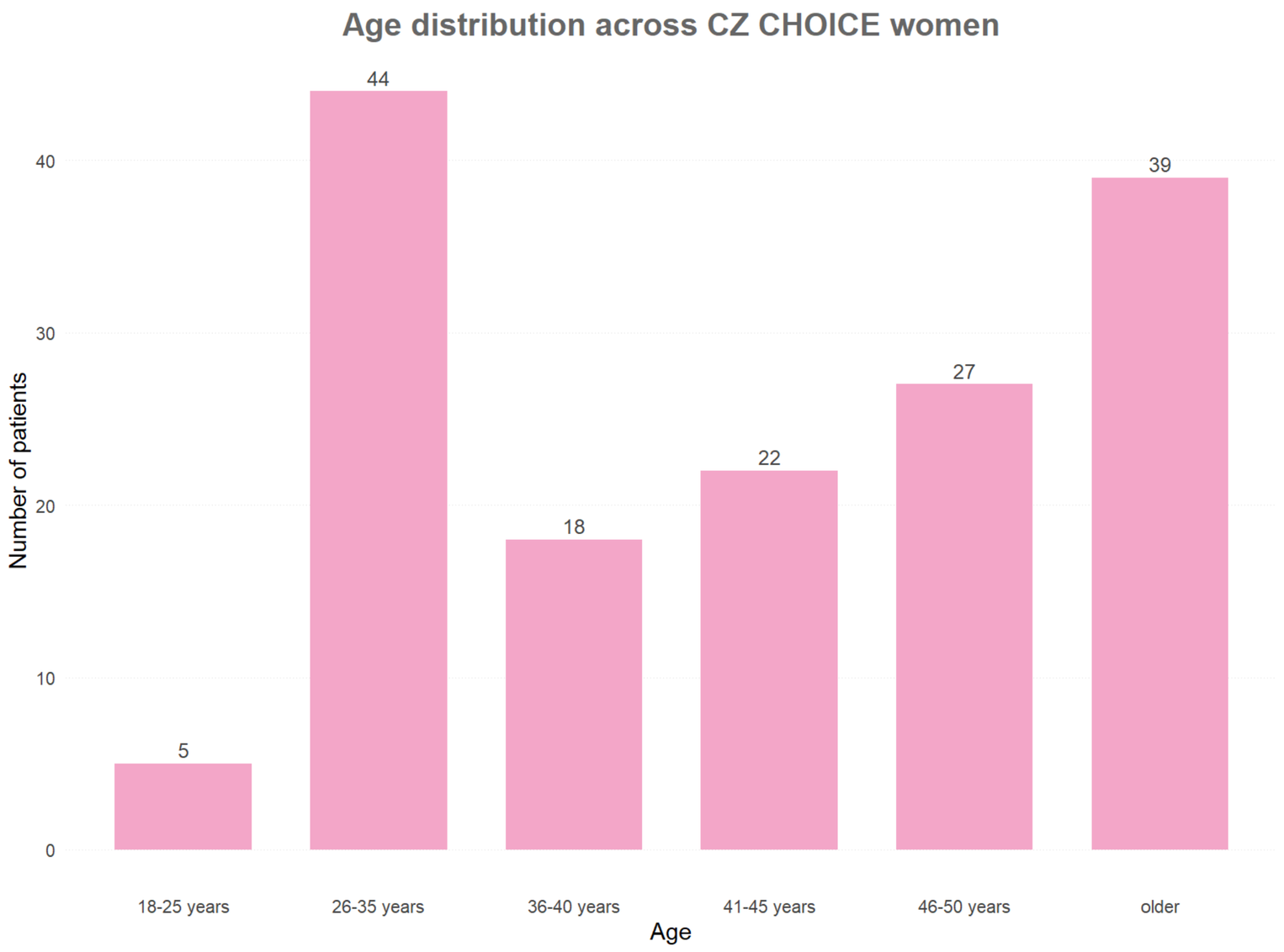
BRCA1	101 (65 %)
BRCA2	54 (35 %)





Context: BRCA1 and BRCA2 comparable in clinical profile **90 %** vs. **91 % unaffected previvors** respectively.

Mutation type does not significantly alter clinical status distribution.


Age distribution across CZ CHOICE women
Number of patients
0
10
20
30
40
5
44
18
22
27
39
18-25 years
26-35 years
36-40 years
41-45 years
46-50 years
older
Age

CHOICE PROJECT — CZECH COHORT

Women description

155	**65 %**	**35 %**	**95 %**	**68 %**
CZ women patients	with BRCA 1 mutation	with BRCA 2 mutation	are aware of mutation >= 6 months	report ≥1 first-degree woman relative with BRCA ½ mutation

155	**90 %**	**49 %**	**25 %**	**11 %**
CZ women patients	with no prior BC diagnosis	report ≥1 first-degree woman relative with BC	report ≥1 first-degree woman relative with OC	have had or are having any cancer treatment

155	**29 %**	**35 %**	**36 %**
CZ women patients	chose RRM	are undecided	chose surveillance

NOVA IMS INFORMATION MANAGEMENT SCHOOL · iba Institute of Biostatistics and Analyses · MUNI MED · ARISTOTLE UNIVERSITY OF THESSALONIKI

CHOICE PROJECT — CZECH COHORT

Key point: Decisions Made

YOUR CURRENT ATTITUDE TOWARDS PREVENTIVE MASTECTOMY	
I have decided to have preventive surgery.	**45 (29%)**
I am considering preventive surgery. I am collecting information and have not decided yet.	54 (35%)
I am not considering preventive surgery. I definitely prefer regular follow-up to surgery.	56 (36%)



⚠ Important note: The proportion of respondents preferring RRM (29 %) is **lower** than the reported RRM uptake (31.5 %). From a physician's perspective, **we would like** to see this proportion increase over time.

CHOICE PROJECT — CZECH COHORT

Main reasons behind decisions made



CHOICE PROJECT — CZECH COHORT

Main reasons behind decisions made



Impression: Czech women tend to make relatively **autonomous decisions** and place considerable importance **on their own health**, while the opinions of others appear to play a less significant role in their decision-making**.**

CHOICE PROJECT — CZECH COHORT

Women description

QUICKLY, FURTHER DISCUSSED

155
CZ women patients

74 %
believe that RRM significantly reduce the risk of BC

59 %
are concerned about post-operative pain

53 %
are feared of surgery

57 %
are worried about losing their feminity

59 %
can not imagine having RRM without breast reconstruction

155
CZ women patients

78 %
report being well-informed about reconstruction options

9 %
felt completely uninformed when informed about mutation

84 %
are aware of RRM advantages and disadvantages overall

155
CZ women patients

74 %
believe RRM significantly reduces breast cancer risk

18 %
believe RRM worsens QoL

32 %
neutral on QoL impact → room for targeted education

NOVA IMS INFORMATION MANAGEMENT SCHOOL · iba Institute of Biostatistics and Analyses · MUNI MED · ARISTOTLE UNIVERSITY OF THESSALONIKI

CHOICE PROJECT — CZECH COHORT

Beliefs

155

CZ women patients

11 %

are not concerned about cancer because of genetic risk

74 %

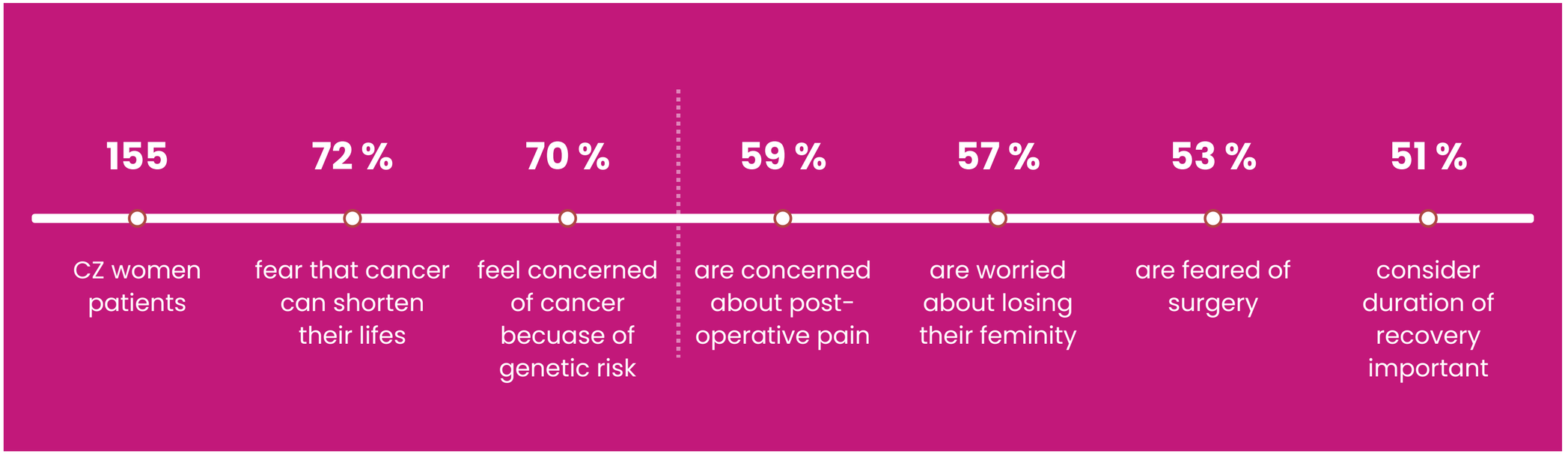
believe that RRM significantly reduce the risk of cancer

18 %

believe RRM worsens QoL

CHOICE PROJECT — CZECH COHORT

Fears



CHOICE PROJECT — CZECH COHORT; KEY POINT

Health Belief Paradox



CHOICE PROJECT — CZECH COHORT

Information & Awareness



155
CZ women patients

83 %
felt sufficiantly informed when informed about mutation

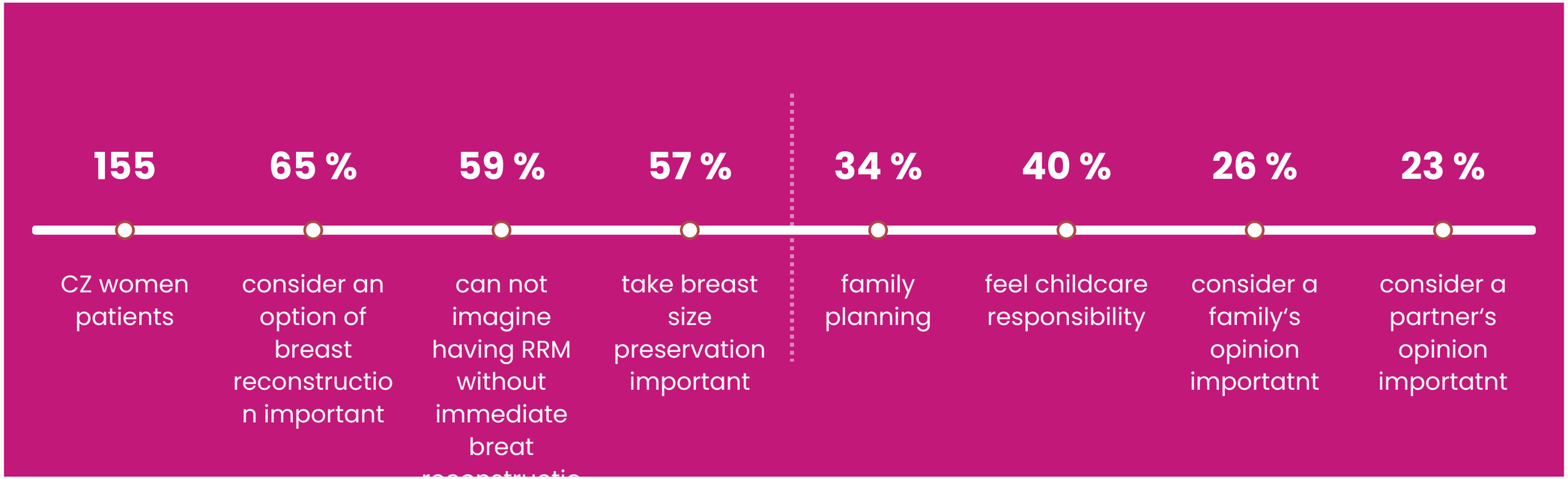
9 %
felt completely uninformed when informed about mutation → residual education gap

83 %
are aware of RRM advantages and disadvantages overall

78 %
report being well-informed about reconstruction options

CHOICE PROJECT — CZECH COHORT

What matters to them when deciding (then)



CHOICE PROJECT — CZECH COHORT; KEY POINT

Reconstruction as prerequisite

57 %

cannot imagine RRM **without reconstruction**

Reconstruction is not merely a preference — for many, it is a **prerequisite.**

Plastic surgeon should be integrated **early in the decision pathway**.

CHOICE PROJECT — CZECH COHORT; KEY POINT

Consultations with Physicians: Plastic surgeons included

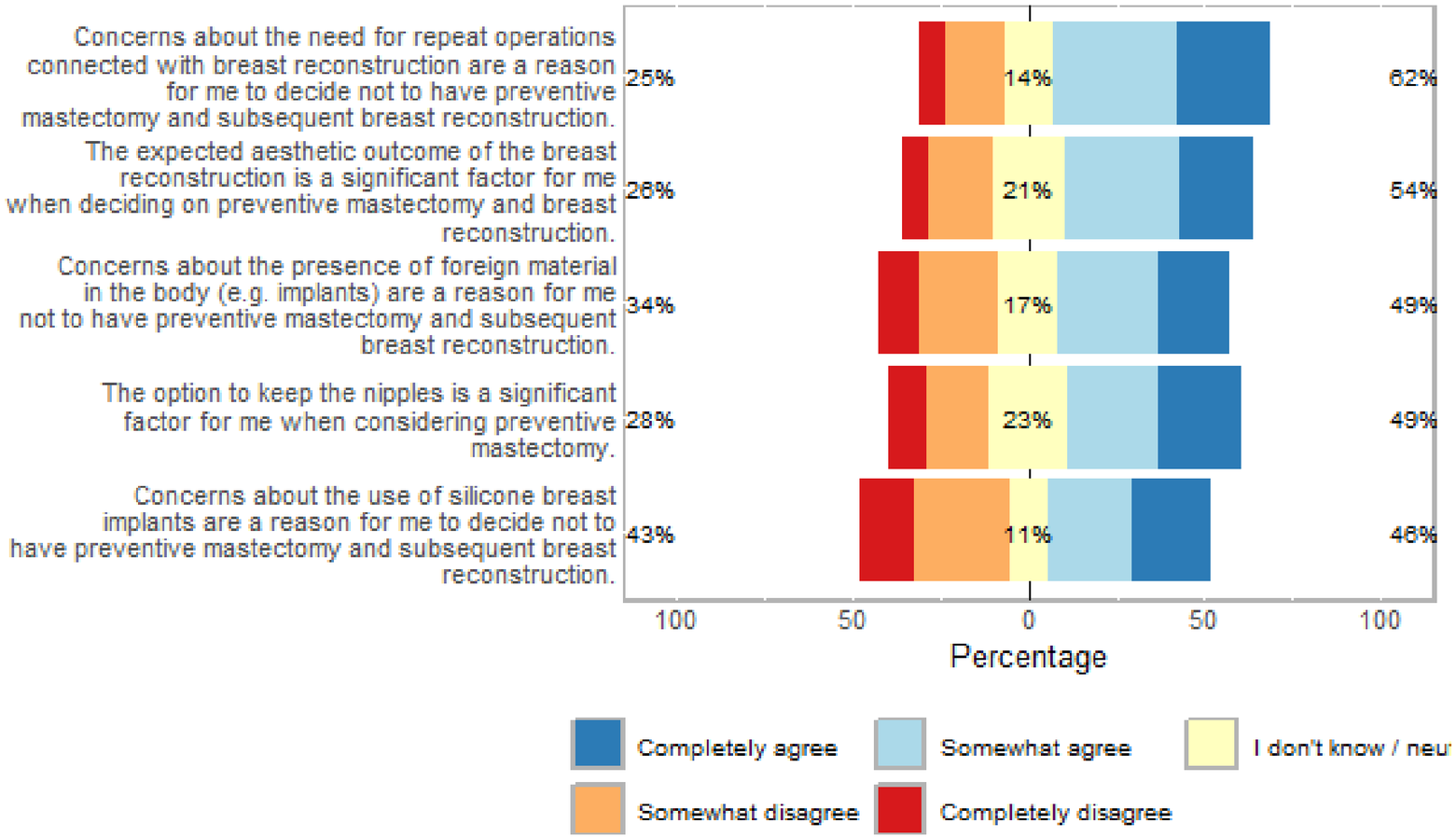


← **18 % of all cases**

Comment: Pre-operative counseling on reconstruction is **as clinically important as the oncologic discussion**.

CHOICE PROJECT — CZECH COHORT; KEY POINT

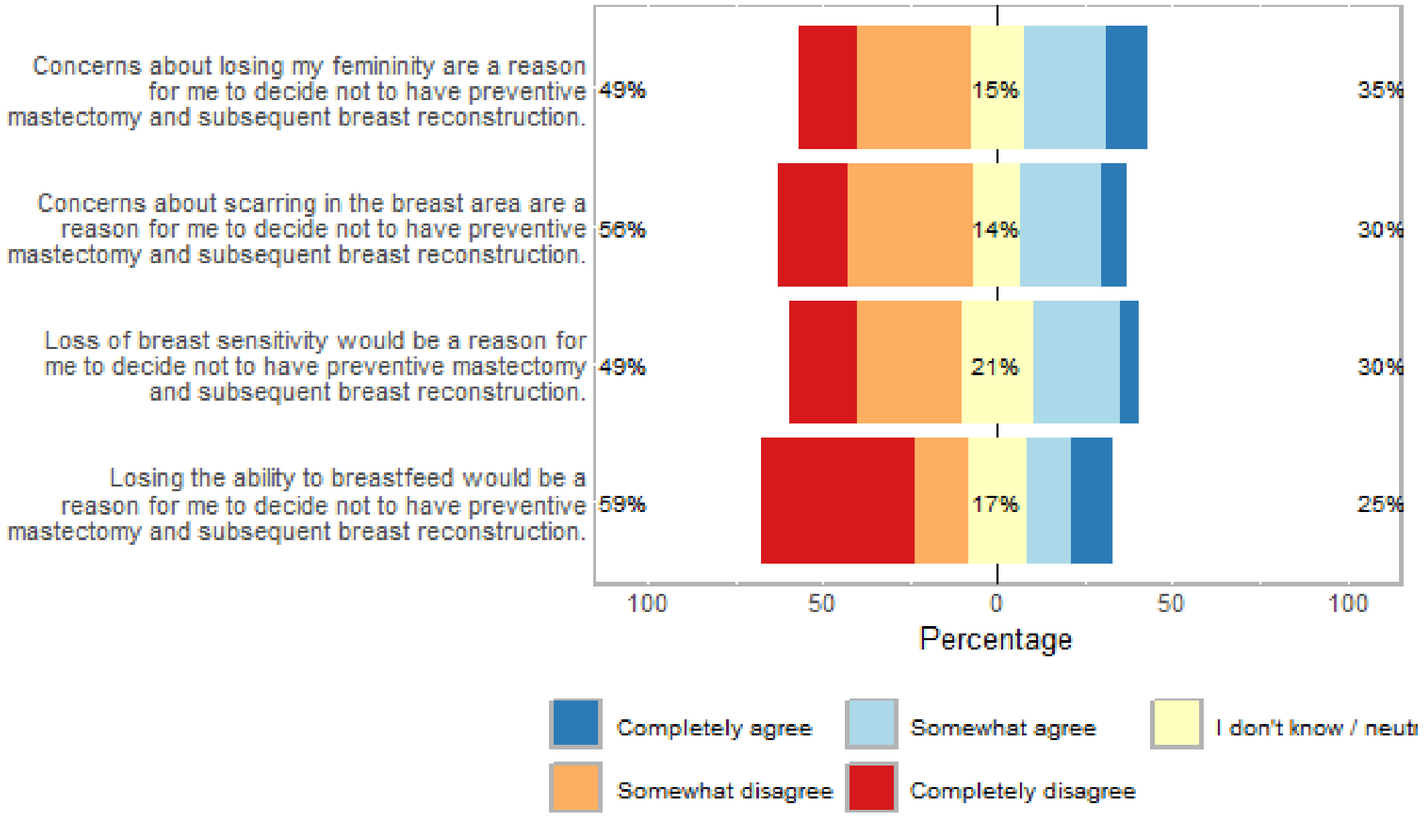
Women’s Topics in Plastic Surgery



Comment: Need for repeated operations(62 %), expected aesthetics result (54 %), nipples removal (49 %), concerns about foreign material (49 %) are primary drivers.

CHOICE PROJECT — CZECH COHORT; KEY POINT

Women's Topics in Plastic Surgery



Comment: Loss of feminity and sensitivity, concerns about scaring and ability to breastfeed, are opposite primary drivers.

CHOICE PROJECT — CZECH COHORT; KEY POINT

Physician Influence on Decision

PLASTIC SURGEON

79 %

of women report plastic surgeon influenced their decision — highest of all specialties*

89 %

of plastic surgeons favour RRM

Yet **only 18 % of women consulted a plastic surgeon**.

Central role: reconstruction options, body image, QoL, oncologic completeness.

⚠ CZ Cause: Lack/..?

CHOICE PROJECT — CZECH COHORT; KEY POINT

Physician Influence on Decision

Standardized MDT board for high-risk carriers before surgery: **recommended but not universal** (NCCN, ESMO Guidelines)

CHOICE PROJECT — CZECH COHORT

Communication Preference

155	91 %	17 %	15 %
CZ women patients	Prefer in-person meeting	Online peer group	Brochure / website

Face-to-face contact preferred over digital and statistic data— consistent with TMIM (Theory of Motivated Information Management) theory (experiential > statistical information)

CHOICE PROJECT — CZECH COHORT

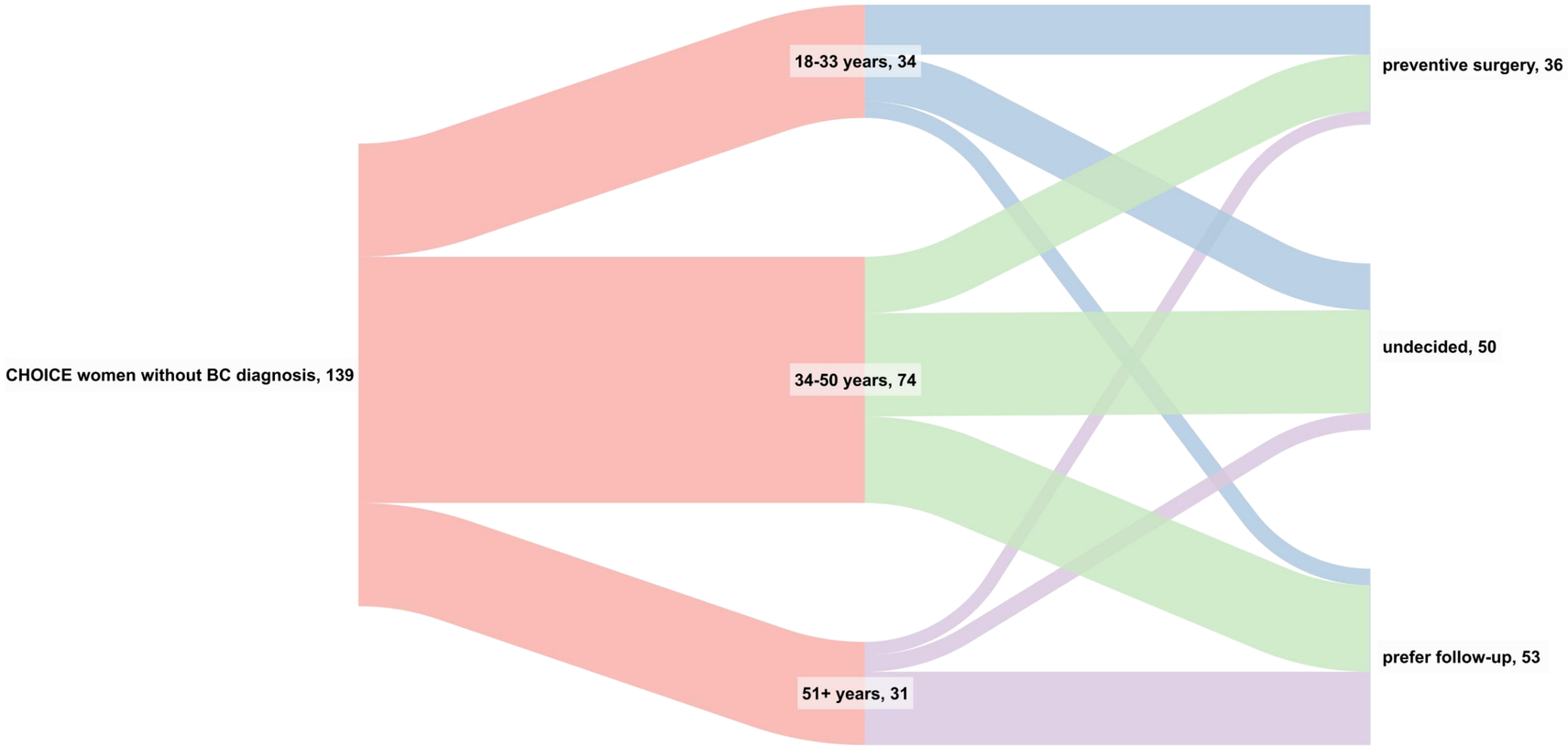
Unmet needs

155	26 %	22 %	18 %	10 %	28 %
CZ women patients	would aprreciate the possibility to speak to a woman who has gone through it	would aprreciate more information about available options	would aprreciate psychological support	would aprreciate a more tactful or empathic approach from physicians	would aprreciate something else

54	28 %	28 %	13 %	9 %	21 %
CZ undecided women patients	would aprreciate the possibility to speak to a woman who has gone through it	would aprreciate more information about available options	would aprreciate psychological support	would aprreciate a more tactful or empathic approach from physicians	would aprreciate something else

CHOICE PROJECT — CZECH COHORT

Attitude Towards Preventive Mastectomy: Closer look

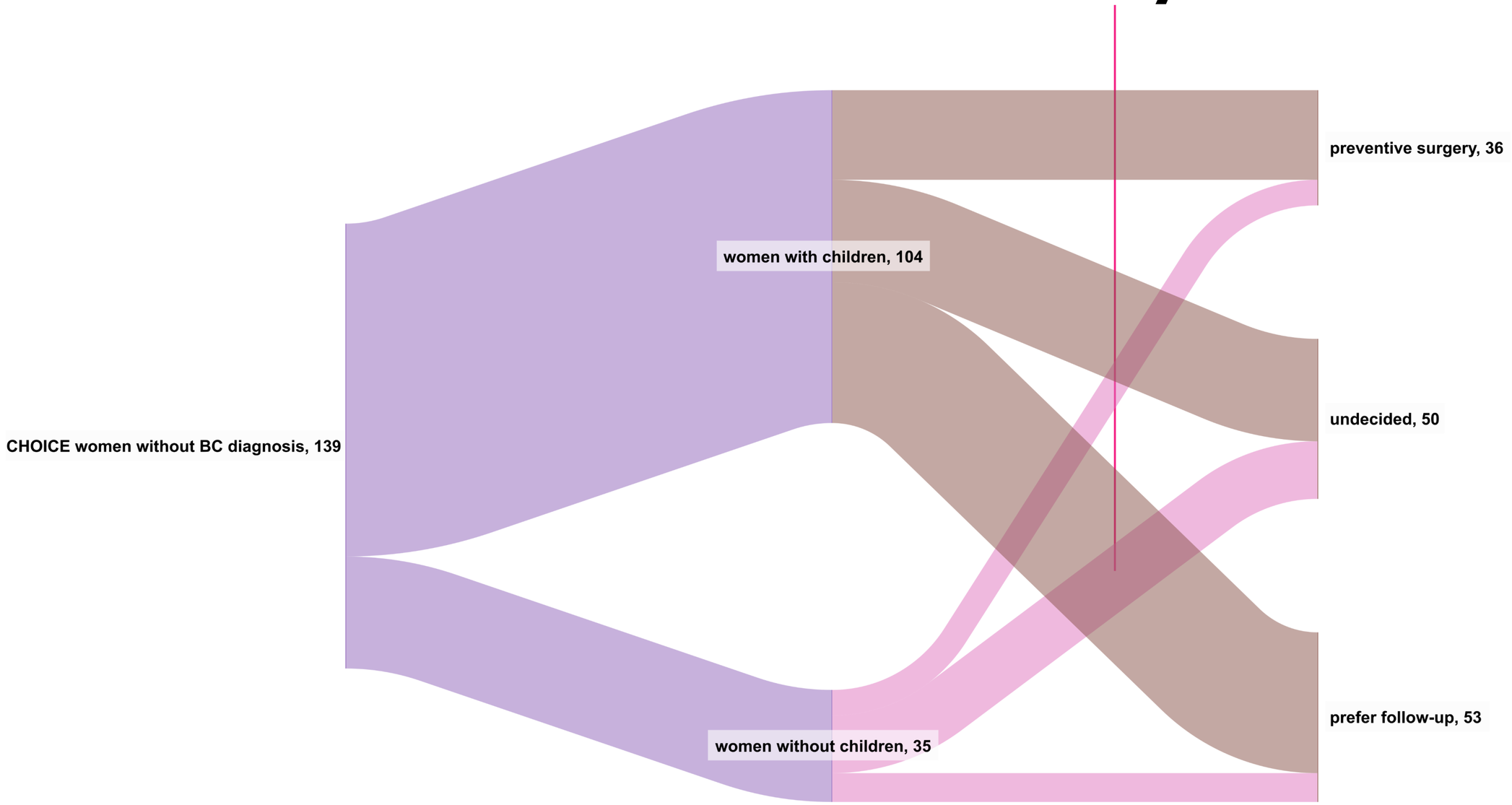


⚠️ **Only 14% of women aged 41–45 opted for risk-reducing mastectomy, despite breast cancer incidence among BRCA1 mutation carriers peaking in this age group.**

This represents the largest gap between available scientific evidence and clinical practice. Potential contributing factors may include fertility-related concerns, childcare responsibilities, and relationship stability.

CHOICE PROJECT — CZECH COHORT

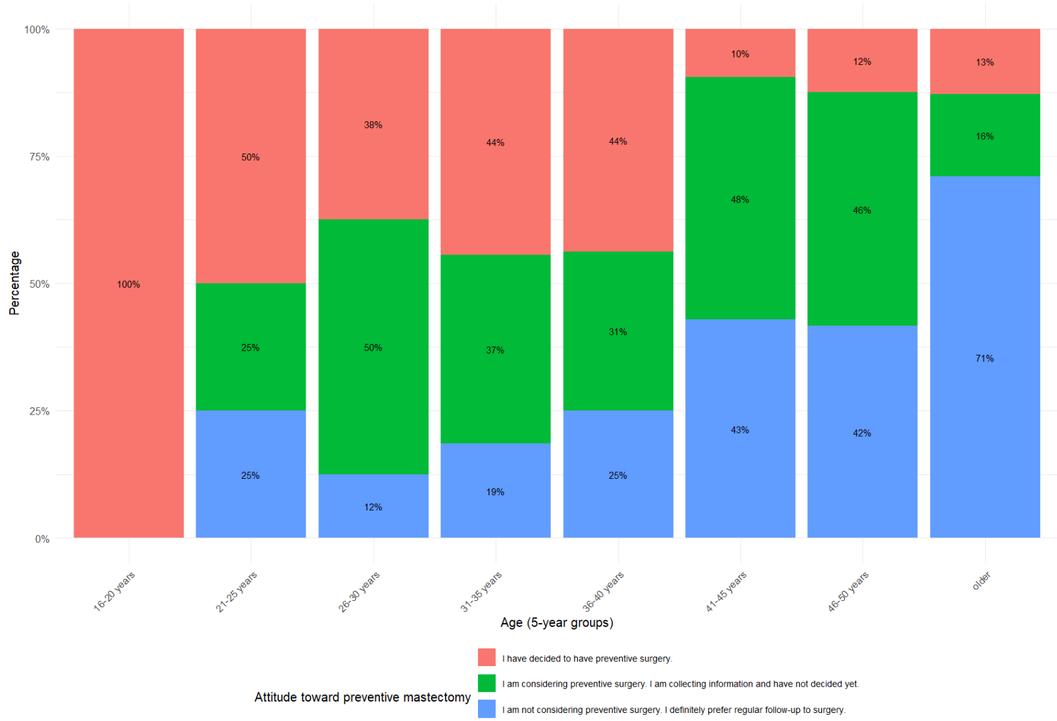
Attitude Towards Preventive Mastectomy: Closer look



CHOICE PROJECT — CZECH COHORT

Attitude Towards Preventive Mastectomy: Closer look

Characteristic	Age 18–33 years N = 34	34–50 years N = 82	51+ years N = 39	Total N = 155
Your current attitude towards preventive mastectomy				
I have decided to have preventive surgery.	15 (44%)	23 (28%)	7 (18%)	45 (29%)
I am considering preventive surgery. I am collecting information and have not decided yet.	14 (41%)	32 (39%)	8 (21%)	54 (35%)
I am not considering preventive surgery. I definitely prefer regular follow-up to surgery.	5 (15%)	27 (33%)	24 (62%)	56 (36%)



With **increasing age**, preferences shift from preventive surgery toward surveillance (44% → 28% → 18% vs. 15% → 33% → 62%), consistent with the anticipated shift in the benefit–risk balance as residual cancer risk and life expectancy decrease.

CHOICE PROJECT — CZECH COHORT

Attitude Towards Preventive Mastectomy: Closer look

Characteristic	Highest attained education			
	Primary N = 5	**Secondary N = 65**	**University N = 85**	**Total N = 155**
Your current attitude towards preventive mastectomy				
I have decided to have preventive surgery.	1 (20%)	20 (31%)	24 (28%)	45 (29%)
I am considering preventive surgery. I am collecting information and have not decided yet.	1 (20%)	16 (25%)	37 (44%)	54 (35%)
I am not considering preventive surgery. I definitely prefer regular follow-up to surgery.	3 (60%)	29 (45%)	24 (28%)	56 (36%)

Education level seems to shape decision pattern, not uptake

University: more undecided → information-driven → **responsive to counseling**

Secondary: more polarized → higher PRO but also higher refusal → **tailored communication strategy is essential**

CHOICE PROJECT — CZECH COHORT; KEY POINTS

Evidence-to-Practice

RRM decision-making in BRCA1/2 carriers is **not limited by knowledge alone**. It is **shaped by fear, body image, reconstruction expectations, family context, and access to care**.

Therefore, effective counseling must move beyond genetics and offer an **integrated pathway** combining oncology, plastic surgery, psychology, and peer support.

- Add peer support pathway
- Offer psychology routinely
- Use age/stage-specific materials
- Standardize high-risk tumor board
- Integrate before RRM decision
- Show realistic outcomes
- Discuss implants, appearance, nipple-sparing
- Prioritize oncologic completeness
- Plan post-RRM follow-up

THANK YOU.

Sources

Blondeaux, E. *et al.* Association between risk-reducing surgeries and survival in young BRCA carriers with breast cancer: an international cohort study. *The Lancet Oncology* **26**, 759–770 (2025).

Casaubon, J. T., Kashyap, S. & Regan, J.-P. BRCA1 and BRCA2 Mutations. in *StatPearls* (StatPearls Publishing, Treasure Island (FL), 2026).

Cipolla, C. *et al.* Breast-Conserving Surgery in BRCA Mutation Carriers: A Paradigm Shift Toward Individualized, Multidisciplinary Care. *Life* **15**, (2025).

Metcalfe, K. *et al.* International trends in the uptake of cancer risk reduction strategies in women with a BRCA1 or BRCA2 mutation. *Br J Cancer* **121**, 15–21 (2019).

Samigatova, A. *et al.* Molecular characteristics and prognostic insights into BRCA-associated breast cancer in Kazakhstan. *Sci Rep* **16**, 5652 (2026).

Population Frequency of Germline *BRCA1/2* Mutations. *Journal of Clinical Oncology* https://ascopubs.org/doi/10.1200/JCO.2016.67.0554.

Paluch-Shimon, S. *et al.* Prevention and screening in *BRCA* mutation carriers and other breast/ovarian hereditary cancer syndromes: ESMO Clinical Practice Guidelines for cancer prevention and screening†. *Annals of Oncology* **27**, v103–v110 (2016).

Sessa, C. *et al.* Risk reduction and screening of cancer in hereditary breast-ovarian cancer syndromes: ESMO Clinical Practice Guideline. *Annals of Oncology* **34**, 33–47 (2023).

Bertozzi, S. *et al.* Risk-Reducing Breast and Gynecological Surgery for BRCA Mutation Carriers: A Narrative Review. *Journal of Clinical Medicine* **12**, (2023).

Kuchenbaecker, K. B. *et al.* Risks of Breast, Ovarian, and Contralateral Breast Cancer for BRCA1 and BRCA2 Mutation Carriers. *JAMA* **317**, 2402–2416 (2017).

Wiberg, R. *et al.* Surgical Outcomes After Risk-Reducing Mastectomy Among BRCA1 and BRCA2 Carriers. *JAMA Netw Open* **9**, e262574 (2026).

CHOICE BREAST CANCER LITERACY

Co-funded by the European Union

NOVA IMS INFORMATION MANAGEMENT SCHOOL

iba Institute of Biostatistics and Analyses

MUNI MED

ARISTOTLE UNIVERSITY OF THESSALONIKI