



ΕΛΛΟΚ
ΕΛΛΗΝΙΚΗ
ΟΜΟΣΠΟΝΔΙΑ
ΚΑΡΚΙΝΟΥ



IMS Health & Quintiles are now
IQVIA™

ALL.CAN Survey

*Presentation of the Results
on behalf of the
Hellenic Cancer Federation- ELLOK*

10. 04. 2019

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- + Objectives and identity of the survey
- + Related to the disease
- + Cancer diagnosis
- + Cancer care and treatment
- + Continuous support and return to social and professional life
- + Financial implications for the patient
- + Patient support groups
- + Overall experience with cancer

All.Can survey: An online survey about the experience of 640 cancer patients and survivors

Survey's objectives

Survey's objectives

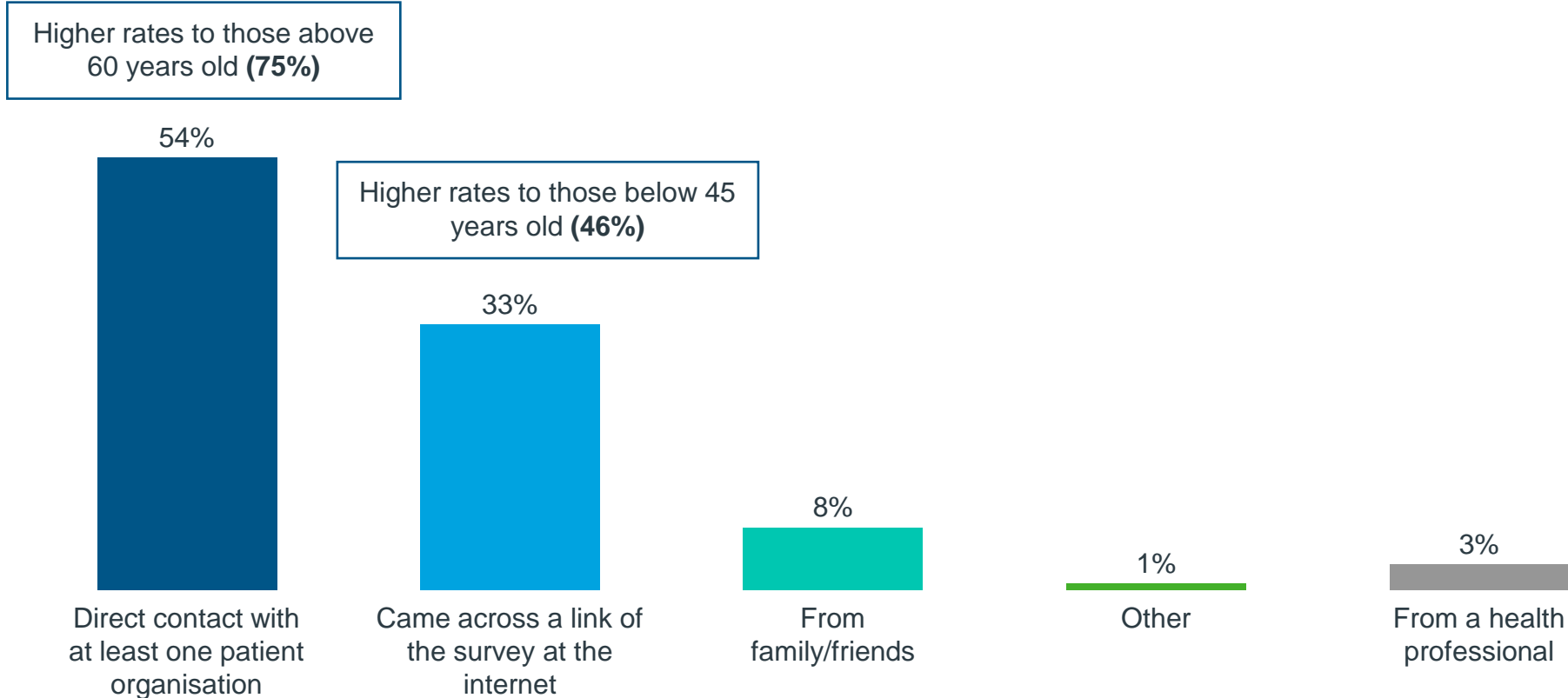
- Survey's main objective is to identify ways of intervention through patients' experience, towards cancer care improvement.
- The survey has been conducted within the All.Can initiative for the elimination of inefficiencies in cancer care. As inefficiency is described every aspect of the oncological care which is not focused on what matters for patients.
- The survey is addressed to cancer patients and people who have cancer experience. It reports information on diagnosis, on cancer care, the return to social and professional life, any relations with patients support groups , as well as the overall experience with cancer.

Identity of the survey

- All.Can survey has been conducted online
- The survey was addressed to cancer patients and people with cancer experience
- Total number of participants: **640 participants with cancer experience**
- A structured questionnaire has been used to meet survey's objectives. Both closed and open ended questions have been used so that participants could express their views and experiences spontaneously.
- Open-ended questions on similar issues have been grouped under certain categories
- The survey has been conducted from December 2018 till February 2019

Patient organisations have been the main source of information for the All.Can survey, following by the Internet

Source of information for the All.Can survey



Ep.34: What was your source of information for the survey?

Source: IQVIA PMR (February 2019)

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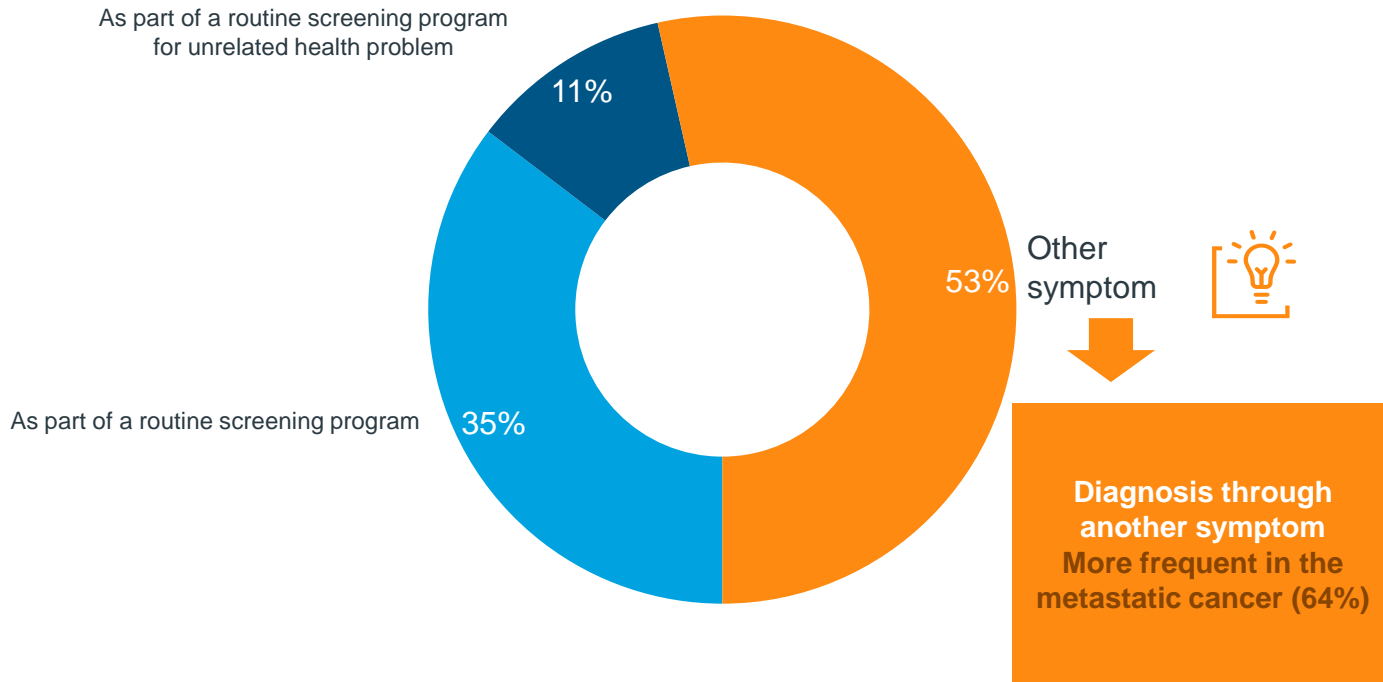
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53% of the diagnoses emerged when examining another health problem; 20% has been initially diagnosed with cancer metastasis

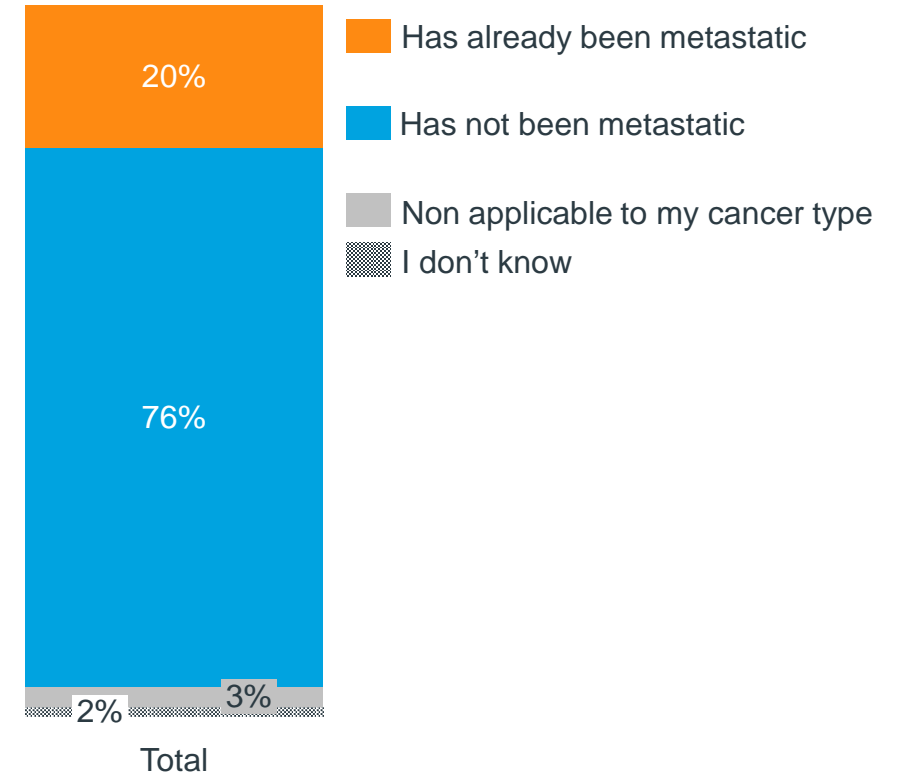
Cancer metastasis during the diagnosis



Diagnosis has been made...



During the diagnosis cancer...



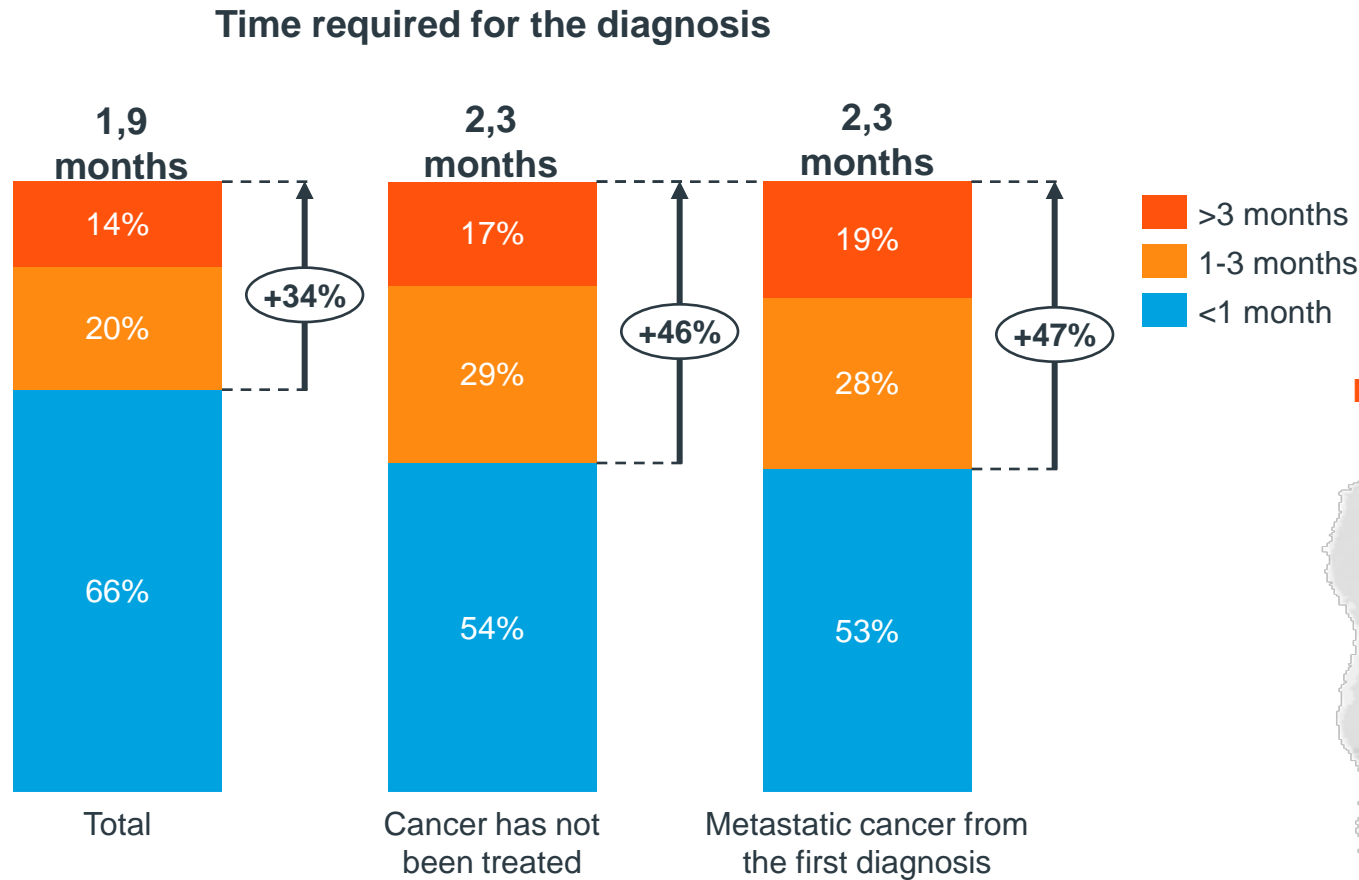
Ep.1: Was your cancer diagnosed as part of a routine screening programme, or as part of a screening programme for an unrelated health problem?
Ep.2: Had your cancer spread to other organs or parts of your body at the time you were first told you had cancer?

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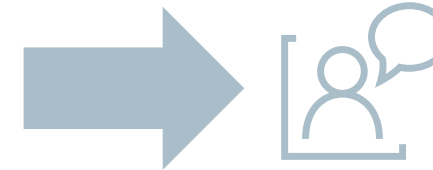
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2 months in average were required for the diagnosis since the patient's visit to the doctor with the first symptoms

Time for diagnosis



Participants commented on:



Diagnoses which required less than a month:

- Delay due to non timely and valid diagnosis or false medical examinations /results
- **Late / Difficult** diagnosis / **Delays**
- Delays due to long waiting for medical examinations and results in public hospitals

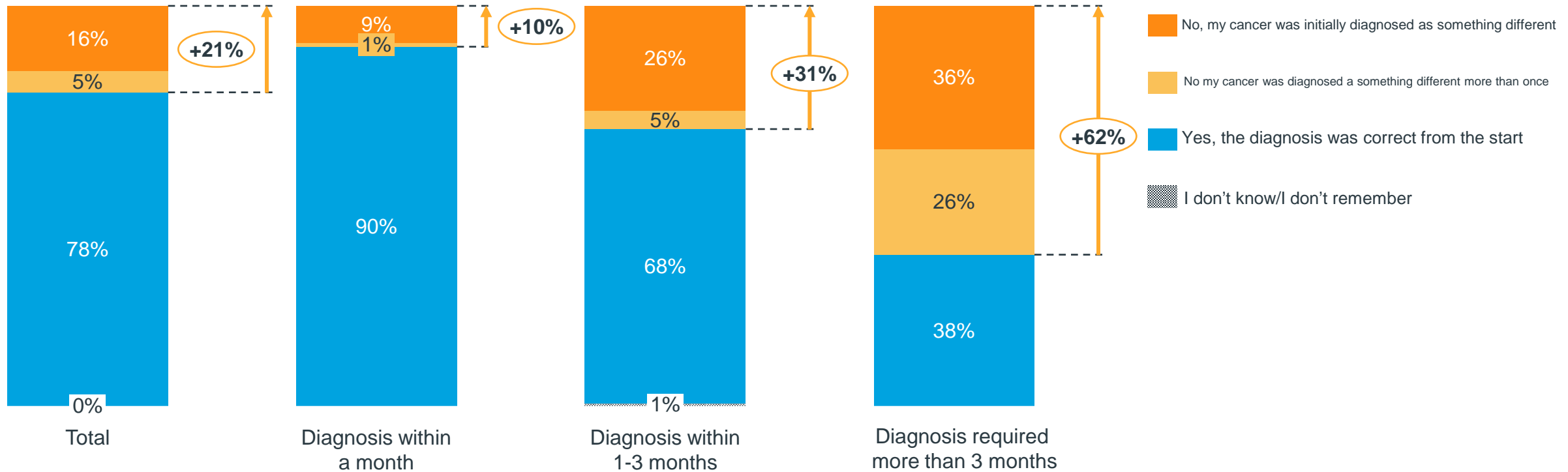
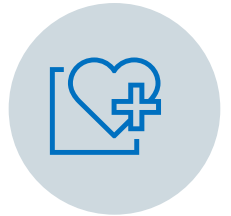
Q.2: After first seeing a doctor about the health problem caused by your cancer, how long did it take to be diagnosed with cancer?

CANCER DIAGNOSIS

21% mentions false initial diagnosis

62% of false diagnoses were made at least three months after first seeing a doctor

Validity of cancer diagnosis



Q.3: Was the diagnosis correct at every point during this time?

Source: IQVIA PMR (February 2019)

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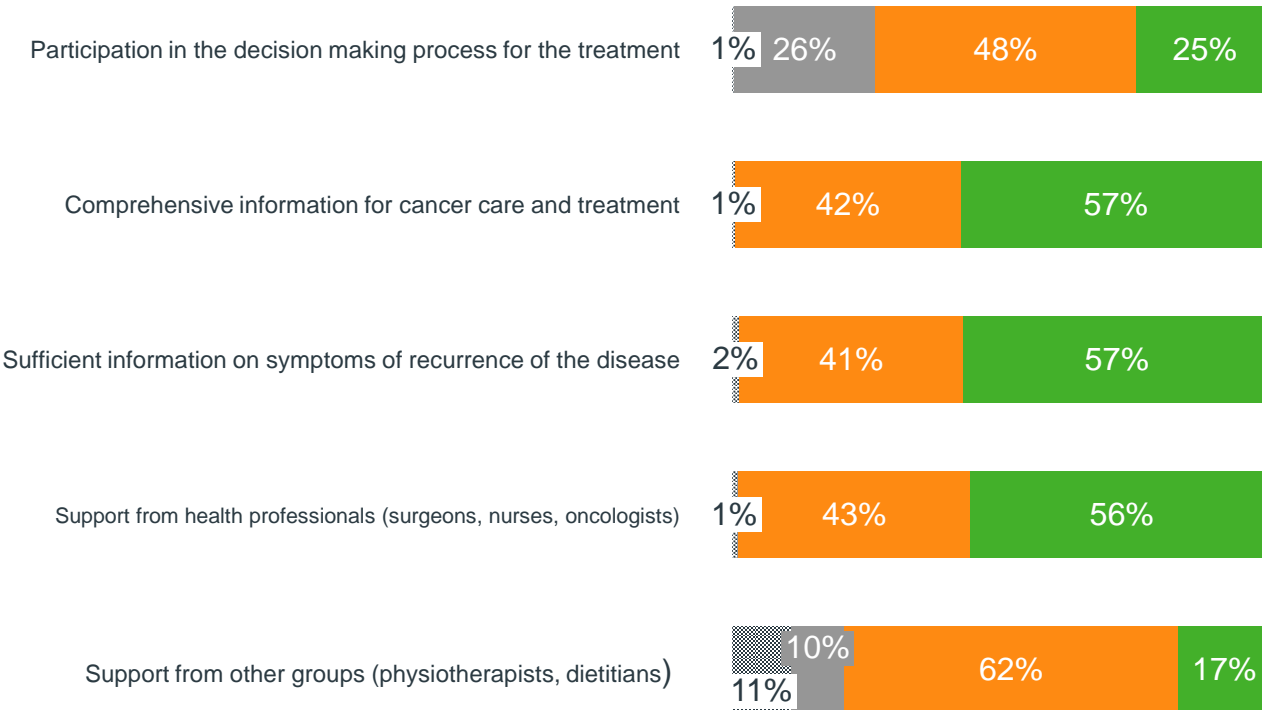
4% state that they received complete information and support during the disease

Information, participation and support



I don't know/I don't remember
 N/A in my case

Up to an extent/Not at all
 Yes



25%
Participated in the decision making process

46%
Received information on treatment and possible future symptoms

14%
Received support from health professionals and other supportive groups

4%
Received information and support at all stages of care during the disease

Q.6: Were you involved as much as you wanted to be in deciding which treatment options were best for you?
 Q.7: Have you always been given enough information about your cancer and treatment in a way that you could understand?
 Q.8: Have you always been given enough information, in a way that you could understand, about signs and symptoms to look out for that your cancer might be returning / getting worse?
 Q.9: There may be many groups of people involved in your care (e.g. surgeons, oncologists, radiologists, nurses, other specialists). Have you always felt well supported by these people to know when you should seek further care?;
 Q.10: If you have needed other support (e.g. from dietitians, physiotherapists, or mental health services), is this always available to you when you need it (public hospital)?

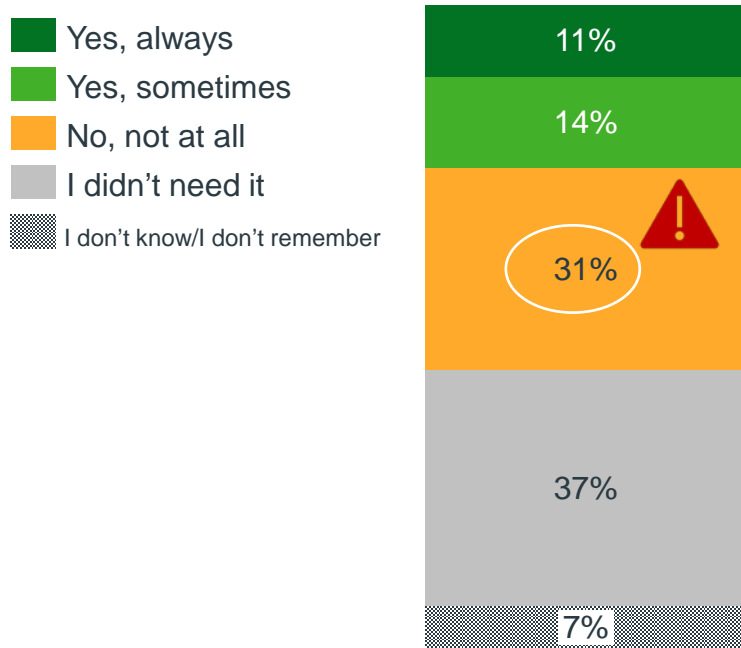
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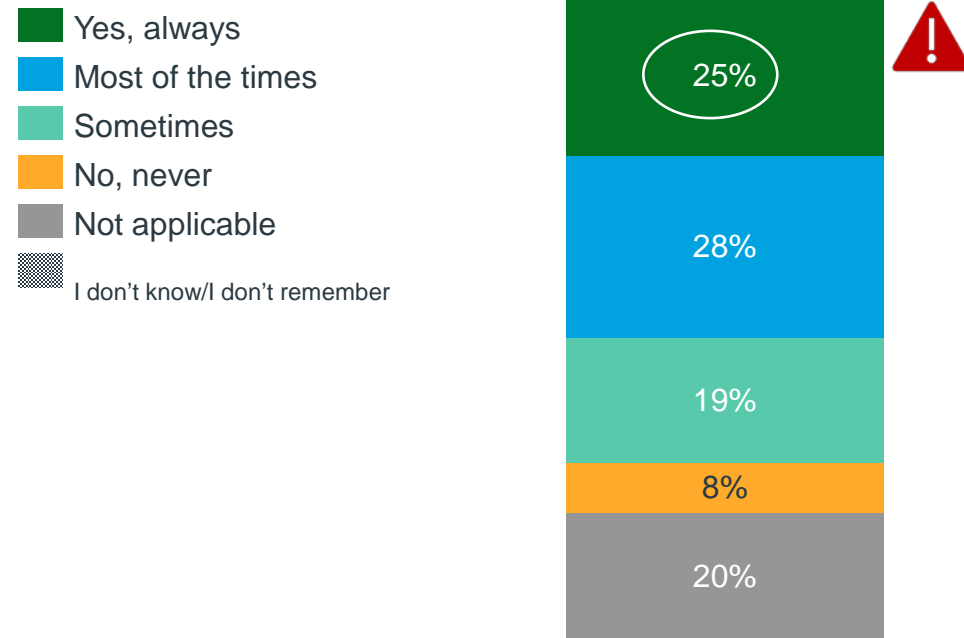
31% did not have any psychological support, while only 1 in 4 received information and care for the pain

Psychological support and treatment of pain

Psychological support during and after cancer care provided by the public health system



Information and care for the treatment of pain

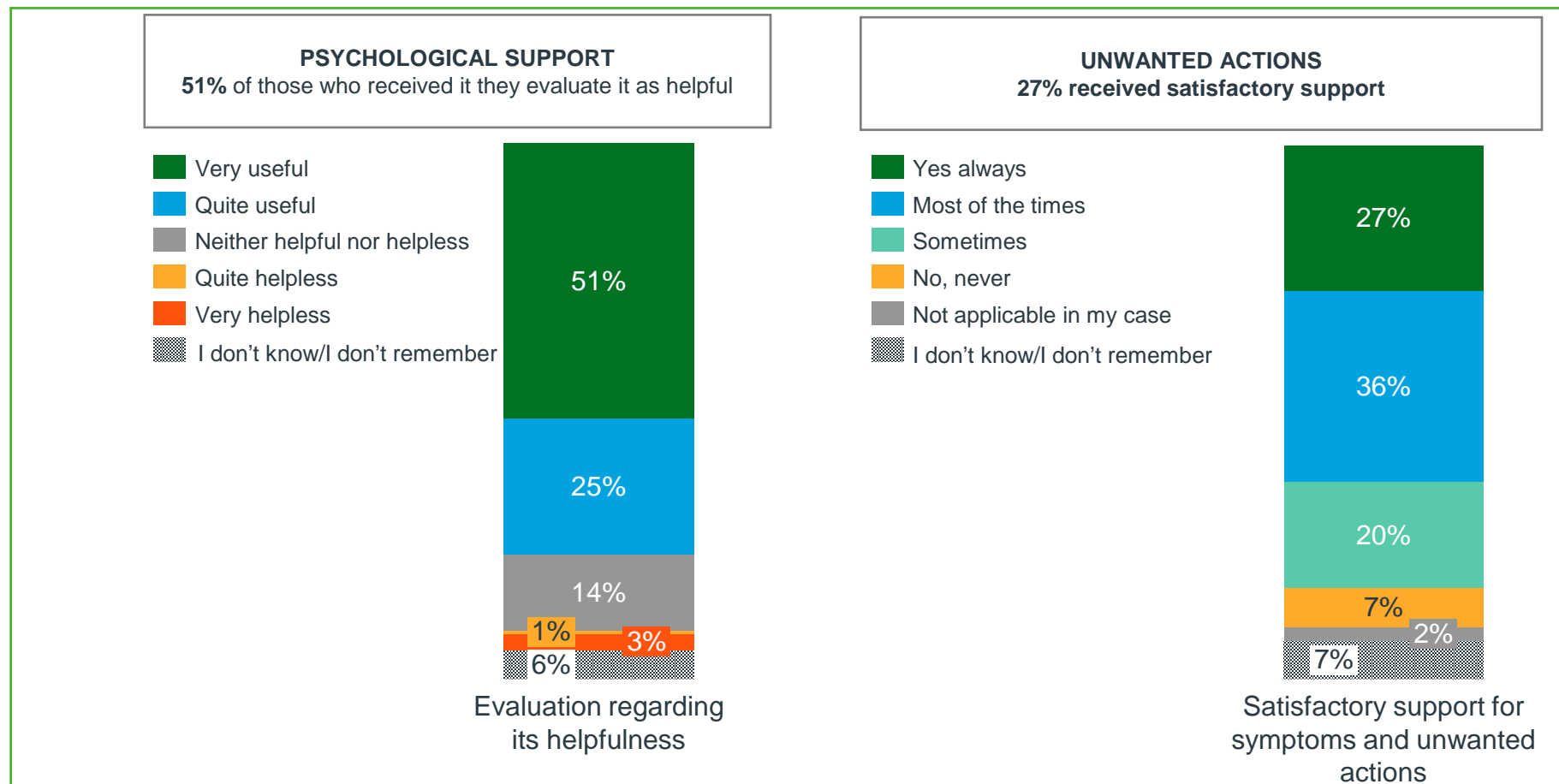


Q.12: Many cancer patients say that they need ongoing psychological support throughout their care, and maybe even afterwards. If you have needed this, has it always been available to you (public hospital)?
 Q.15: Looking specifically at pain, do you feel that you have always been given sufficient information and care to deal with the pain you might have experienced?

1 in 4 received psychological support. Half of them stated that it had been very helpful

Psychological support, its helpfulness and patients' satisfaction

25% received psychological support



Q.12: Many cancer patients say that they need ongoing psychological support throughout their care, and maybe even afterwards. If you have needed this has it always been available to you?

Q.13: How helpful has this psychological support been?

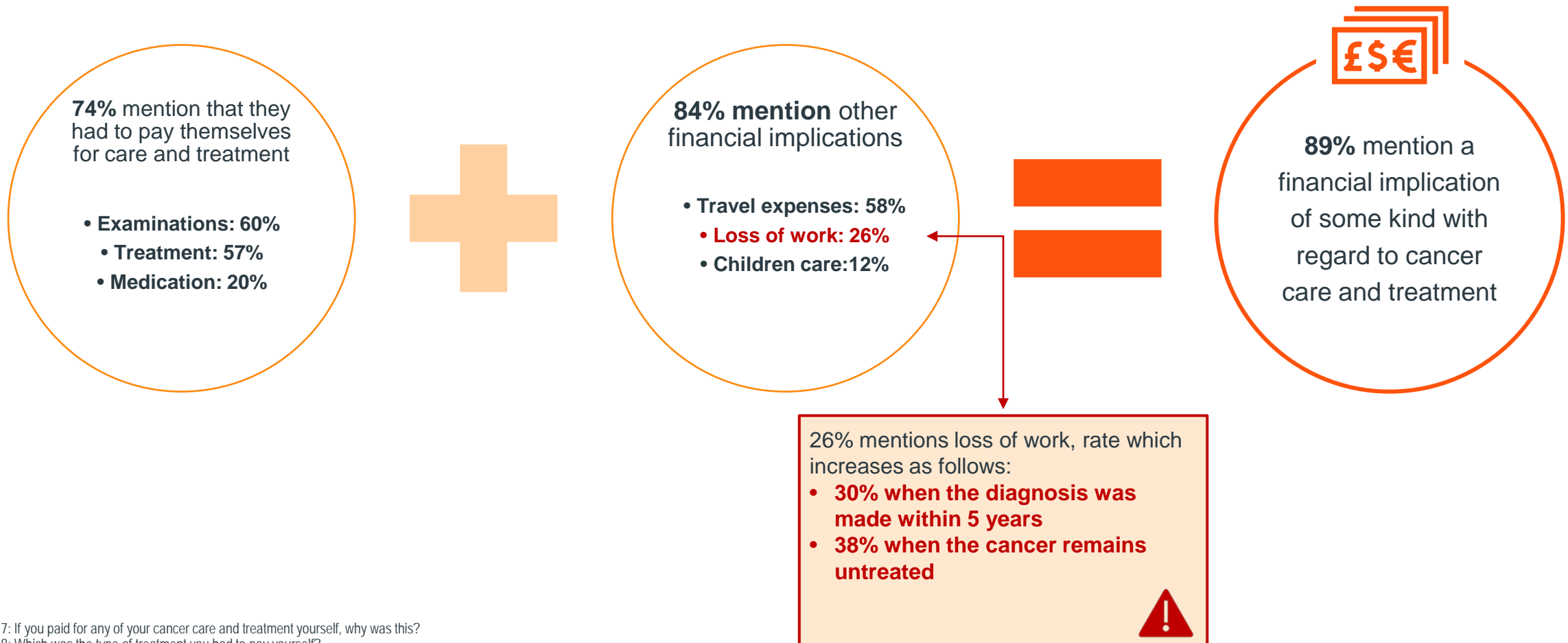
Q.14: Do you feel you have always been given enough support to deal with any ongoing symptoms and side effects, even beyond the phase of active treatment (if applicable)?

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In total, 89% mentions a financial implication of some kind during their disease. 1 in 4 mentions loss of work

Financial implications for the patient



Q.17: If you paid for any of your cancer care and treatment yourself, why was this?
Q.18: Which was the type of treatment you had to pay yourself?
Q.19: Were there any other financial implications of your cancer care and treatment?

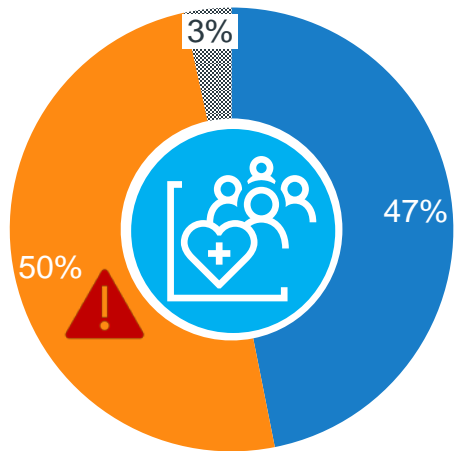
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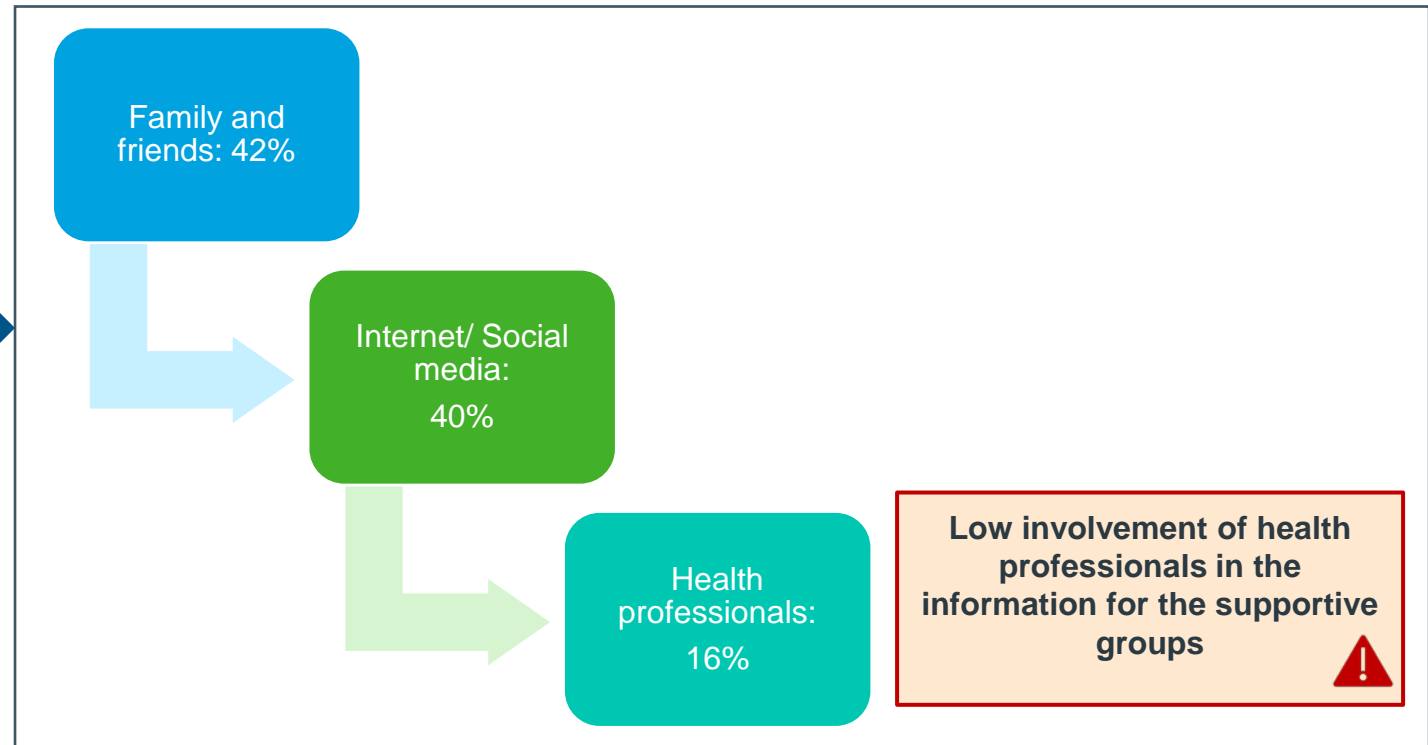
1 in 2 patients received no information at all for supportive groups, low involvement of health professionals

Information for supportive groups

■ Yes
■ No
■ I don't know/I don't remember



Main sources of information



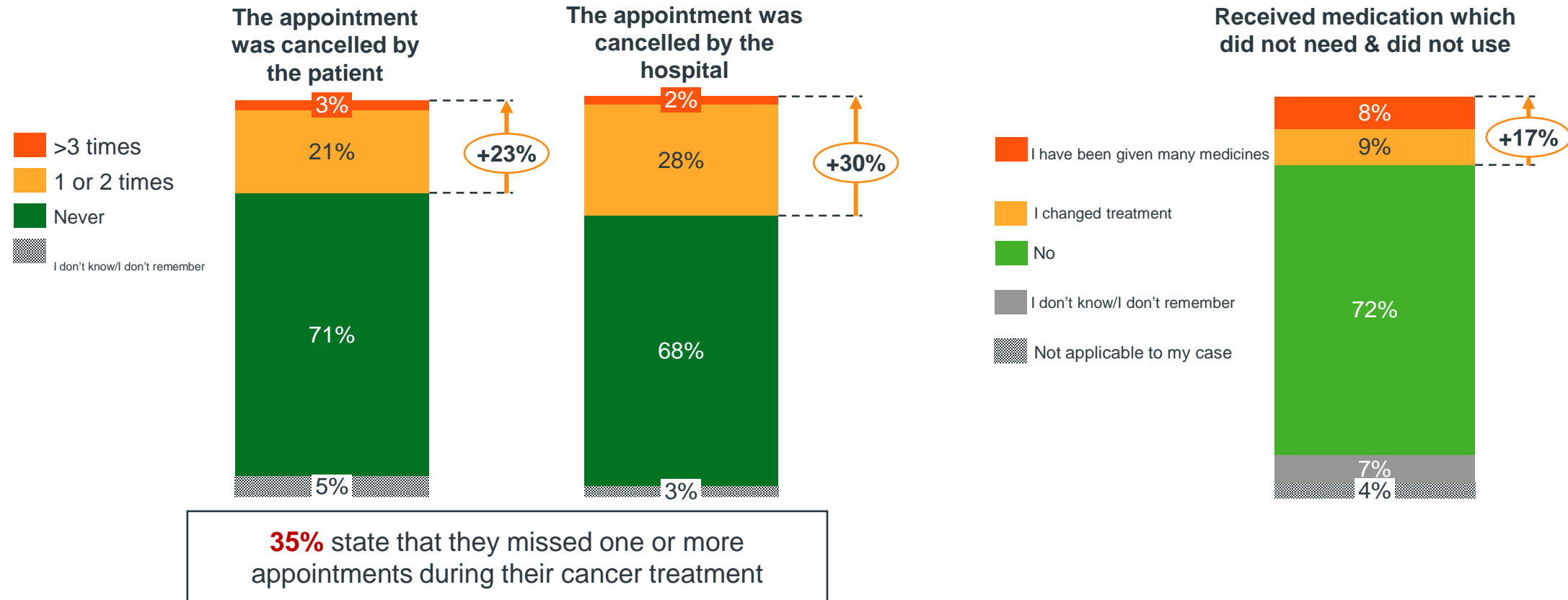
Q.20: Were you given information about patient groups, charities and other organisations that might be able to support you through your diagnosis and care?
Q.21: How did you find out about these groups? What kind of support did you look for?

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1 in 3 experienced some cancellation of a scheduled appointment, and 17% received medication they did not use

Factors which prevented smooth treatment and cancer care



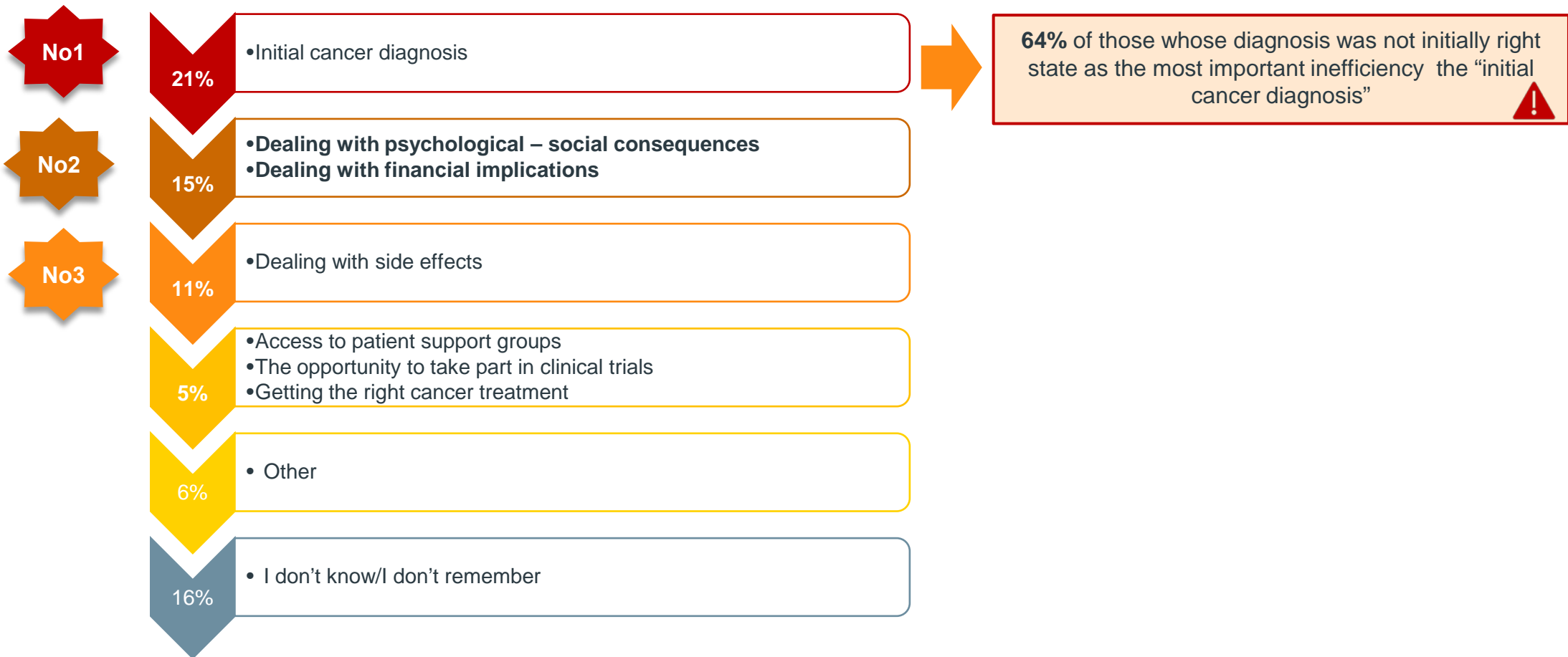
Q.23: During the whole of your care and treatment for cancer, did you have to miss or cancel appointments at short notice?

Q. 24: During the whole of your care and treatment for cancer, how often were appointments cancelled by the hospital or clinic you were due to attend?

Q.25: During the whole of your care and treatment, have you been given any excess medication that you did not need?

The initial cancer diagnosis emerged as the most important inefficiency, following by the social-economic consequences




The most important inefficiency during cancer treatment – ONE CHOICE



Q.26: During the whole of your cancer care and treatment where do you feel there was most inefficiency?

Η «αρχική διάγνωσή» είναι η Νο1 ανεπάρκεια σε Καναδά και Μ. Βρετανία, ενώ στην Πολωνία είναι οι «ανεπιθύμητες ενέργειες»

Σημαντικότερη ανεπάρκεια κατά τη θεραπεία του καρκίνου – Σύγκριση με άλλες χώρες

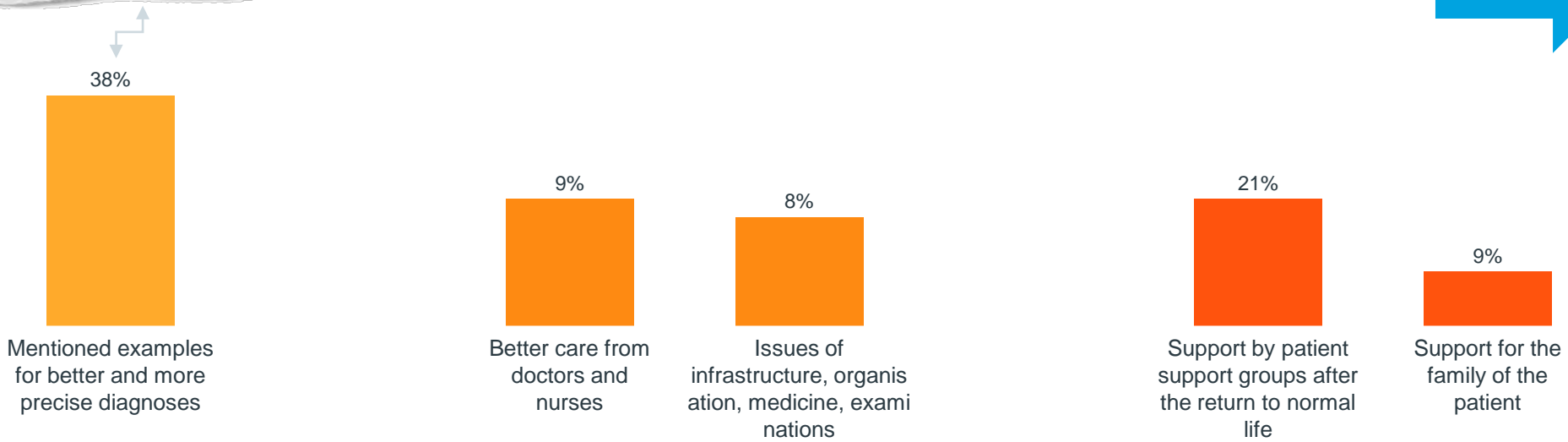
Καναδάς 	Πολωνία 	Μεγάλη Βρετανία 			
Η αρχική διάγνωση του καρκίνου	25%	Η αντιμετώπιση των ανεπιθύμητων ενεργειών	27%	Η αρχική διάγνωση του καρκίνου	34%
Η αντιμετώπιση των ανεπιθύμητων ενεργειών	17%	Η αντιμετώπιση των ψυχοκοινωνικών επιπτώσεων	18%	Η αντιμετώπιση των ανεπιθύμητων ενεργειών	19%
Η αντιμετώπιση των ψυχοκοινωνικών επιπτώσεων	15%	Η αρχική διάγνωση του καρκίνου	14%	Η αντιμετώπιση των ψυχοκοινωνικών επιπτώσεων	15%
Η αντιμετώπιση των οικονομικών επιπτώσεων	12%	Χορήγηση σωστής θεραπείας για τον καρκίνο	13%	Συμμετοχή σε κλινικές μελέτες	6%
Χορήγηση σωστής θεραπείας για τον καρκίνο	9%	Η αντιμετώπιση των οικονομικών επιπτώσεων	10%	Πρόσβαση σε οργανώσεις υποστήριξης ασθενών	5%
Πρόσβαση σε οργανώσεις υποστήριξης ασθενών	7%	Συμμετοχή σε κλινικές μελέτες	9%	Χορήγηση σωστής θεραπείας για τον καρκίνο	5%
Συμμετοχή σε κλινικές μελέτες	4%	Πρόσβαση σε οργανώσεις υποστήριξης ασθενών	5%	Η αντιμετώπιση των οικονομικών επιπτώσεων	4%
Άλλο	10%	Άλλο	3%	Άλλο	10%

Ερ.26: Σε όλη τη διάρκεια της φροντίδας και της θεραπείας σας για τον καρκίνο, πού πιστεύετε ότι υπήρχε η μεγαλύτερη ανεπάρκεια;

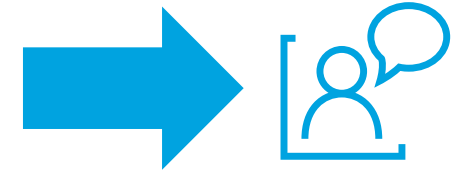
Participants expressed their views and desires for better diagnoses-care-return to normal life

Examples of focused actions for the improvement of cancer treatment

- Better and more valid examinations/diagnoses
- Not unnecessary examinations
- Less delays for examinations/surgery, etc



The participants mentioned...



Examples for better diagnosis **Examples for better cancer care and treatment** **Examples for the reduction of the emotional burden**

Q.4: Please think about your cancer diagnosis. Do you have any examples of how this could have been improved? In particular, were there things that you felt were wasting time, money or other resources?

Q.11: Do you think that your care and treatment were efficient enough with regard to the available resources (doctors, clinics, medication etc) of the public health system? How do you think that resources could have been more efficiently used by the healthcare system during your cancer care and treatment?

Q.27: Many cancer patients talk about the emotional burden on them and their families, as they go through cancer care. Have you come across any examples of how the healthcare system could have worked differently, or did work to reduce this?

Please contact us for more information



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