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Barriers in early diagnosis

Survey results



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Introduction

- A main objective of the whole WP5 is to identify barriers to early detection and its management
- Specifically, task 5.1 addresses early detection
- In order to examine early detection strategies from several perspectives, WP5 produced a Survey on perceptions of attitudes of barriers to early detection (Milestone 5.1)
 - The survey schedule was postponed from M5 to M11, February 2019 for accurate and well devised content
- Initially, the survey was planned to include 4-6 countries but was enlarged to the whole European level



Background

- As background material, we used the [WHO Guide to cancer early diagnosis](#)
- The WHO guide uses the definition for early diagnosis related to **the recognition of symptomatic cancer** in patients
 - Thus the second dimension of early detection, covering cancer screening, was not in a focus in the survey
- According to WHO, the focus of cancer early diagnosis is in people who have symptoms and signs consistent with cancer. The objective is to identify the disease at the earliest possible opportunity and the link to diagnosis and treatment without delay. When done promptly, cancer may be detected at a potentially curable stage, improving survival and quality of life.
- Also, scientific literature on barriers, benefits and harms of early diagnosis was searched and benefited as background material (see References)



Methods

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Cancer types

- Based on the above-mentioned background materials CSF compiled a working paper on early diagnosis of cancer in cancer control strategies
- It included examples of programmatic services of interest which were discussed in an online-meeting of WP5 task 5.1 (early diagnosis) working group
- As a result, the cancer types chosen for the survey were:
 1. Oral cancers and precancers by dentists looking for early signs
 2. Identifying skin cancers by checking and surveillance for moles
 3. Possible early prostate cancer: symptoms as a sign for action to improve early diagnosis
 4. Diverse breast cancer symptoms: better awareness and recognition to improve early diagnosis
 5. Other, freely chosen according to interest



Barriers

- Initially, 11 barriers were drafted but after expert discussions, these were decreased to six (6):
 1. Lack of evidence base on benefits and harms; evidence-based guidelines can't be formed due to lack of knowledge. This barrier relates also to health policy planning: is there enough research resource for necessary knowledge production.
 2. Limited access to primary care due to long distances, lack of transportation, i.e., non-availability of services in the local setting.
 3. Lack of awareness: Poor health literacy leading to shortcomings in the knowledge of cancer symptoms and on diagnosis and treatment pathways, thus delaying seeking for care.



Barriers

4. Cancer stigma as sense of devaluation by individuals or communities related to cancer patients. Beliefs and values associated e.g. to gender, social class or religion, leading to reluctant attitude or fear to seek or comply to care.
5. Patient-level financial constraints in certain population groups (ethnic, social class) to access primary health services and treatment.
6. Poor organization of patient pathway: Poor coordination of services and loss to follow-up, lack of referral pathways, too many facilities for patients leading possibly to duplicate services or overuse of services, poor communication between providers, absence of patient identifiers and reliable health information system.



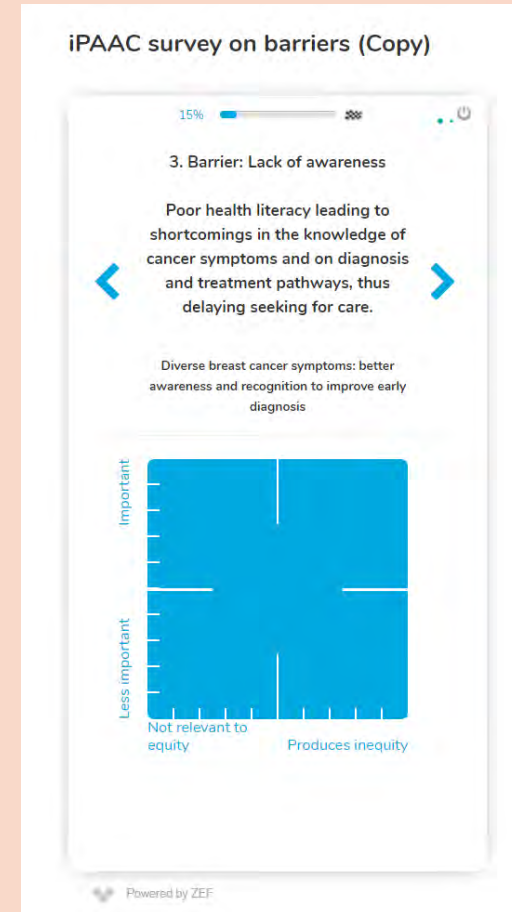
Compiling survey

- When a draft version of the survey was compiled, an advisory group tested and commented it
 - The advisory group members were: Patricia Fitzpatrick (UCD), Marta Hernandez Garcia (Fisabio), Ana Molina Barcelo (Fisabio), Jennifer Priaulx (EU-topia), David Ritchie (ECL), Wendy Yared (ECL)
- The survey was executed by the Finnish company ZEF and its survey tool
- Answers were collected and handled anonymously and according to GDPR



Survey methodology

- Respondents chose first the cancer type wanted to be evaluated
- Next, they placed each barrier in a four-fold table with the response dimensions:
 1. Not relevant to equity – Produces inequity (X-axis)
 2. Important – Less important (Y-axis)



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Invitations

- The survey was sent by CSF and ECL to approx. 175 respondents including both persons and organisations
- The invited actors consisted of among others the iPAAC consortium, cancer patient and advocacy groups, WHO and its suborganisations, cancer societies, ECL members and collaborative partners, cancer industry, cancer prevention organisations, health care professional organisations
- The survey was also requested to be shared and disseminated by invited contacts
- The first invitations were sent 31 January and 1-2 reminders in Mid and/or late February
- The survey was open from answers from 31 January to 10 March
 - The initial closing date was 28 February but was extended in order to achieve a higher response rate



Respondents

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	N	%
Visited survey	981	100
Did not participate	641	65.3
Started answering	340	34.7
Interrupted	187	19.1
Completed answering	153	15.6



Connection of respondent to survey (N=147)

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Organization	N
iPAAC	77
Other	37
ECPC and Europa Donna	17
EU Institution	7
ECL	6

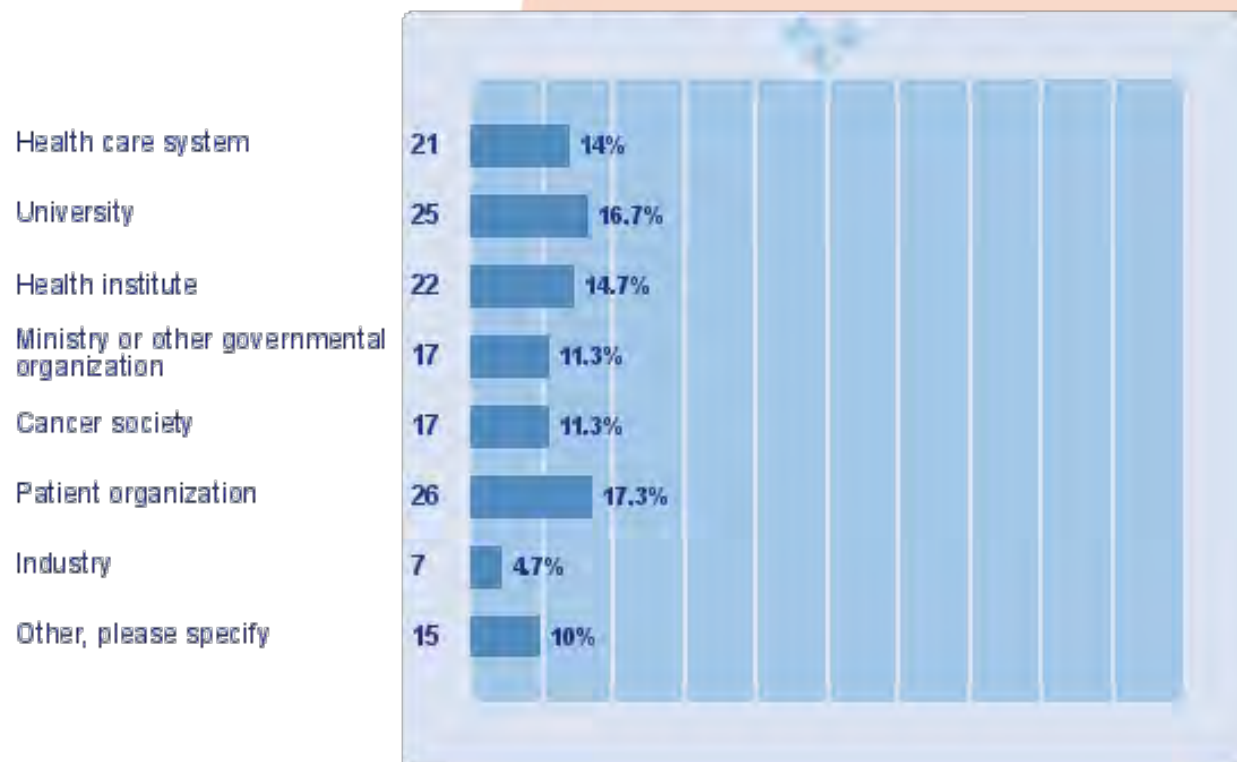
Other respondents:

- Cancer societies and leagues
- WHO
- Other patient organisations and networks
- Industry
- Universities and academia
- Health care system



Professional affiliations

2. Professional Affiliation of respondent



Other affiliations:

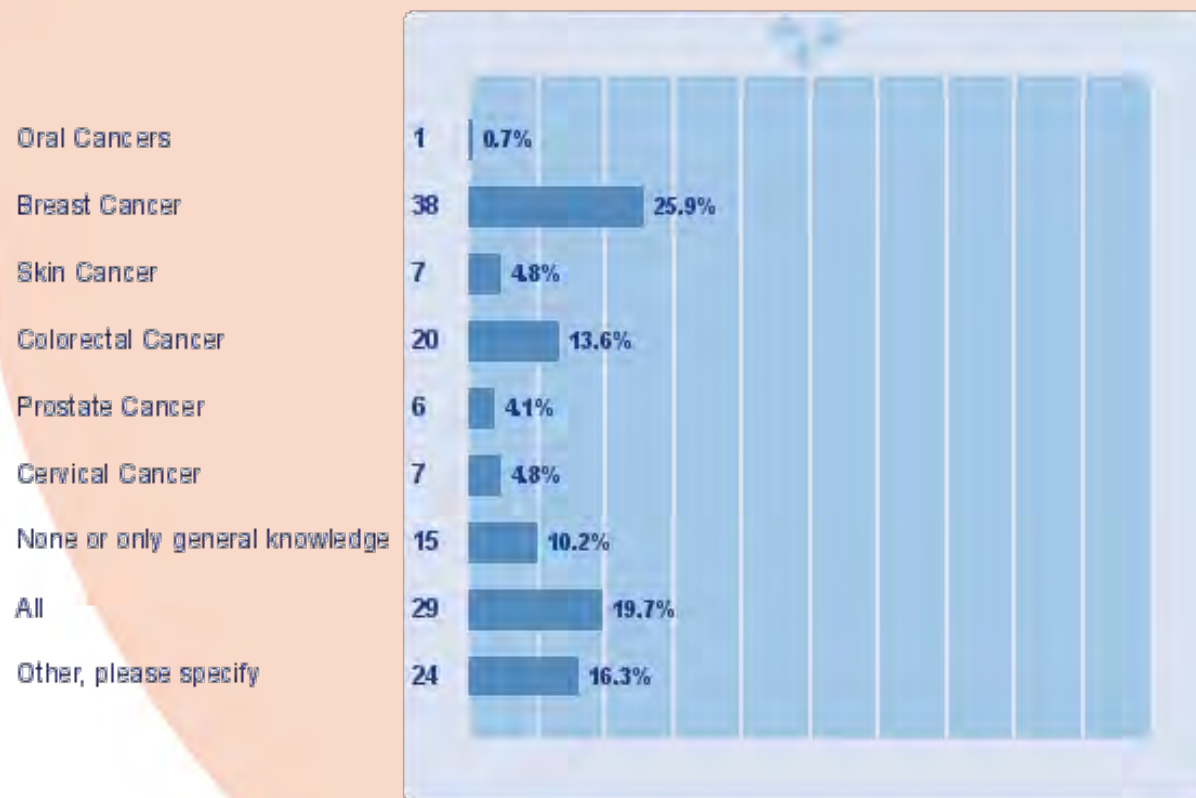
- Research
- Cancer registries
- Private health care professionals



Expert knowledge

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3. Expert knowledge mostly in



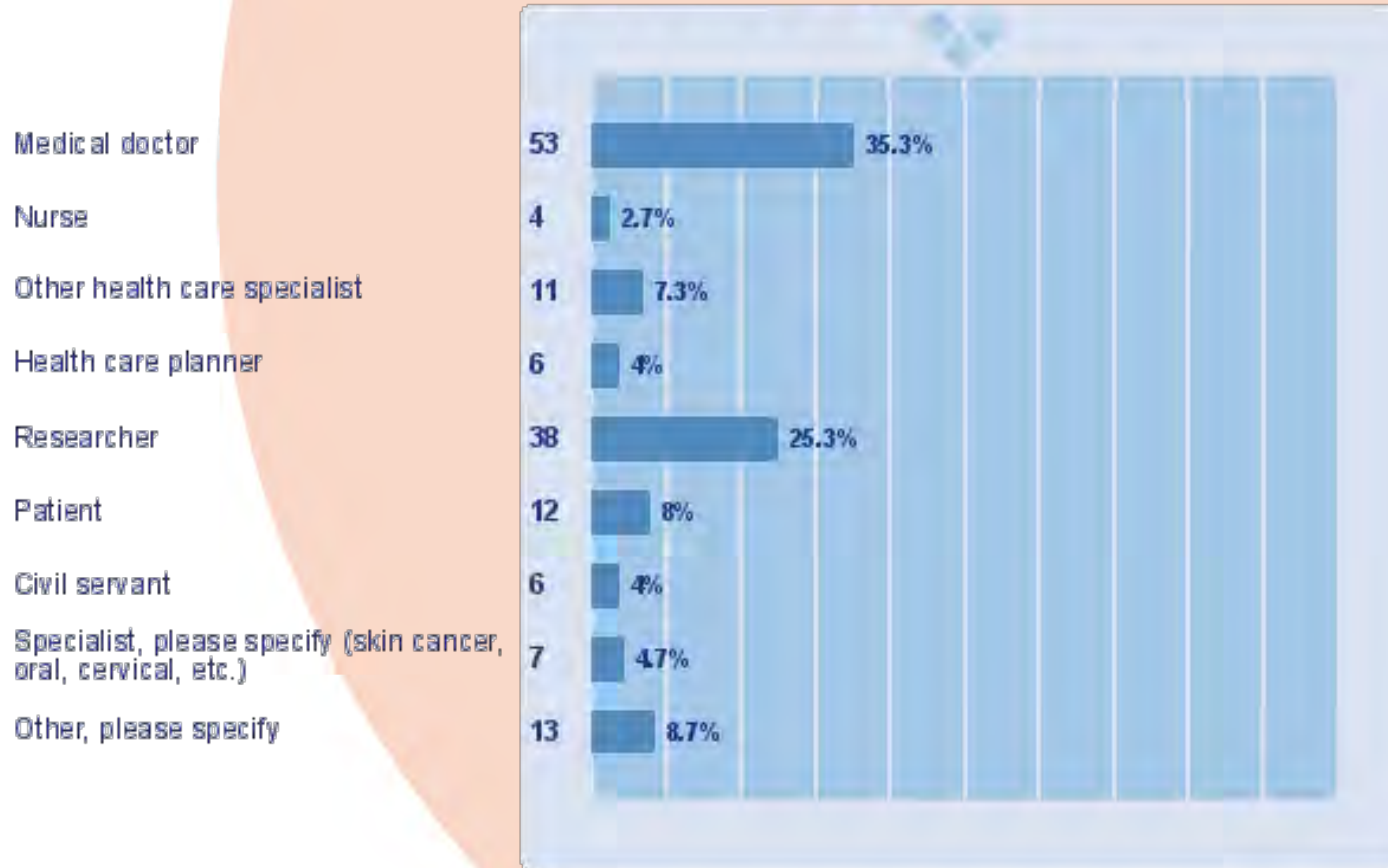
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Professional background

4. Professional Background



Respondents by country (N=140)

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Country	N
Italy	15
Spain	15
Norway	12
Belgium	10
Germany	8
Netherlands	7
Serbia	7
Denmark, Greece, Lithuania, Malta, Great Britain	5
Albania, Armenia, Austria, Bulgaria, Croatia, Cyprus, Czech Republic, Finland France, Latvia, Luxemburg, Poland, Portugal, Romania, Russia, Slovakia, Slovenia, Sweden, Switzerland, Turkey	<5



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Results



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Presentation of results

- Results of the survey were presented as such (original results)
- ZEF also uses a method called Z-scored Electronic Feedback referring to relative, i.e. normalized results
 - This method is utilized with the aim of removing attitude distortion
 - In this method, relative answers are calculated by moving the average to the centre of the response area and distributing all answers to the whole response area giving thus normalized answers



Cancer type (n=329)

2. Choose the cancer type you want to evaluate.

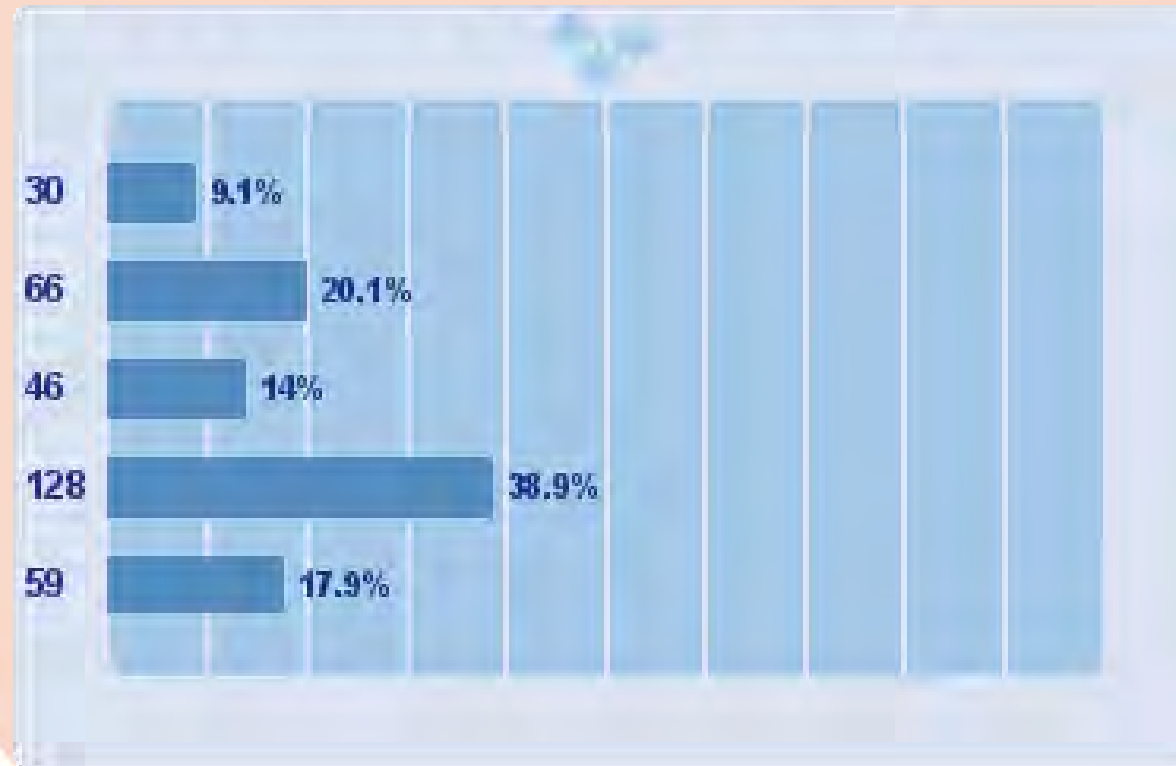
Oral cancers and precancers by dentists looking for early signs

Identifying skin cancers by checking and surveillance for moles

Possible early prostate cancer: symptoms as a sign for action to improve early...

Diverse breast cancer symptoms: better awareness and recognition to improve e...

Other cancer, please specify



Other cancers:

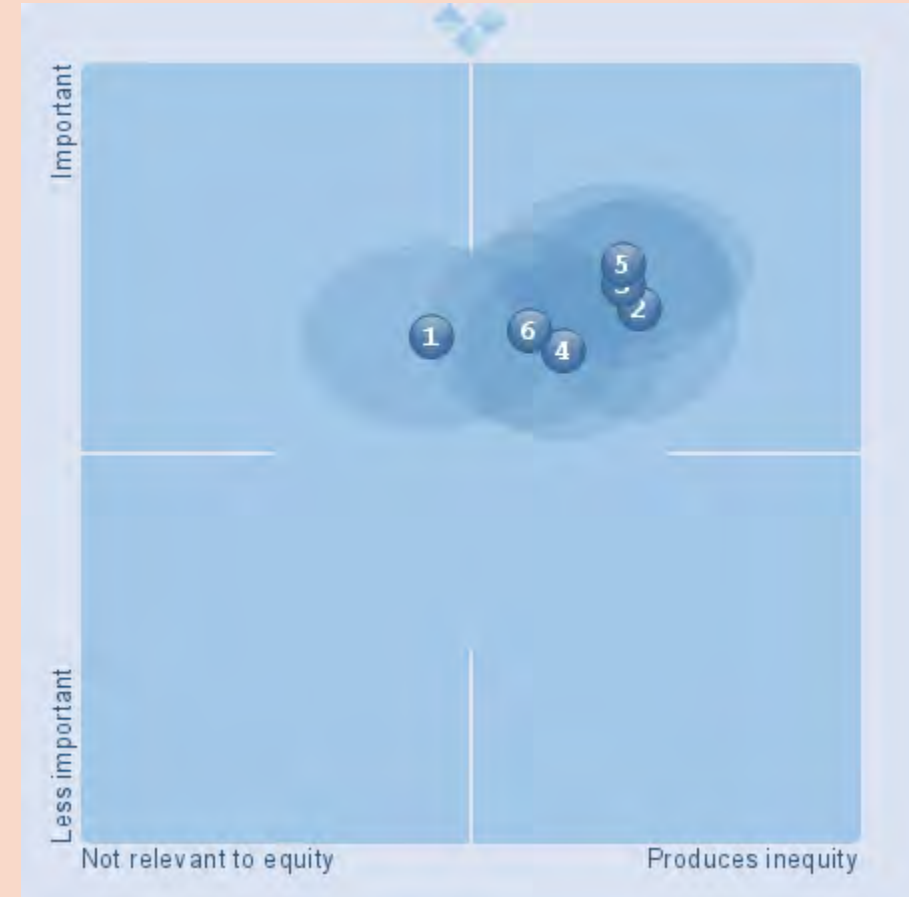
- Appendix cancer (postmenopausal)
- Bladder cancer
- Blood/hematologic cancer
- Cervical cancer
- Chronic myelogenous leukemia
- Colorectal cancer (also from age 40)
- Gastric cancer
- Digestive/GI cancers
- Gastrointestinal Stromal Tumor (GIST)
- Gynaecological cancer
- Head and neck cancer
- Laryngeal cancer (early signs)
- Lung cancer
- Lymphoma
- Multiple myeloma
- Oesophagus cancer
- Ovarian cancer
- Pediatric cancers
- Rare cancers
- Sarcoma
- Uveal Melanoma



Oral cancers

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- 1. Barrier: Lack of evidence (N=21) (X: 45,13 Y: 64,98)
- 2. Barrier: Limited access to primary care (N=15) (X: 71,69 Y: 68,36)
- 3. Barrier: Lack of awareness (N= 15) (X: 69,67 Y: 71,64)
- 4. Barrier: Cancer stigma (N=14)(X: 61,87 Y: 63,16)
- 5. Barrier: Patient-level financial constraints (N=12) (X: 69,58 Y: 74,20)
- 6. Barrier: Poor organization of patient pathway (N=13) (X: 57,66 Y: 65,77)

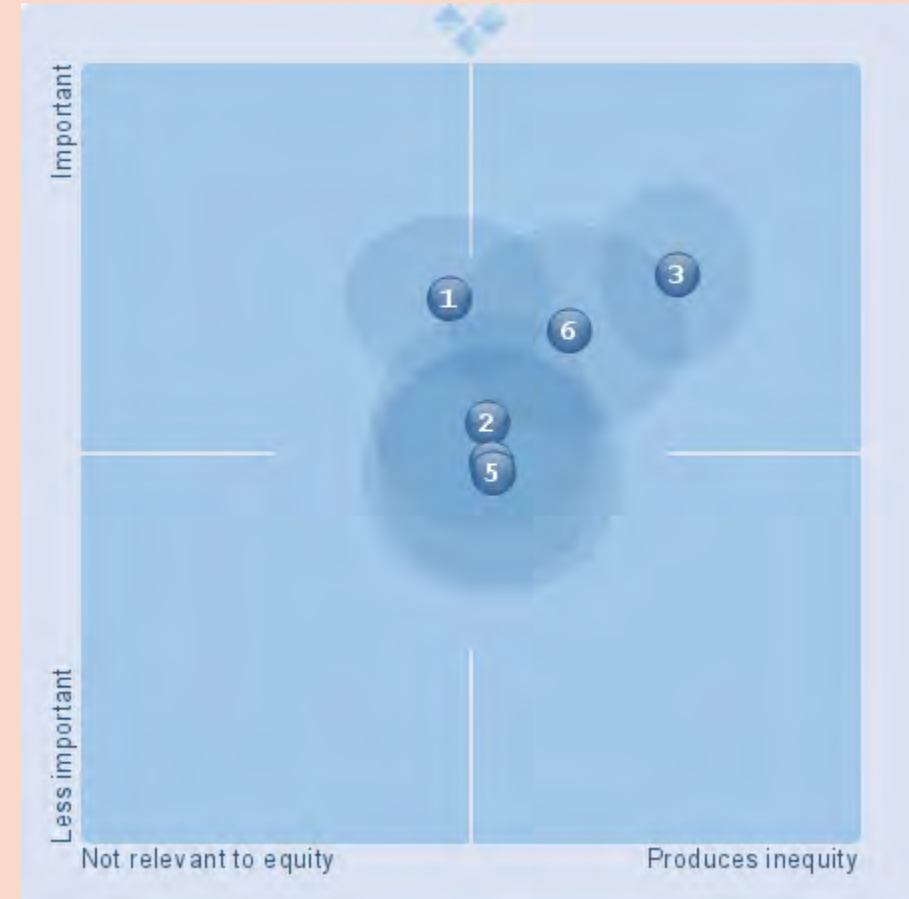


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Skin cancers

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- 1. Barrier: Lack of evidence (N=32) (X: 47,40 Y: 69,82)
- 2. Barrier: Limited access to primary care (N=31) (X: 52,12 Y: 53,93)
- 3. Barrier: Lack of awareness (N=27) (X: 76,60 Y: 72,82)
- 4. Barrier: Cancer stigma (N=27) (X: 52,71 Y: 48,75)
- 5. Barrier: Patient-level financial constraints (N=26) (X: 53,02 Y: 47,56)
- 6. Barrier: Poor organization of patient pathway (N=27) (X: 62,68 Y: 65,58)



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Prostate cancer

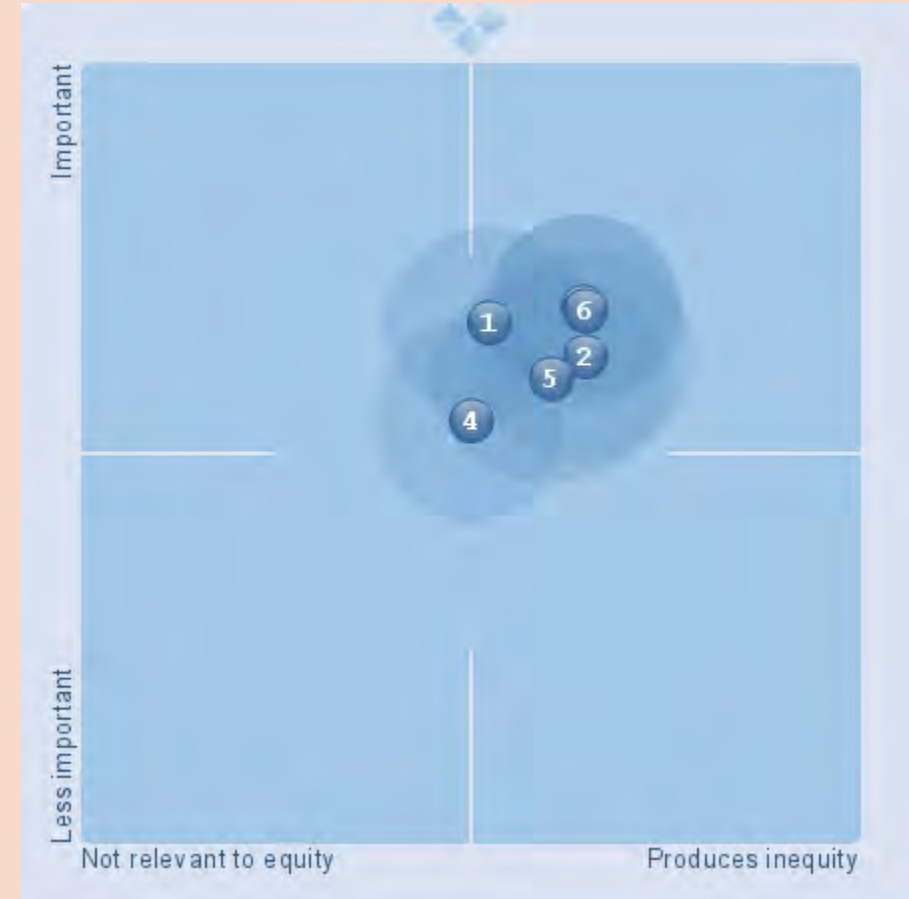
- 1. Barrier: Lack of evidence (N=32) (X: 53,35 Y: 67,91)
- 2. Barrier: Limited access to primary care (N= 29) (X: 58,45 Y: 46,82)
- 3. Barrier: Lack of awareness (N=26) (X: 64,97 Y: 65,33)
- 4. Barrier: Cancer stigma (N=26) (X: 60,93 Y: 57,68)
- 5. Barrier: Patient-level financial constraints (N=25) (X: 65,43 Y: 52,45)
- 6. Barrier: Poor organization of patient pathway (N= 24) (X: 60,77 Y: 65,58)



Breast cancer

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- 1. Barrier: Lack of evidence (N=82) (X: 52,31 Y: 66,55)
- 2. Barrier: Limited access to primary care (N=75) (X: 64,71 Y: 62,30)
- 3. Barrier: Lack of awareness (N= 72) (X: 64,44 Y: 68,68)
- 4. Barrier: Cancer stigma (N=71) (X: 50,19 Y: 54,02)
- 5. Barrier: Patient-level financial constraints (N=67) (X: 60,32 Y: 59,39)
- 6. Barrier: Poor organization of patient pathway (N= 65) (X: 64,81 Y: 68,22)



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Other cancers

- 1. Barrier: Lack of evidence (N= 40) (X: 53,68 Y: 74,38)
- 2. Barrier: Limited access to primary care (N= 37) (X: 54,00 Y: 54,29)
- 3. Barrier: Lack of awareness (N=38) (X: 56,65 Y: 68,76)
- 4. Barrier: Cancer stigma (N=34) (X: 46,96 Y: 54,56)
- 5. Barrier: Patient-level financial constraints (N=32) (X: 56,60 Y: 61,48)
- 6. Barrier: Poor organization of patient pathway (N=31) (X: 53,52 Y: 62,03)



Summary & Discussion

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Barriers according to importance

Importance	Oral cancers	Skin cancers	Prostate cancer	Breast cancer	Other cancers
Most important	5	3	1	3	1
2. important	3	1	6	6	3
3. important	2	6	3	1	6
4. important	6	2	4	2	5
5. important	1	4	5	5	2
Least important	4	5	2	4	4

Barriers: 1. Lack of evidence 2. Limited access to primary care 3. Lack of awareness 4. Cancer stigma 5. Patient-level financial constraints 6. Poor organization of patient pathway



Barriers according to (in)equity

Equity	Oral cancers	Skin cancers	Prostate cancer	Breast cancer	Other cancers
Produces most inequity	2	3	5	6	3
2. most inequity	3	6	3	2	5
3. most inequity	5	5	6	3	2
4. most inequity	4	4	4	5	1
5. most inequity	6	2	2	1	6
Not relevant to inequity	1	1	1	4	4

Barriers: 1. Lack of evidence 2. Limited access to primary care 3. Lack of awareness 4. Cancer stigma 5. Patient-level financial constraints 6. Poor organization of patient pathway



Discussion

- In general, the three most important barriers of early detection were 1. Lack of evidence, 3. Lack of awareness and 6. Poor organization on patient pathway
 - The least important was 4. Cancer stigma
- Respectively, 2. Limited access to primary care, 3. Lack of awareness, 5. Patient-level financial constraint and 6. Poor organization of patient pathway way perceived to produce inequity
 - 1. Lack of evidence and 4. Cancer stigma were not as relevant to equity
- Variation between cancer type was found



Discussion

- The number of respondents decreased significantly between those who addressed the survey, started answering and completed answering
- Explanations for this include the new and unfamiliar survey method, possible irrelevance of the scope of the survey in relation to respondents' expertise, lack of knowledge of the specific questions; and unfamiliarity of the iPAAC
 - Most responses (77) finalised among those with a connection to iPAAC
 - We think that the results represent rather well the perceptions within the iPAAC partners
- In summary, this survey reveals a large amount of information of barriers of early detection of cancer in Europe
- The results are to be examined further in order to achieve more detailed information according to cancer types, barriers and background factors (countries, professions etc.) Also scoring needs further attention.



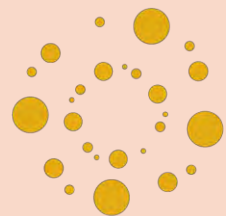
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THANK YOU!



iPAAC
INNOVATIVE PARTNERSHIP
FOR ACTION AGAINST CANCER



Co-funded by
the Health Programme
of the European Union



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