Insight and effectiveness of early diagnosis

Work Package 5, task 5.1. Early detection: Conference report

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Abbreviations

CANCON	Cancer Control Joint Action
CME	Continuing medical education
EPAAC	European Partnership for Action Against Cancer
EU	European Union
iPAAC	Innovative Partnership for Action Against Cancer
JA	Joint Action
MRI	Magnetic resonance imaging
PSA	Prostate-specific antigen
WP5	Work Package 5

Executive summary

When cancer is diagnosed at earliest possible opportunity, it is potentially at a curable stage, increasing survival and quality of life. It is important that disease is diagnosed and treated without delays. There are two approaches that enable timely diagnosis and treatment of cancer: early diagnosis, that is the recognition of symptomatic cancer in patients; and cancer screening, which is the identification of asymptomatic disease in an apparently healthy target population. It is necessary to separate two different strategies, even if both aim at early detection.

In this report, the focus is on early diagnosis. The report *Insight and effectiveness of early diagnosis* is a result of collaboration, drawing its conclusions from three sources: a European-wide survey (n=153) of barriers to early detection, a background paper and co-creational conference of early diagnosis. Innovative Partnership for Action Against Cancer (iPAAC) is a Joint action funded by the Third Health Programme 2014–2020 of the European Union. Its Work package 5 has specific tasks of early detection and cancer prevention. This report is the first one and will be followed by cancer screening and prevention reports. The key deliverable of iPAAC is the *Roadmap on Implementation and Sustainability of Cancer Control Action* contributing to cancer policy on European level.

We discuss early diagnosis of cancer as part of comprehensive cancer control where it means recognition of symptomatic cancer in patient with links to treatment without delays. Early diagnosis requires that there is good awareness of early signs of cancer. Another important factor is health system and especially easy access to primary health care without delays and affordable cost. Early diagnosis can increase inequalities if there are unnecessary tests leading to overuse of health care services. Currently, there is only limited amount of systematic data on early diagnosis in clinical settings. Cancer types differ greatly in their early stage and progression. Lack of evidence is one barrier identified in the survey and carefully planned pilots of early diagnosis could be welcome part of future research agenda.

When addressing barriers to early diagnosis there should be a special focus of impact of these barriers to **inequalities**. There is much to gain if disadvantaged groups are specifically addressed, including tailored communications and messages. Both oral cancers and skin cancers have highest delays of early detection due to inequalities, according the European-wide survey done for the task 5.1. Yet, further research is needed to establish programmatic services with good data management and appropriate balance of harms and benefits.

Patient-level constraints were highest in oral cancers in the iPAAC survey of barriers. Dental services vary across Europe but there is also lack of awareness of risk factors, such as tobacco and alcohol. Health literate Europe should advance both early diagnosis and cancer prevention.

The early signs of many cancers may be very diverse or not yet known. Especially prostate cancer, leading cancer type among men, needs further research and better awareness. In aging Europe finding cancer early but avoiding overdiagnosis and overtreatment is a long-term investment. For prostate cancer, decision-making tools were suggested as helpful way to note complexities of the disease.

High-risk groups may not be identified well in several cancer types. There is also a lack of appropriate clinical trials: designs and protocols need to be developed to investigate benefits and harms of early diagnosis activities. One possible solution is to develop and use validated risk scores and tailored interventions to serve high-risk groups. The role of informing people of early cancer signs is very valid. Mis- and disinformation were identified as a worrying trend that could delay early diagnosis and treatments.

The main conclusions of the task 5.1. on early diagnosis of cancer are the following:

1. It is important to identify not only the barriers to early diagnosis of cancer, but also the impact of such barriers on inequalities. According to the survey, both oral cancers and skin cancers have highest delays of early detection due to inequalities. There is a call to tackle the social inequalities in early detection.

2. Evidence for early diagnosis and treatment requires well planned piloting, better data management and examining appropriate balance of harms and benefits. Further research is essential for establishing programmatic services.

3. The role of informing people of early cancer signs is very valid. Misinformation was identified as a worrying trend that needs to be addressed.

4. Lack of evidence was highest barrier in other cancers than the four cancer types chosen for the survey (breast, prostate, oral and skin cancers). In breast cancer both access to primary care and poor organization of patient pathway were reasons for inequality. Other cancers included pancreas, lung, colorectal, bladder, blood, gastric cancers and lymphomas.

5. One important conclusion is that we do not know it all. Thus, early diagnosis is not possible in all cancer types. There are cancers with no early warning signs; there are rare cancers and cancers where there is not enough knowledge of early signs.

6. High risk groups and vulnerable populations need tailored approaches.

1 Introduction and background

Cancer is a disease which being detected early, is more probable to successfully respond to treatment. This improves the probability of survival and, in addition, results in less adverse effects, lower treatment expenses and morbidity as well as improved quality of life.

There may also be some drawbacks due to early diagnosis, such as longer lifetime with awareness of the disease, or so-called overdiagnosis of non-progressive lesions. Efforts to early detection can also lead to increased use of health services of people who turn out not to have cancer. Health inequalities should be addressed in relation to early detection. The aim of detecting cancer early means that barriers to timely cancer diagnosis and high-quality cancer management and care must be addressed.

This report is conducted as part of the Innovative Partnership Joint Action (iPAAC) which aims to build upon the outcomes of previous EPAAC and CANCON Joint Actions on cancer. iPAAC is funded by the Third Health Programme 2014−2020 of the European Union. The key deliverable of iPAAC is the *Roadmap on Implementation and Sustainability of Cancer Control Actions.* The prime target group of iPAAC is policymakers at national, regional and local levels. iPAAC includes 44 partners (Competent Authorities and Affiliated Entities) from 24 European countries. It has 10 Work Packages and the work of this report falls under Work Package 5 (WP5) Cancer Prevention.

IPAAC is the third project in the continuum of Joint Actions on cancer. The work started with European Partnership for Action Against Cancer (EPAAC) for 2009−2013 by supporting Member States in their efforts to tackle cancer.

Perhaps the most tangible outcome of the Joint Action was the development of a National Cancer Control Programme in every EU Member State. Regarding early diagnosis, the objective was to develop a pan-European consensus on quality criteria for health checks. Key findings of EPAAC have been published in a well-represented book Boosting Innovation and Cooperation in European Cancer Control edited by Jose M. Martin-Moreno, Tit Albreht and Sandra Radoš Krnel (2013).

EPAAC was followed by Cancer Control Joint Action (CANCON) being active in 2014−2017. The main oucome of Cancon was the Cancon Guide (officially European Guide on Quality Improvement in Comprehensive Cancer Control edited by Tit Albreht, Régine Kiasuwa and Marc Van Den Bulcke (2017). The Guide had the aim of helping to reduce not only the cancer burden throughout the EU but also the inequalities in cancer control and care that exist between Member states. One of the CANCON policy papers, Tackling Social Inequalities in Cancer Prevention and Control for the European Population, (Peiro et al. 2017) relates especially to this report https://cancercontrol.eu/archived/uploads/PolicyPapers27032017/Policy_Paper_4_Tackling.pdf and chapter 4 of this report.

The aim of iPAAC JA Work Package 5 (WP5) Cancer Prevention is to foster cancer prevention, health promotion and to reduce inequalities by strengthening health in all policies promoting, the European Code Against Cancer (ECAC), implementing population-based screening programmes, and addressing barriers to early detection.

The main objectives of WP 5 are:

- **to identify barriers to early detection and its management**
- to strengthen quality aspects of population-based screening policies by developing decision making tools, including cost-effectiveness and analysis of harms and benefits
- to investigate the possibilities and barriers of risk-stratified protocols, in all their facets, within the frameworks of population-based cancer screening programmes
- to monitor and review European Code Against Cancer in the long-term perspective focusing on policy tools and guidance given to the general public
- to analyse how governmental policies adopted in Member States foster successful cancer prevention, emphasizing cancer-site specific determinants in each country
- to review and plan better endorsement of recommendations within the European Code Against Cancer and to increase aspects of health for all and in every policy for local, regional and EU-level.

WP5 consists of four tasks:

- **5.1 Strategies for early detection of cancer**
- 5.2 Effective solutions for population-based screening programmes
- 5.3 Cancer prevention and health promotion
- 5.4 Drafting of the Roadmap – cancer prevention

Each task will end with a dedicated conference with co-creation which are formulated into comprehensive reports. This report is part of task 5.1 Early detection and the overall timeline of WP5 activities is presented in the Figure 1.

The aim of this report is to introduce key concepts and barriers of early diagnosis at the European level. It will be followed by a report of population-based screening programmes due in 2020. The two reports are aiming at finding clear ways forward to advance early detection of cancer.

Expert work, *Insights and effectiveness of early diagnosis*, for the report was drafted under supervision of Ahti Anttila, research director of the Finnish Cancer Registry and work package leader in Joint Actions EPAAC and CANCON. It was then commented and further developed in four online meetings with associated partners of the task and shared as a main discussion paper at the dedicaded conference (see discussion on data in chapter 3 Methodology).
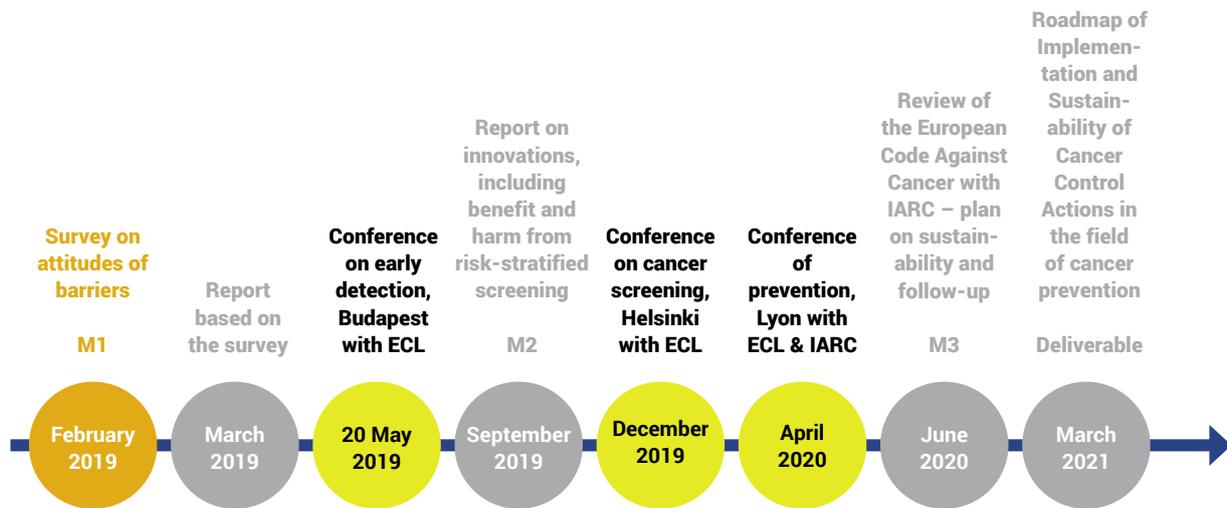
Figure 1. Timeline of key activities of iPAAC WP5.

Inequality is a cross-cutting theme of WP5 main tasks. The Foundation for the Promotion of Health and Biomedical Research of Valencia Region, FISABIO, will identify good practices in actions on cancer prevention and health promotion to reduce social inequalities in cancer in Europe.

2 Defining the problem

The World Health Organization has in its guide (1) defined how the **Early detection module** describes two approaches that enable timely diagnosis and treatment of cancer: (i) early diagnosis, that is **the recognition of symptomatic cancer** in patients; and (ii) **cancer screening**, which is the identification of asymptomatic disease in an apparently healthy target population. It is necessary to separate two different cancer early detection strategies: i) population-based screening programmes as public health measures; and ii) intensified surveillance or counselling of particular high-risk groups. Both strategies focus on early detection or cancer prevention. (2) Screening will be the focus on iPAAC task 5.2. where also risk-stratified screening will be discussed in more detail.

The WHO guide is meant for exploring the importance of early diagnosis in comprehensive cancer control. We are defining early diagnosis of cancer as part of comprehensive cancer control where it means recognition of symptomatic cancer in patient and linking it to treatment without delays.

According to the WHO document, 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 link to diagnosis and treatment without delay. When done promptly, cancer may be diagnosed at a potentially curable stage, improving survival and quality of life. There are three steps to early diagnosis:

- Step 1: Awareness of cancer symptoms and accessing care; could associate also with awareness of risk factors and about particular high-risk groups into this step affecting awareness of symptoms; awareness of cancer prevention; distribution of risk factors affecting treatment outcome; as well as awareness on use of available health services.
- Step 2: Clinical evaluation, diagnosis and staging; and
- Step 3: Access to treatment, including pain relief.

The WHO recommends that an evidence-informed assessment of current capacity and potential harms versus benefits must be performed before introducing or scaling a programme for cancer early diagnosis or screening.

Barriers to early diagnosis are generally analogous to those in the cancer screening process and include limited awareness and access to diagnostic tests and pathology; poor follow-up and coordination; inaccessible high-quality, timely treatment; and, e.g., financial obstacles. When considering early diagnosis within individual patient perspective (without a programmatic view such as population-based cancer screening), awareness of the disease has an important role: individuals might not have the crucial knowledge about the symptoms, or e.g. barriers to reach the true population at risk. In a population-based screening

programme, people are systematically invited to or reminded about the screening service. With an awareness or information campaign the population at risk, respectively, cannot be reached with a similar coverage.

One important suggestion in the WHO guide is that in the absence of systematic cancer screening programmes, policies and programmes to overcome the barriers in early diagnosis should still be in a focus, prior to implementing cancer screening when possible. And with a systematic cancer screening in place, developing high-quality early diagnosis services are still essential in cancer control, relevant e.g. for age groups outside the target population of screening, for symptomatic people, as well as for high-risk groups.

2.1 Key concepts

The EU recommendations and guidelines on cancer screening define **cancer screening** having a population-based approach with systematic quality assurance at all levels (3). The population-based approach indicates that cancer screening programmes target the populations defined by age and gender as a whole, i.e., can include both asymptomatic and symptomatic people and average as well as high-risk groups (3–6). In addition due account should be taken of specific needs of persons who may be at higher cancer risk for particular reasons; e.g., due to biological, genetic, lifestyle, environmental, or occupational reasons (3–6). Further aspects of cancer screening – also systematic cancer screening in high-risk groups or e.g. principles of tailoring cancer screening based on risk factors – will be handled in more detail in the Task 5.2. of the WP, not in this task.

In an EPAAC document (7), **health checks** are defined as services that offer examinations for presumably healthy people with the aim of detecting a health or disease condition or risk factor. Sometimes it may be impossible to separate whether the client had been healthy, or with some condition, symptom, or risk factor when participating in the health check and affecting the contents of the health check.

The early detection modules in health checks can correspond to opportunistic testing mainly in asymptomatic, or to mixed testing modalities in asymptomatic and symptomatic. They can also increase awareness among symptomatic and make people aware of the risks to their health, thus allowing them to modify and adjust their lifestyles or prevent carcinogenic exposures. Health checks have disadvantages as well, by incorporating a serious risk of unnecessary medical procedures and may lead to an unwanted rise in medical expenses due to a high number of false positive results, overdiagnosis and overtreatment; or false reassurance in case of false negative results.

The balance between advantages and disadvantages is often precarious, due to lack of appropriate evidence. Health checks can provide interesting links with early diagnosis of cancer where similar balance of harms and benefits needs to be explored.

2.2　Potentially interesting services for early diagnosis

Early diagnosis requires that both for individuals and on population level there is good awareness of early signs of cancer. Another important factor is health system and especially easy access to primary health care without delays and affordable cost.

In principle, the above WHO guide describes early diagnosis to take place mainly in systematic population-based programmes; based e.g. on clinical examination of breast cancer symptoms in order to improve access to cancer services and improve prognosis. It is worthwhile considering in the EU context also *early diagnosis in the usual patient-oriented clinical setting when and individual patient seeks for diagnostic confirmation and treatment*.

Some examples of potentially interesting programmatic services

- Clinical breast examination, and breast self-examination. Note that in the IARC evaluation (2016) no adequate evidence for efficacy for these two modalities were found (8). Some physical breast examination can also be part of the data collection system for the population-based mammography screening programmes (9).
- Skin cancer. Activities on early diagnosis of skin cancers based on inspection and surveillance of alterations of moles; these activities can include also detection of pre-cancers, such as campaigns on UV protection, and early cancer detection in the CANCON (skinmama.eu). There are no trials available on efficacy, and the current evidence base, indicating what benefits and harms have been achieved by this is largely unclear. One important question is therefore how to obtain appropriate evidence required for policy making and informing the population. There is no good monitoring data available about the magnitude of the services either.
- Dental and primary health care services on recognizing oral cancers and precancers early – should this become a feasible option for all? What is required to decide about such a policy and develop best practices?
- Awareness and self-examination for testicular cancer: should such a campaign be launched; and if launched what aspects need to be taken into account in order to evaluate its success?
- Health check by various services providers; such as schools, military service, occupational healthcare; enabling initialization of the diagnostic pathways based on interviews and clinical examination of possible symptoms.

Patient-level examples

- Awareness and access to services based on symptoms for *breast, cervix, prostate, mouth, colon rectum, thyroid and skin cancers* can provide useful examples on highlighting the challenges in early diagnosis. There may be specific challenges for different cancer sites and there may be unique questions also for several other primary sites. Cancer symptoms and signs may be unspecific for recognizing

a progressive disease; and if clear signs of progression are already manifest the prognosis may not be good anymore. In slow-growing tumors, the prognosis may be very good irrespective of the diagnostic activity and time of diagnosis. Cancer is a heterogeneous group of diseases in this sense.

- There are also topics that are relevant for early diagnosis of cancer, not covered further in the task, such as cancer in children; and secondary cancers.

It would be very difficult to deal with a large number of individual cancer sites and symptoms within the task 5.1. It is possible to focus on just a few selected cancer sites.

2.3   Balances of benefits and harm in relation with early diagnosis

Cancer burden. Major contributions in accurately measuring cancer burden in relation with early diagnosis consists of a range of indicators:

- incidence, survival and mortality;
- taking into account e.g. prevalence of risk factors at the population level and
- stage of diagnosis.

Survival when used alone is not an appropriate indicator. Furthermore, evaluations of treatment outcomes in the patient materials as well as of evaluations of preventive interventions are required (modified from (11)).

One effort should be to describe the associations of early diagnosis and population-based cancer burden using the above set of indicators – and maybe some selected further indicators. This would likely reveal major changes in the disease patterns towards more favourable prognosis due to improved treatments and earlier diagnosis, or sometimes towards less improvements achieved in contrast to harm, over many cancer sites.

Evaluation and current knowledge base. *Overdiagnosis*: In cancer screening evaluation, overdiagnosis is defined as detection of such cancers or pre-cancers (or other such conditions) by screening which would not have been otherwise detected and would not cause death, serious harm or symptoms. For early diagnosis of cancers in symptomatic patients, overdiagnosis of cancer refers to detection of such non-progressive cancers or pre-cancers that do not affect mortality nor will have serious adverse effects in the later course of life of the patient (12), possibly also among symptomatic patients e.g. on breast, prostate and thyroid cancers (12; 13; 14; 15). There were no specific studies identified using individual-level management histories or, e.g., randomised controlled trials to evaluate the balances of benefit and such harms. Still, the balance of harm and benefit is often very different in patients with clear signs or even unspecific symptoms of cancer, compared with cancers diagnosed in population-based screening or opportunistic testing in asymptomatic. Considering testing in particularly in asymptomatic, also the related problem of overuse of

services should be taken into account; meaning that people can be tested or managed without appropriate indication for the diagnostic test or management procedure (18; 19; 20; 21; 22; 23).

It is not yet straightforward how evidence on the balances of benefits and harms can be acquired on the patient management level. This includes current limitations in the knowledge base and methods for quantifying benefits and harms in the health care. Information on the initiation of the diagnostic pathway, and phase of symptoms, is not available in health care databases for most cancer cases or persons having taken a diagnostic test. Optimally, beneficial and adverse effects of early diagnosis and related management histories should be investigated through the whole management history on cancer incidence and mortality patterns and serious adverse effects in detailed randomized controlled trials developing the diagnostic and management procedures. Analysis may be required also at the population level. Also, there may be limitations in the information to be provided to the patients, accordingly, in absence of longitudinal RCTs. In the patient management guidelines, it is a requirement still that the patient needs to be informed appropriately about the balances of benefits and harms. The evidence-base for this requirement is often incomplete concerning the approaches for early diagnosis.

Small non-progressive local tumors or well-differentiated in situ carcinoma can be examples of overdiagnosis due to early diagnosis. Lesions called 'cancer' or 'carcinoma' by pathologists can have very different growth rates, affecting also over-diagnosis. Patients in whom indolent, non-progressive cancers are detected may not benefit and can experience harm, for example the worry associated with a cancer diagnosis and some complications of the therapy. On the other hand, small indolent tumors need not necessarily be treated aggressively. Therefore, the impact on quality of life of such a case may be rather small, compared with the prevention of a death or management of an aggressive cancer. There are concerns on overdiagnosis e.g. on breast, prostate and thyroid cancers (9, 13, 14, 15). Overdiagnosis can occur in many other primary sites, too; even though there may be no distinct methods to identify its magnitude (12, 16, 17).

Overdiagnosis of some disease statuses milder than cancer should also acknowledge the burden that the use of unvalidated methods for early diagnosis can induce; for example use of breast thermography; HPV self-sampling with an unvalidated method; or e.g. a cytology test with sub-optimal diagnostic quality, launching unnecessary follow-up or management. This imply both on individuals as well as on the health systems. There is also a related problem of *overuse of services*: people are tested or managed without appropriate indication for the diagnostic test or management procedure. Actually, overuse could occur also when a woman seeks mammography after a relative was diagnosed with breast cancer. There may be no appropriate detailed guidelines, or the available guidelines were not adhered to appropriately. Thus evidence-based and appropriate guidelines need still to be developed. (18–23)

Accordingly, there could also take place *overtreatment* of these cases. Note that in addition overtreatment could occur if a cancer case/patient was treated with an unnecessarily aggressive strategy.

It is not yet straightforward how *evidence on the balances of benefits and harms* can be acquired on the patient management level – what is the current knowledge base and with which methods the benefits and harms are quantified in the health care. Information on the diagnostic pathway and phase of symptoms is not available in the health care databases for most cancer cases or persons who underwent a given diagnostic test. It is therefore difficult to compare impacts related e.g. to symptoms awareness reflected e.g. to the duration of a given symptoms phase. Optimally, beneficial and adverse effects of early diagnosis should be investigated on cancer incidence and mortality patterns and on serious adverse effects in a population-based manner. This necessitates appropriate, systematic databases on the indications and pathways to diagnosis, as well as on the diagnostic and management procedures and e.g. on side effects throughout the whole patient management histories.

Also, there may be limitations in the information available for patients subject to a given diagnostic procedure respectively. In patient management guidelines, it is a requirement that the patient needs to be informed appropriately about the balances (see e.g. recent discussion on PSA testing in men with some unspecific symptoms indicating the need of the PSA test, or tested eventually without any symptoms (24)). In the case of PSA testing, evidence-based information should be provided for the patients on the benefits as well as adverse aspects such as overdiagnosis also when tested based on some unspecific clinical indications such as urinary dysfunction in older males. However, practically speaking, such information is not available in every detail. There is also a European wide recommendation to avoid spontaneous screening, valid also for prostate cancer; however, spontaneous screening of asymptomatic men is apparently very common and benefits and harms are still largely unstudied.

3 Methodology of the task 5.1

In cancer control, the discussion of early diagnosis usually refers to awareness of early signs of the disease or available services. As pointed out earlier, there is only limited amount of systematic data on early diagnosis in clinical settings and cancer types differ greatly in their early stage and progression. In what terms well prepared and planned pilots of early detection could be then possible to find out necessary information of harms and benefit balance?

With Europe´s aging population, effective prevention and early detection can be seen as long-term investments. There is an alarming observation that in some wealthy countries life expectancy has slowed down and is even falling, especially in United States, France and Netherlands. Particularly bad year was 2015, when average life expectancy fell in 19 OECD countries (39)

However not all policies support prevention and early detection in optimal way. These strategies need to address health inequalities in order to be effective. They need also support from policy-makers of health policy. These two strategic aspects are part of WP5 work: putting special emphasis on inequalities and including co-creational elements
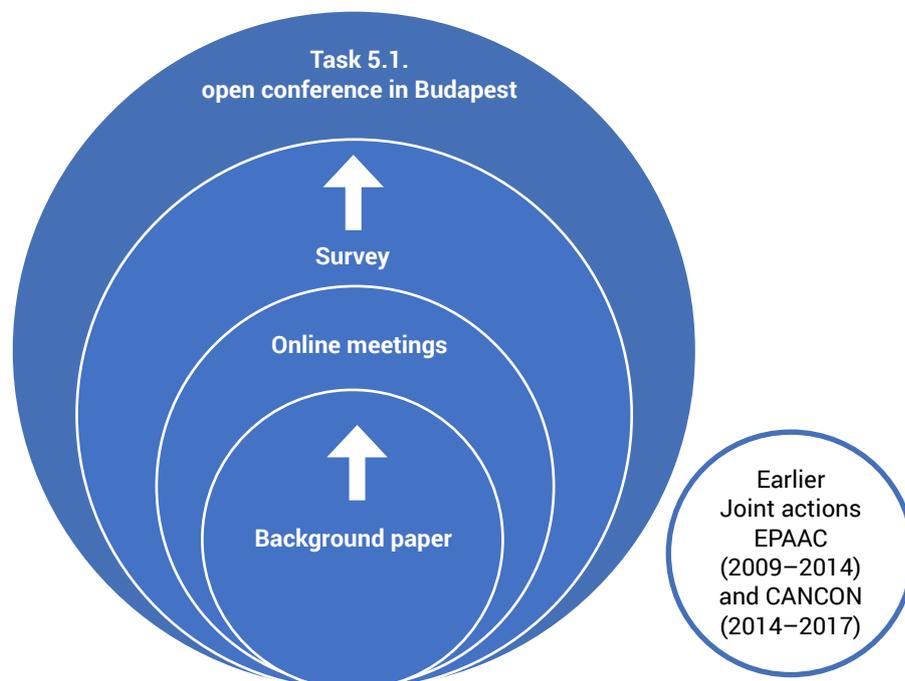

Figure 2. Levels of information produced. The conference produced presentations, discussions, group work, facilitatiors´reports and voting results into this report.

in the work programme to understand better the relation between evidence and health policy implementation. Co-creation here means facilitating discussion and dialogue, thus increasing engagement across participants (40).

Co-creational working methods usually increase engagement and understanding of stake-holders view. Sometimes balancing with difference levels of knowledge can be difficult and in this way co-creationally produced knowledge has similarities of business intelligence or policy-making situations.

In recent years both public organisations and private sector have tried to put emphasis on involving and engaging people. There are several reasons: end-users are important in designing services, bottom-up approaches and cross-sectoral working groups give societal ownership (40).

The task 5.1. information is based on these documents

- Insights and effectiveness of early diagnosis – the Backgound paper for the online meetings (41)
- Online meetings, group work and voting
- Results from the survey on barriers, using the ZEF survey tool iPAAC Milestone 5.1.
- 1st WP5 conference,

Thus, conclusions do draw from different levels of data. The findings, discussions and co-creational outcomes form this report. It reflects perspectives from all partners of WP5 including stakeholders that participated in the open conferences. We are thankful for all contributions.

Figure 3. The WP5 work overview where green marks online meetings, orange survey and grey research based data.

Early detection examples from WP5 online meetings: Spain, Slovenia and Italy

Online meetings discussed the Background paper and experiences from the Member states. Below in the boxes three examples from early detection that came up in these meetings.

Early detection of melanoma in Valencia, Spain:
- Free on-line training for primary care and specialized health care professionals.
  Two 20-hour editions per year accessible since 2010. So far, approximately 2.000 health professionals have benefited from the training.
- A clinical practice guide on melanoma early detection published. There are two versions available, a brief one and a cmplete one.
- Health professionals support tool for identification of skin lesions.
- Posters and leaflets for general public dissemination.
- Short videos in public transport buses broadcasting circuits aiming a broad audience.

Evaluation in the field of early detection of symptomatic cancers from Slovenia:
- Overdiagnosis in early detection of symptomatic cancers, acknowledging the burden of using unvalidated methods for early diagnosis (for example breast thermography, HPV self-sampling with unvalidated method, bioresonance) with implications on individuals as well as on the health system
- Are there guidelines how to assess the risk in situations when a person approaches the health system with a positive result of an unvalidated test?
- Gender-related inequalities in early detection as the difference between men and women, especially if there is the difference in symptom appraisal and health-seeking behaviour
- For barriers of early diagnosis of cancer, additional barriers: for example, individuals have to have some knowledge about symptoms of early cancer and risk factors. How to effectively reach population at risk with awareness and information campaigns and how to measure the quality and effectiveness of such campaigns?
- How can NGOs contribute to early detection – how they help tackle barriers
- Should early detection activities and management be centralized as in screening, more decentralized – how important is the local context and environment – or in combination?

The project on melanoma early detection, named "Progetto ReteMela", from Veneto, Italy:
- A network of institutions, including a multidisciplinary group that works according to predefined guidelines
- General Practitioners having attended a certified training evaluate patients (1st level) and send those at risk to
- Dermatologists working outside the reference center who evaluate the lesions, acquire digital images, and perform biopsies of the lesions (2nd level, dedicated slots reserved for these patients)
- In case of melanoma diagnosis or risk of relapse, patients are referred to one of three reference centers for a larger excision (3rd level)
- Pathologists and genome biologists analyze and characterize excised samples
- All cases are discussed by multidisciplinary group (4th level) to define the best therapeutic strategy

4 Social inequalities in health

Social inequalities in health are those differences in health, which are systematic, socially produced, unnecessary and avoidable, as well as unfair and unjust (25). **Social inequalities in cancer** refer to health inequalities spanning the full cancer continuum, and involve social inequalities in prevention, incidence, prevalence, detection and treatment, survival, mortality and other cancer-related health conditions and behaviors (26).

Inequalities in cancer survival exist both between and within countries (27, 28, 42). Equitable access to early diagnosis of cancer is crucial to improve equity in cancer prognosis. Evidence suggests that population-based screening programmes that include comprehensive quality assurance and personalised invitations to all individuals in the eligible target population ensure greater equity in access to timely and high-quality diagnosis than opportunistic testing (29). Nevertheless, inequalities in the population based programs have also been identified (30). Furthermore, screening itself may not correct for the disparities between social classes in their life expectancy caused by differences in their risk factors and access to health services outside the screening programmes.

Taking into account that *barriers to cancer screening programmes are similar to those in early diagnosis of cancer*, it could be assumed that the same occur for the mechanisms leading social inequalities. On one hand, participation rates in cancer screening programmes are often lower in socially vulnerable groups (30, 31). On the other hand, socio-economic gradients in stage and grade at diagnosis have been identified, not only in cancers where population screening doesn't exist, such as lung cancer (32), but also for those with organised programmes, such as breast cancer (33). Finally, inequalities in delay in cancer treatment have been also highlighted (34). These inequalities are a consequence of a complex interaction of social determinants of health, that are the specific characteristics and the ways in which social conditions affect health (35).

In order to reduce these inequalities several recommendations have been made in the context of the previous Joint Action CANCON (36). These include recommendations that have key relevance for improving early diagnosis of cancer. The recommendations include a proportionate universalism approach, based on universal actions but with a scale and intensity that are proportionate to the level of disadvantage (37).

Tackling social inequalities in cancer prevention and control
(Source: Cancon policy paper, Peiro et al. 2017)

Cancon policy report addressed primary and secondary prevention, not specifically early detection. Recommendations number 7 to 13 are focused on primary prevention, screening, treatment and survivorship. Recommendation 8 addresses cancer screening programmes.Barriers to cancer screening programmes are similar to those in early diagnosis of cancer. It could be assumed that the same occur for the mechanisms leading social inequalities.

Recommendation	Specific Recommendation
Capacity-building for cancer prevention and control	
1: Embed equity within the cancer prevention and control policies in all European Union Member States.	S.R. 1.1: Formulate specific objectives that aim to tackle social inequalities in cancer across the whole population with additional emphasis on socially vulnerable groups.
	S.R. 1.2: Include indicators of social inequality within the quality criteria established for cancer prevention and control programmes.
2: Align cancer prevention and control policies with a Health in all Policies approach.	S.R. 2.1: Create a multi-sectoral working group that includes experts on social inequalities in health to embed a Health in all Policies approach within cancer policies.
	S.R. 2.2: Assess the impact of current and new policies, programmes, and health services on social inequalities in cancer.
	S.R. 2.3: Produce a report on social inequalities in cancer, and make it available to the public.
3: Adopt a Health Equity Impact Assessment framework.	S.R. 3.1: Assess the evidence on social inequalities in cancer and identify any gaps in knowledge.
	S.R. 3.2: Introduce a unique national identifier to facilitate safe record linkage between different databases in each European country in order to monitor social inequalities in cancer.
	S.R. 3.3: Collect information on patient reported outcome measures (PROM), and link this information with cancer registry data.
	S.R. 3.4: Use the Health Equity Impact Assessment tool to assess systematically the impact of policies on social inequalities in cancer.
4: Engage and empower communities and patients in cancer prevention and control activities.	S.R. 4.1: Involve communities and patient associations in decision making processes.
	S.R. 4.2: Ensure that socially vulnerable groups are involved in the design, implementation and evaluation of health policies related to cancer prevention and control.
	S.R. 4.3: Ensure that all patients receive up-to-date and accurate information and are proactively involved in their care.
5: Promote the exchange of good practice and support development of professional expertise in social inequalities in cancer in all European Union Member States.	S.R. 5.1: Foster exchanges of professional experience in all European Union Member States in tackling social inequalities in cancer.
	S.R. 5.2: Provide appropriate training for cancer prevention, care, and rehabilitation professionals to tackle social inequalities in cancer.
6: Support the development of European research programmes that help deliver equity in cancer prevention and control in all European Union Member States.	

Primary and secondary cancer prevention policies	
7: Implement proportionate universalism policies to develop and maintain living environments favouring compliance with the European Code Against Cancer.	S.R. 7.1: Ensure that tobacco and alcohol control policies, as well as other interventions promoting healthy behaviours, are addressed to the whole population, with additional emphasis among socially vulnerable groups.
8: Improve equitable access and compliance with cancer screening programmes.	S.R. 8.1: Provide screening processes that address the whole population with additional emphasis among socially vulnerable groups.
	S.R. 8.2: Ensure the development and implementation of guidelines for quality assurance in cancer screening, which must include equity as a quality criterion.
Cancer treatment, survivorship and rehabilitation policies	
9: Ensure equitable access to timely, high-quality and multi-disciplinary cancer care. S.R. 9.1: Implement an integrated model of cancer care management, whereby primary and secondary care are seamlessly linked.	S.R. 9.2: Implement measures to ensure access to and use of appropriate treatments that are addressed to the whole population with additional emphasis on socially vulnerable groups
	S.R. 9.3: Ensure the development and implementation of guidelines in all involved disciplines, which must include equity as a quality criterion.
10: Ensure equitable access to high-quality surgical care in all European Union Member States.	S.R. 10.1: Establish optimal benchmarking standards for surgical oncology in all European Union Member States to help reduce the current inequalities experienced by cancer patients.
	S.R. 10.2: Promote the creation of national information sources on the volume of surgeries per cancer centre, to provide patients with accurate activity data to aid in their choice of surgical centre.
11: Ensure availability of sufficient radiotherapy capacity with appropriate technology innovation in all European Union Member States.	
12: Ensure that all patients have timely access to appropriate systemic therapy.	S.R. 12.1: Promote access to innovative therapies that deliver value-based, effective care, by harmonising Health Technology Assessment in all Member States.
13: Develop national cancer rehabilitation and survivorship policies, underpinned by an equity perspective.	S.R. 13.1: Make survivorship and rehabilitation an integral component of the patient care pathway from the time of diagnosis.
	S.R. 13.2: Raise awareness about late effects, with the aim of providing recommendations to all patients and tailoring information specifically for socially vulnerable groups.
	S.R. 13.3: Integrate employment programmes into follow-up survivorship care, with additional emphasis among socially vulnerable groups, to support return to work after acute treatment.
	S.R. 13.4: Develop financial incentives to help employers introduce adaptations to work environments/situations in order to accommodate survivors' return to work.

5 Results

5.1 European wide survey on barriers

Barriers to achieve benefit from early diagnosis are generally analogous to those in the cancer screening process and include, e.g., limited access to diagnostic tests and pathology; poor follow-up and coordination; inaccessible high-quality, timely treatment; and financial obstacles.

The cancer types 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

The following 6 barriers were in the survey:

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

The advisory group members were: Patricia Fitzpatrick (UCD), Marta Hernández García (Fisabio), Ana Molina Barceló (Fisabio), Jennifer Priaulx (EU-topia), David Ritchie (ECL), Wendy Yared (ECL). The technical tool for the survey was commissioned by WP5 to the Finnish company ZEF company which allows two-dimensional survey questions.
We chose dimensions to evaluate the actions: Produces inequity – Not relevant to equity Less important – Important.

When answering the survey, respondents chose first the cancer type to be evaluated. Next, they placed each barrier in a four-fold table with the response dimensions:

1. Produces inequity – Not relevant to equity
2. Less important – Important

Who answered the survey?

- iPAAC consortium
- WP5 partners and collaborators
- Members and stakeholders of ECL

The survey was open for answering from 31 January to 10 March 2019.

There was fluctuation in response activity. There was possibility to choose which questions to answer and yet complete the survey.

iPAAC survey on barriers (Copy)

3. Barrier: 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.

Diverse breast cancer symptoms: better awareness and recognition to improve early diagnosis

Figure 3. Example of answering survey. Both X and Y axis were graded from 0 to 100 i.e. if answering bottom left corner, answer was given value 0 for both axes. Similarly, a response in the middle was given value 50 for both axes.

Table 1. Response activity of survey

	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

The majority of responses, 77, was from the iPAAC Consortium.

Major professional background of respondents was: medical doctor (35.3 %), researcher 25.3 %, other 8.7 %, and patient 8 %. Countries: Italy and Spain (both 15), Norway and Belgium (12, 10), Netherlands, Serbia, Denmark, Greece, Lithuania, Malta, Great Britain, Albania, Armenia, Austria, Finland, Bulgaria, Croatia, Cyprus, Czech Republic, France, Latvia, Luxemburg, Poland, Portugal, Romania, Russia, Slovakia, Slovenia, Sweden, Switzerland, Turkey.

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ORAL CANCER

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
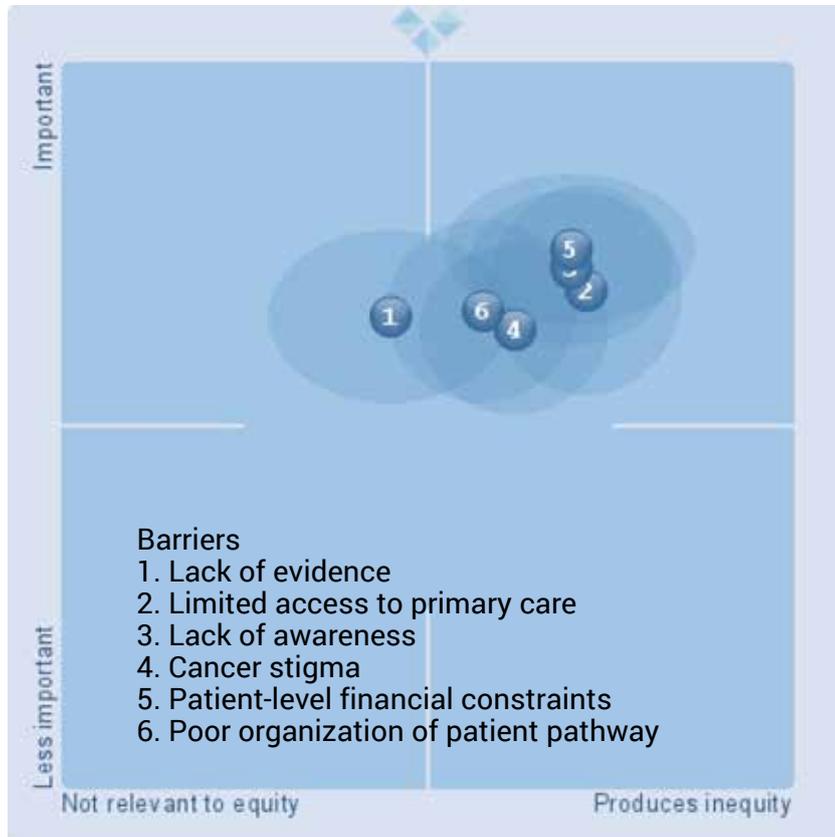
The scores of barriers are based on the survey Less important to important (0-100) and Not relevant to equity to produces inequity (0-100).

Barriers of early detection grouped by importance	
Patient-level financial constraints	74
Lack of awareness	72
Limited access to primary care	68
Poor organization of patient pathway	66
Lack of evidence	65
Cancer stigma	63

Barriers of early detection grouped by order of producing inequity	
Limited access to primary care	72
Lack of awareness	70
Patient-level financial constraints	70
Cancer stigma	62
Poor organization of patient pathway	58
Lack of evidence	45
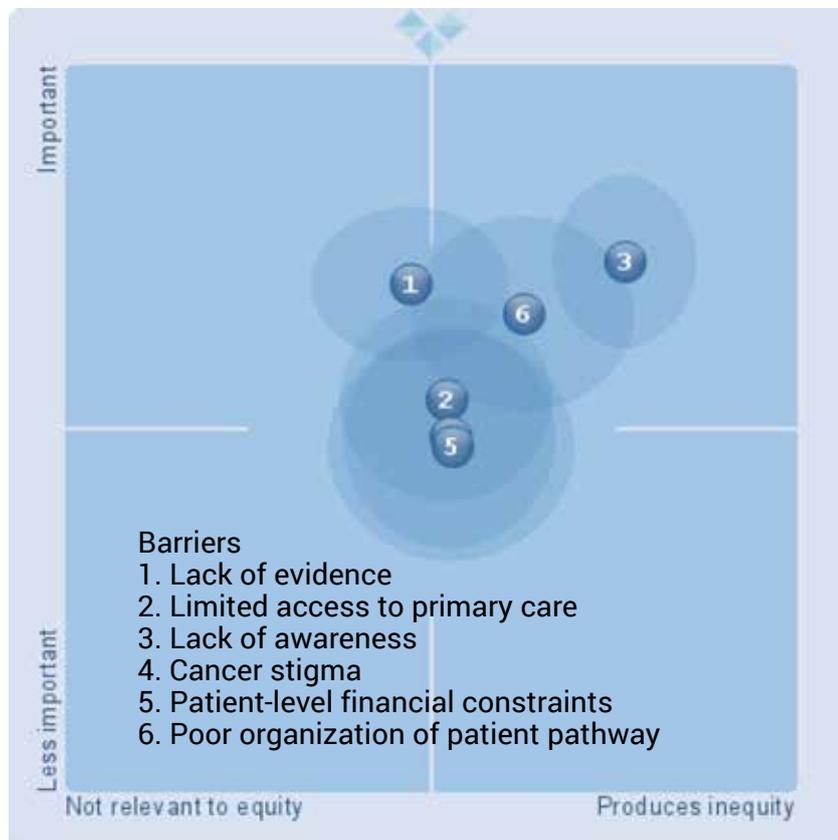
![iPAAC - Innovative Partnership for Action Against Cancer]

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SKIN CANCER

The scores of barriers are based on the survey Less important to important (0-100) and Not relevant to equity to produces inequity (0-100).

Barriers of early detection grouped by importance	
Lack of awareness	73
Lack of evidence	70
Poor organization of patient pathway	66
Limited access to primary care	54
Cancer stigma	49
Patient-level financial constraints	48

Barriers of early detection grouped by order of producing inequity	
Lack of awareness	77
Poor organization of patient pathway	63
Patient-level financial constraints	53
Cancer stigma	53
Limited access to primary care	52
Lack of evidence	47

PROSTATE CANCER
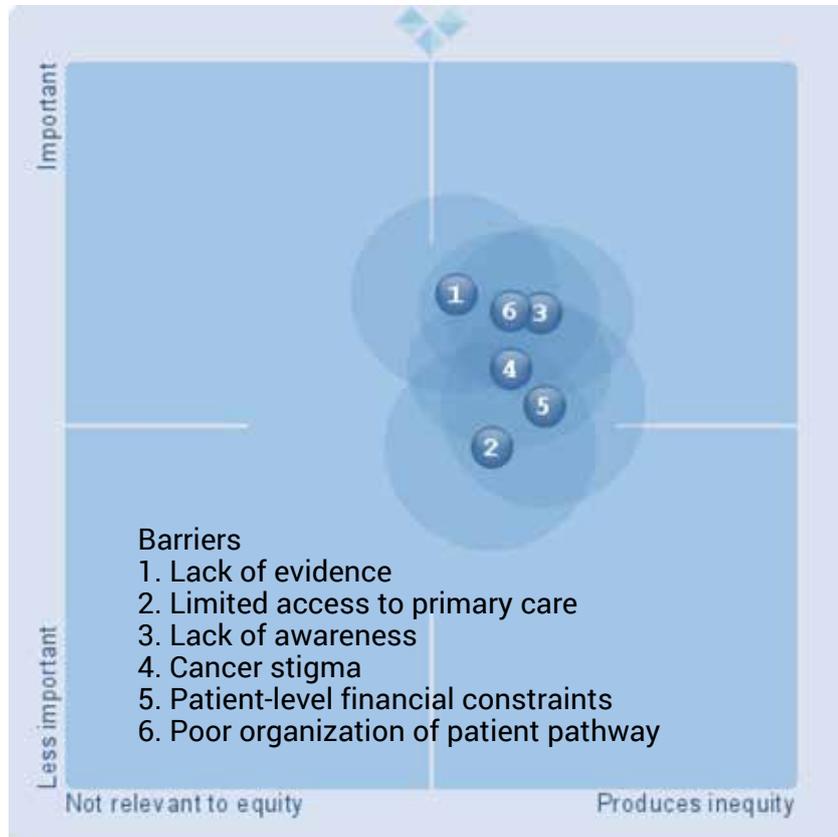
The scores of barriers are based on the survey Less important to important (0-100) and Not relevant to equity to produces inequity (0-100).

Barriers of early detection grouped by importance	
Lack of evidence	68
Poor organization of patient pathway	66
Lack of awareness	65
Cancer stigma	58
Patient-level financial constraints	52
Limited access to primary care	47

Barriers of early detection grouped by order of producing inequity	
Lack of awareness	65
Patient-level financial constraints	65
Poor organization of patient pathway	61
Cancer stigma	61
Limited access to primary care	58
Lack of evidence	53
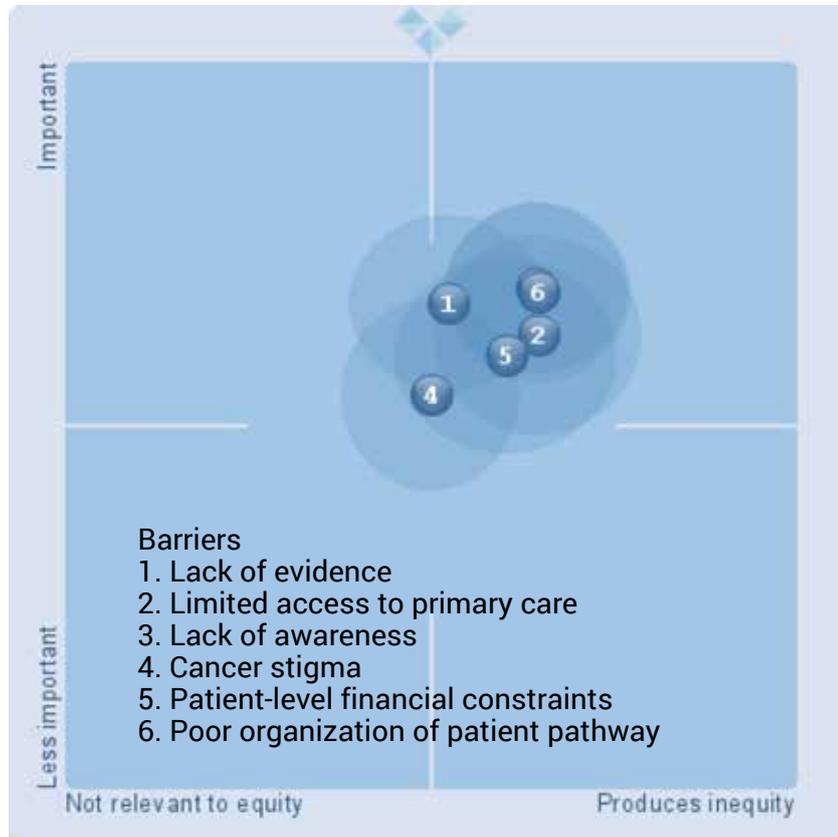
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BREAST CANCER

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

The scores of barriers are based on the survey Less important to important (0-100) and Not relevant to equity to produces inequity (0-100).

Barriers of early detection grouped by importance	
Lack of awareness	69
Poor organization of patient pathway	68
Lack of evidence	67
Limited access to primary care	62
Patient-level financial constraints	59
Cancer stigma	54

Barriers of early detection grouped by order of producing inequity	
Limited access to primary care	65
Poor organization of patient pathway	65
Lack of awareness	64
Patient-level financial constraints	60
Lack of evidence	52
Cancer stigma	50
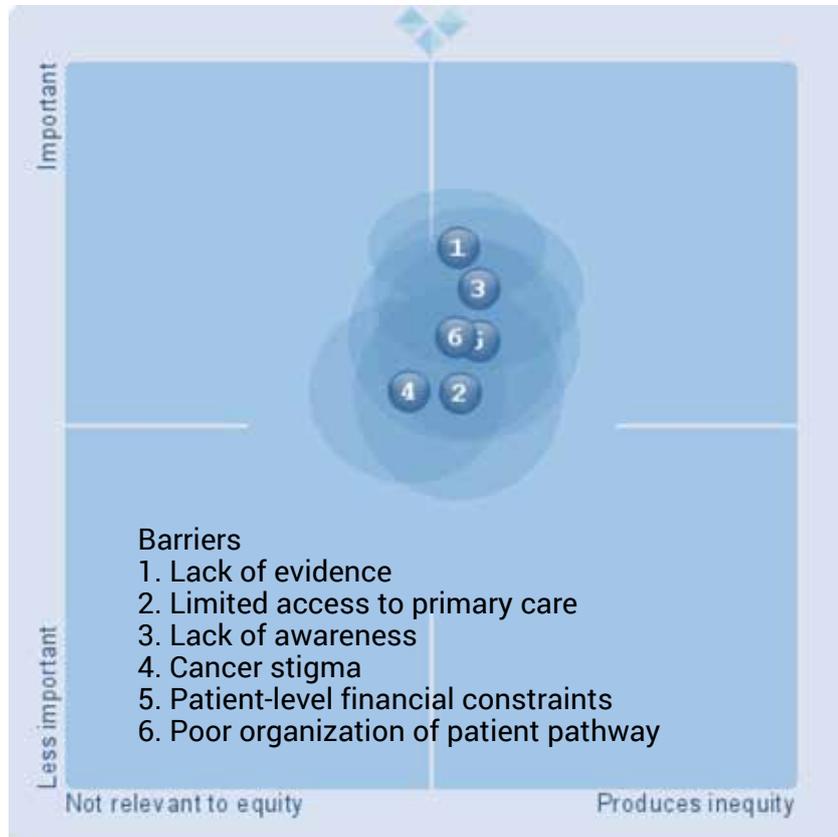
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OTHER CANCERS*

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

The scores of barriers are based on the survey Less important to important (0-100) and Not relevant to equity to produces inequity (0-100).

Barriers of early detection grouped by importance	
Lack of evidence	74
Lack of awareness	69
Poor organization of patient pathway	62
Patient-level financial constraints	61
Cancer stigma	55
Limited access to primary care	54

Barriers of early detection grouped by order of producing inequity	
Lack of awareness	57
Patient-level financial constraints	57
Limited access to primary care	54
Poor organization of patient pathway	54
Lack of evidence	54
Cancer stigma	47

* in the survey respondents could also evaluate cancers of their own choice. Other cancers category entailed various cancer types, including pancreas, colorectal, lung, blood, gastric, bladder cancers and lymphomas.

No	Barrier short name	Description	Domain
1	Lack of evidence base	Lack of evidence base on benefits and harms; evidence-based guidelines cannot be formed due to lack of knowledge. Relates also to health policy planning – to which purposes research resources are allocated?	Health system
2	Limited access to primary care	Limited access to primary care due to long distances, lack of transportation, i.e., non-availability of services in the local setting	Health system
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	Population
4	Cancer stigma	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	Population
5	Patient-level financial constraints	Financial constraints in certain population groups (ethnic, social class) to access primary health services and treatment	Population
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	Clinical services

Figure 5. Barriers and their definitions from the survey

The results represent rather well the perceptions within iPAAC partners, because 77 were from the consortium. In summary, this survey reveals a large amount of information of barriers of early detection of cancer in Europe.

Taking together, lack of awareness was perceived the key barrier for both of the dimension (importance and inequity). There were variations between cancer types in the perceptions of the included barriers.

Table 2. Barriers of early detection grouped by importance

Barrier (by order of the overall score)	Oral cancer	Skin cancer	Prostate cancer	Breast cancer	Other cancers	Overall
Lack of awareness	72	73	65	69	69	70
Lack of evidence	65	70	68	67	74	69
Poor organization of patient pathway	66	66	66	68	62	66
Patient-level financial constraints	74	48	52	59	61	59
Limited access to primary care	68	54	47	62	54	57
Cancer stigma	63	49	58	54	55	56

Table 3. Barriers of early detection grouped by order of producing inequity

Barrier (by order of the overall score)	Oral cancer	Skin cancer	Prostate cancer	Breast cancer	Other cancers	Overall
Lack of awareness	70	77	65	64	57	67
Patient-level financial constraints	70	53	65	60	57	61
Limited access to primary care	72	52	58	65	54	60
Poor organization of patient pathway	58	63	61	65	54	60
Cancer stigma	62	53	61	50	47	55
Lack of evidence	45	47	53	52	54	50

5.2 Conference in Budapest: 70 experts have their say

The iPAAC WP5 Conference was co-organized by National Institute of Oncology (Hungary) who was in charge of the logistics as well as with ECL being responsible of the practicalities of the conference. In turn, Cancer Society of Finland accounted for the conference programme. Developments in early diagnosis of head and neck, prostate and breast cancers were in a specific focus.

There were approximately 70 participants with the target group of consisting of experts in professional and scientific organisations.

The presentations of the conference programme are attachments of this report.

Thematic groups were compiled based on the survey and conversations of the final working (conference) group.

Prostate cancer

The following strategies were suggested for overcoming these barriers and problems:

1. Awareness and knowledge campaigns for general public;
2. Training of health care professionals and
3. Development of decision aids/tool;
4. Research and development of new technologies (such as new diagnostic markers predicting progressive disease, use of multiparametric MRI) and
5. Opening the door for appropriate screening satisfying the general cancer screening criteria and where patients need to be properly and neutrally informed on benefits and possible harms of screening.

Breast cancer

What should people know on early diagnosis? Comprehensive diagnosis is needed. For each cancer, there is a need for definition of what is 'early diagnosis'? Also, high risk group identification is not defined for each cancer types – there are needs for criteria to do this. Technology is expensive, and e.g. MRI is not regulated as well as radiology.

Concerning referral & patient pathway, referral programmes are required, trying to link to preventive initiatives for young women. Cervix cancer screening can be a vehicle to inform for family history also about breast cancer. One aspect discussed was that participation to breast cancer screening is decreasing in the Netherlands and the reason is unclear.

Topics discussed during the group work included also good definition of early detection with help of palpation, biomarkers and image scans; and improved young women with identification for breast cancer and their follow-up algorithms and respective guidelines.

Head and neck cancers

1. Collaboration between the dentists and the general practitioners would be very important.
2. We would not advocate the better access to primary care but the improvement of dental hygiene. Perhaps for the older patient add the cancer screening by dental hygienists. Note that the head and neck cancers are at least 2 separate categories of cancer (oral cavity & others).
3. Teach both patients and medical professionals the early symptoms. Accreditation courses should be updated to include those early symptoms recognition programs (CME – continuous medical education and good leaflets for patients)
4. Human papilloma virus vaccination, to define the risk population – pre-screening by the nurses – education for these nurses. Innovation – put in the report formula for cancer case – the question when was the last dental check-up
5. Decrease the financial barrier – separate the 2 categories (oral cavities, others). Bring together the dental hygiene program and cancer screening programs – already established.
6. To stress in the direction of the health authorities the low costs of a potential screening program which can lead to early diagnosis.

Health literacy

Health literacy refers to the capacity of people to make sound decisions concerning health in daily life – at home, at work, in health care and in the political arena. Here, we tackle health literacy of European populations as a key variable for effective cancer prevention and early diagnosis. Initiatives, campaigns and interventions should be designed in such a way that they improve health literacy of individuals, and/or reduce environmental complexity. Concomitant scientific evaluation of model projects is mandatory. Ideally, approved approaches subsequently funnel into *National Cancer Prevention Strategies*.

The following means and activities were suggested:

1. Improve health literacy of the individual
- Outreach to living environments (kindergarten, school, occupational fields, leisure time facilities, health systems),
- Target life events (pregnancy, parenthood, diagnosis of a relative with cancer),
- Improve knowledge, literacy, numeracy, motivation,
- Crucial factor: (digital) media literacy.

2. Reduce complexity of the environment (focusing on living environments and on the national health systems)
- Facilitate cancer prevention by reduction unhealthy life stile factors, environmental conditions, and occupational hazards through appropriate health policies,
- Individual risk assessment and identification of persons at higher risk to strengthen prevention and early diagnosis provided by health care professionals (e.g., general practitioners, occupational health practitioners, nursing staff, and others).

Lack of evidence

There is room for innovation, as evidence from randomized clinical trials is not any more possible to gather for such services that are already in wide use. In future, one focus area is how to acquire appropriate evidence based on randomised controlled trials, throughout the steps from early diagnosis to the treatment and management pathways. Evidence from real-world data will be likely also needed for the diagnostic and management services, with linkage to administrative data and population registries. Good use of such data sources to inform early detection policies may need new research designs and protocols to clarify the benefits and harms of services in early diagnosis. In principle, similar monitoring systems for the services are needed as recommended nowadays for the population-based cancer screening programmes.

It will be also necessary to identify risk factors, and consider criteria for genetic testing, to make identification of high-risk population groups possible. Developing and using validated risk scores, as well as evaluation of tailored early detection interventions, will be needed in the future. Developing evidence criteria is also needed. Gathering of evidence and selection of high-risk individuals may be coupled with development of apps helpful for self-assessment and self-examination.

It is likely that there are healthcare practices with aim of early detection, where benefits do not exceed potential harms. 'Wild' prostate screening, where part of men receive high-intensity PSA testing, is likely such an example; at least when considered according to the evidence created for population-based screening programme research. On the other hand, for PSA testing based on indication (such as unspecific urinating symptoms) evidence for the benefit and harm is not available. Even though the latter testing is justified in the clinical current care guidelines for the symptomatic patients, it is unclear if the patient received prompt information on the benefits and harms.

We believe that better cancer control policies should also acknowledge the role of research, namely health services research with focus on screening and early detection.

Voting summary

The group work was summarised at the end of the meeting from voting the best suggestions. Below main results from the voting.

1. **Misinformation on the internet** is one factor related to lack or poor awareness of early diagnosis, and this requires systematic responses from cancer control community. The experts identified misinformation online as large part of the problem that needs to be tackled. Misinformation may include usually deliberate actions to distort the line between facts and bad information.

   Solutions: collaboration with technology producers, accreditation of quality web sites and education to identify misinformation in general are possible solutions to widespread misinformation. People need systematic help on how to spot factual

information. This puts pressure on education system, training and how experts communicate their findings in user-friendly terms.

2. **Inadequate health literacy** is also related to poor awareness. The individuals need more knowledge of early diagnosis and motivation to act. Media competence is also a key. People should be targeted during relevant times of their life events, such as parenthood.

3. **Psycho-social factors** in awareness to early signs of cancer are also important. Medical doctors, nurses, dentists and other professionals working at the health care services could support health systems to boost early diagnosis better than nowadays. Communication campaigns should be conveyed in well targeted manner, ensuring that social media messages and collaboration are across different fields of science. Health care service providers need further training in order to improve understanding of barriers and on the balances of benefit and harm.

4. One of the proposals focused particularly on **early diagnosis of head and neck cancers,** Lack of awareness both at the population level and among health care professionals were found especially in oral cancers, where Hungary has heavy burden. One solution is to develop early detection programs for targeted populations. For head and neck cancers, this means people aged over 50 as well as identifying high-risk groups having co-morbidities. Similar barriers were identified also for breast cancer, prostate cancer and in relation to limited access to care.

5. Finally, there is **a barrier of lack of evidence**. It came up as a cross-cutting barrier relating to for example setting up new programs of early diagnosis or evidence when a novel test/diagnostic practice is going to be set up into practice. Appropriate trials are lacking, assessing the consequences on benefit and harm throughout the management history. Some cancers do not have early signs or the signs are not known well enough. High-risk groups may not be identified appropriately. One potential solution for the practices currently in wide use is better data collection on indications and symptoms, uses of test and management services and benefits and harms for real world data. There is also a lack of appropriate clinical trials: designs and protocols need to be developed to investigate benefits and harms of early diagnosis activities. One possible solution is to develop and use validated risk scores and tailored interventions in order to develop services for high-risk groups.

Summaries of group work, voting and wrap-up discussions are attached to this report.

The conference in Budapest was evaluated by iPAAC Evaluation work package (WP3) and by questionnaire from ECL, who is involved in WP5 conference planning and organization.

Discussion and conclusions

The main sources for the work of the task 5.1. were background paper discussed in online meetings and at the conference and a European wide survey on barriers to early diagnosis. Online meetings were done to save travel time – the decision proved to reflect well the 2019 autumn discussion of air travels and climate change. Short online meetings are not equal to meeting face to face. Because iPAAC follows two earlier Joint actions, many people knew each other; otherwise this strategy would have been risky.

Overall feedback from the online meetings and the conference in Budapest 20 May 2019 has been positive. The attendance in Budapest was as expected with 70 participants. We also developed during the meeting with Hungarian colleagues an idea of a country pilot, which would address oral cancers.

The survey on European level gave clear indication that the barriers and the selected cancer types were adequately well chosen. There were some comments of missing colorectal cancer in the survey. Because colorectal, cervical and breast cancers will be dealt in screening task 5.2. there was a need to go beyond those cancer types that are recommended for screening programmes in the EU member states.

From EPAAC work we found quality criteria for health checks. It may be useful in any programmatic planning of early diagnosis. From CANCON the policy paper on tackling inequalities is another useful source.

When addressing barriers to early diagnosis there should be a special focus of impact of these barriers to inequalities. There is much to gain if disadvantaged groups are specifically addressed, including tailored communications and messages. Both oral cancers and skin cancers have highest delays of early detection due to inequalities. Yet, further research is needed to establish programmatic services with good data management and appropriate balance of harms and benefits.

Patient-level constraints were highest in oral cancers. Dental services vary across Europe but there is also lack of awareness of risk factors, such as tobacco and alcohol. Health literate Europe should advance both early diagnosis and cancer prevention.

The early signs of many cancers may be very diverse or not yet known. Especially prostate cancer, leading cancer type among men, needs further research and better awareness. In aging Europe finding cancer early but avoiding overdiagnosis and overtreatment is a long-term investment. For prostate cancer, decision-making tools were suggested as helpful way to note complexities of the disease.

High-risk groups may not be identified well in several cancer types. There is also a lack of appropriate clinical trials: designs and protocols need to be developed to investigate benefits

and harms of early diagnosis activities. One possible solution is to develop and use validated risk scores and tailored interventions to serve high-risk groups. The role of informing people of early cancer signs is very valid. Mis- and disinformation were identified as a worrying trend that could delay early diagnosis and treatments.

To conclude:

1. It is important to identify not only the barriers to early diagnosis of cancer, but also the impact of such barriers on inequalities. In Europe, aging population and inequalities can cause both human suffering and negligence and this burden to health systems could be reduced if systematically addressed. According to the survey, both oral cancers and skin cancers have highest delays of early detection due to inequalities. There is a call to tackle the inequalities in early detection.

2. Evidence for early diagnosis and treatment requires well planned piloting, better data management and examining appropriate balance of harms and benefits. Further research is essential for establishing programmatic services.

3. The role of informing people of early cancer signs is very valid. Misinformation was identified as a worrying trend that needs to be addressed. Lack of awareness was highest in oral and skin cancers. Patient level constraints were highest in oral cancers. Health literacy and plain language communication were considered necessary.

4. Lack of evidence was highest barrier in other cancers which shows that the four cancer types chosen (breast, prostate, oral and skin cancers) all be could potential candidates for pilots. In breast cancer both access to primary care and poor organization of patient pathway were reasons for inequality.

   Other cancers included many different cancer types, among frequently mentioned were pancreas, lung, colorectal, bladder, blood, gastric cancers and lymphomas. Lack of evidence was defined in the survey as lack of evidence base on benefits and harms; evidence-based guidelines cannot be formed due to lack of knowledge; relation also to health policy planning – to which purposes research resources are allocated.

5. One important conclusion is that we do not know it all. Thus, early diagnosis is not possible in all cancer types. There are cancers with no early warning signs; there are rare cancers and cancers where there is not enough knowledge of early signs. In the survey lack of evidence was the second overall barrier to early diagnosis, while lack of awareness was the most common barrier in overall results.

6. High risk groups and vulnerable populations need tailored approaches.

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List of annexes

1. Online meetings, summary of discussions
2. Programme, briefing the group work, group tables
3. Presentations
4. Press releases
5. Facilitator´s report
6. Conference evaluation
7. Participants

Summary on online meetings on GoTo Meeting platform dates

10 December 2018, 25 February 2019, 29 April 2019

Balances of benefits and harm in relation with early diagnosis

- The current survival status in different countries is important reflecting cancer burden and it should be based on data and literature
- Early diagnosis is challenging in asymptomatic cancers and therefore prompt diagnosis is topical. With relation to (organized/ unorganized) cancer screening, the amount of early diagnosis outside organized screening programmes should be described. Some data on this exists, especially for breast, cervical and colorectal examination performed privately, however making interpretation of data difficult.
- Opportunistic screening is a large topic in several countries. Thus, the work for the conference should focus on 1−3 topics, e.g. clinical breast examination or health checks relating also to the outcome of the previous meeting of 1−2 cancer sites
- Early diagnosis of head and neck cancers is topical in Hungary, however there is the importance of evidence-based back-up for justification. Evidence exists in Hungary on high incidence due to life habits.
- Other suggested topics include UV radiation and skin cancer; the role of health professionals: GPs in awareness of signs especially in skin cancers as well as dentists and head and neck cancers. Also, financial aspects are important in relation to health care professionals, allowing a cost-effective way to conduct early diagnosis
- With head and neck cancers, after screening the next step of early diagnosis encounters financial barriers as patients/people do not go to dentists despite being a cheap health check. However, if people suffer from symptoms, they visit GP's easier. There exists a paper on head and neck cancers, and also an expert speaker for the conference was suggested.
- Measuring cancer burden for melanoma was reminded
- The status of health literacy will be clarified

Melanoma early detection: examples of Valencia, Veneto region, Slovenia

Valencia
- Free on-line training is available for primary care and specialized health care professionals. Two 20-hour editions per year are accessible since 2010.
- A clinical practice guide on melanoma early detection has been designed and published. There are two versions available, a brief one and a complete one
- Health professionals support tool for identification of skin lesions
- Posters and leaflets have been produced for general public dissemination
- Short videos have been showed through public transport buses broadcasting circuit aiming a broad audience.
- Rapid pathways in case of clinical suspicion (specifically for melanoma, but also for overall cancer). These include a check-list for confirming clinical suspicion as well as specific time and instructions for referring patients to specialists (please see attached regional health ministry ordinances).

Veneto region
- A project on melanoma early detection, named "Progetto ReteMela". It is a network of institutions, including a multidisciplinary group that works according to predefined guide-lines, as follows:
- General Practitioners who attended a certified training evaluate the patients
  (1st level) and send those at risk to
- Dermatologists working outside the reference center who evaluate the lesions, acquire digital images, and perform the biopsies of the lesions (2nd level, dedicated slots reserved for these patients)

- in case of a diagnosis of melanoma at risk of relapse, the patients are referred to one of the three reference centers for a larger excision (3rd level)
- pathologists and genome biologists analyze and characterize the excised samples
- all the cases are discussed by the multidisciplinary group (4th level), to define the best therapeutic strategy

Slovenia

Interested in evaluation in the field of early detection of symptomatic cancers.

- the use of term that screening programmes target »unselected population« – this is not entirely true since the »target population« is always defined (selected) at least by age and sex – in tailored screening also other determinants could play an important role in risk-stratified screening and management of screen-positive women, such as HPV vaccination status (in cervical screening), BRCA genetic status and other relevant determinants that could be assessed and measured in breast screening, etc... One could see tailored screening just as an upgrade of the existing screening programmes that might use the same IT infrastructure, quality system etc.
- overdiagnosos in early detection of symptomatic cancers – we might also acknowledge the burden that the use of unvalidated methods for early diagnosis (for example breast thermography, HPV self-sampling with unvalidated method, bioresonance.) imply on individuals as well as on the health system – do we have guidelines how to assess the risk in situations when a person approaches the health system with a positive result of an unvalidated test? Do we need them?
- are the inequalities in early detection in the scope of this WP? If yes, we might consider to tackle (also, among other things) the difference between men and women (for example in the stage distribution at diagnosis of same cancers) – especially if there is the difference in symptom appraisal and health-seeking behaviour
- how can NGOs contribute to early detection – can/how they help tackle barriers in Step 1?
- if cancer screening programmes are typically centralised, should early detection activities/management be centralised also, more decentralised (how important is the local context and environment) or in combination?

Questions, expectations and wishes about the Budapest conference

- The health literacy project implemented in Germany includes a genetic testing approach for early detection of familiar ovarian cancer and breast cancer already in this task (5.1) but its entirety in relation to the whole WP5 will be done later. In the project, patients are linked through genetic testing which acts as a prerequisite for screening. As part of it, information leaflets are being prepared as well as other material (e.g. videos) for relatives on the complex matters. Topics of the material include describing what mutations and genetic testing mean, what are consequences of the procedures, and what can be done for to the tested people. The aim of the project is to be broadened and to act as a way to approach people and thus as a blueprint. Also, people with low education are targeted in order to have them informed. BRCA applies to breast cancer forming one group
- Hungarian colleagues are happy to facilitate the head and neck group work.
- It was suggested that after registration and prior to the conference, attendees are assigned to check their countries' situation and existing guidelines which could be brought to the conference. National guidelines can be areas of disagreement, for example regarding opportunistic screening. There will provide input from German guidelines and the background guidelines from Norway will be checked for the conference but not before. Similarly, Hungarian guidelines for oral cancer screening and local protocols were developed and are used for screening and these protocols are taught in dental schools.
- Participants' interests on the topics should be asked in connection with registration

Literary sources for the meetings

Background paper prepared for the participants of the Budapest conference, unpublished draft, Anttila A (2018)

Tackling social inequalities in cancer prevention and control for the European population, Cancon policy brief 5 https://cancercontrol.eu/archived/uploads/images/PolicyBriefs/CanconPolicyBrief05.pdf

Full papers available at https://cancercontrol.eu/archived/, including Policy Paper on Tackling Social Inequalities in Cancer Prevention and Control for the European Population https://cancercontrol.eu/archived/uploads/PolicyPapers27032017/Policy_Paper_4_Tackling.pdf

Joint Action EPAAC, Health care services – Quality criteria for health checks – CEN Workshop Agreement http://epaac.eu/images/END/Final_Deliverables/WP_6_Annex_8.1_Quality_Criteria_for_Health_Checks_CEN_Workshop_Agreement.pdf

Participant name list (21), organisations (14) and countries (12) of the 3 online meetings for the task 5.1. early diagnosis

Ana Molina Barcelo and Marta Hernandez Garcia	The Foundation for the Promotion of Health and Biomedical Research of Valencia Region (FISABIO), **Spain**
Marco Zappa	Cancer Research and Prevention Institute (ISPRO), under National Institute of Public Health (ISS), **Italy**
Erzsébet Podmaniczky, Edit Marosi	National Institute of Oncology (OOI), **Hungary**
Wendy Yared and Elisabeth Dupont	Association of European Cancer Leagues **(ECL), Belgium**
Satu Lipponen, Ahti Anttila, Clarissa Bingham	Cancer Society of **Finland** (CSF)
Annarosa Del Mistro	Istituto Oncologico Veneto (IOV) under National Institute of Public Health (ISS), **Italy**
Peggy Furic	French National Cancer Institute (INCa), **France**
Urska Ivanus	Institute of Oncology Ljubljana (OIL), **Slovenia**
Ondrej Majek and Ondrej Ngo	Institute of Health Information and Statistics of the Czech Republic (UZIS), **Czech Republic**
Carmen Ungurean	National Institute of Public Health Romania (INSP), **Romania**
Mari Nygård and Margrethe Meo	Cancer Registry of Norway (OUS), **Norway**
Joachim Schuz	International Agency for Research on Cancer **(IARC), France**
Susanne Weg-Remers	German Cancer Research Center (DKFZ) under Federal Ministry of Health (BMG), **Germany**
Petra Čukelj	Croatian Institute of Public Health (CIPH), **Croatia**

EARLY DIAGNOSIS - 5 THINGS YOU NEED TO KNOW

First WP5 iPAAC Conference - Hosted by the National Institute of Oncology

Monday, 20 May 2019

National Institute of Oncology, Budapest, Hungary

iPAAC
INNOVATIVE PARTNERSHIP
FOR ACTION AGAINST CANCER

Aims and scope of the conference:

Early diagnosis of cancer - that is the recognition mainly of symptomatic cancer in patients - is in the focus of this conference. The objective of early diagnosis is to identify the disease at the earliest possible opportunity and lead to diagnosis and treatment without delays. When done promptly, cancer may be detected at a potentially curable stage, improving survival and quality of life.

Early diagnosis practices can sometimes induce harms in the patient population, such as over-diagnosis or over-treatment. Possible harms are relevant for patient information. There are also several barriers linked to suboptimal impact and social inequalities in health. These include e.g. health illiteracy, lack of awareness or resources, poor organization of the patient pathways, or lack of evidence. The scope of the conference is to deal with the above key issues in order to understand better the current state and challenges, and to improve European agenda on early diagnosis of cancer.

Developments in early diagnosis of head and neck, skin, prostate and breast cancers will be in a specific focus. The conference will deal also with other primary sites depending upon the interests among the participants. Please note that developments in other fields of early detection of cancer, such as in cancer screening programmes, will not be a topic for this conference and will be dealt later in another dedicated task of the Work Package.

Conference mode:

This is a task specific conference with co-creation. Co-creation means facilitating discussion and dialogue, increasing engagement across participants in small groups and fostering problem solving to identify best policies. We will be working towards drafting a plan of early detection and its management, including over-diagnosis.

Background materials:

Background materials, useful for the group work and reports, will be sent to the registered conference participants.

iPAAC JA target audience:

The primary target group of the iPAAC Joint Action will be policymakers at the EU level and decision makers at the national, regional and local levels. All of the innovative actions covered by the JA work packages will be assessed on the basis of sustainability and integration into national policies.
The target group of this conference will consist also of experts in professional and scientific organisations, who will have direct benefit from the JA by sharing expertise and experience regarding cancer control issues.
Cancer patients and patient organisations, who stand to benefit from the focus on innovation and implementation of cancer control actions and strategies, are also in the potential target group. Higher quality of life for cancer patients is a key focus of the JA, which will cover prevention, screening, cancer registries, innovative treatments and cancer care organization, among other topics.

Specific conference outcomes:

WP5 has 3 tasks addressing early detection, cancer screening, and health promotion. Each task will produce comprehensive reports, reflecting perspectives from all partners of the WP5 rather than reports and reviews by working groups. Desired outcomes from this 1st iPAAC conference are:
1.   early detection and management are getting more emphasis in cancer control
2.   contribution of a draft plan which advances early detection on European, regional and local level
3.   barriers to early detection are more widely known and better understood on policy level

EARLY DIAGNOSIS - 5 THINGS YOU NEED TO KNOW
First WP5 iPAAC Conference - Hosted by the National Institute of Oncology

Monday, 20 May 2019 - National Institute of Oncology
NIO, Building 3, Rath György u. 7-9, Budapest, Hungary

iPAAC
INNOVATIVE PARTNERSHIP
FOR ACTION AGAINST CANCER

AGENDA

08:30 - 09:00	**Registration and coffee**
09:00 - 09:30	**Welcome remarks** *Prof. Dr. Csaba Polgár, National Institute of Oncology, Director General* *ECL Welcome* *Mr Rozványi Balázs, Hungarian Cancer League, President*
09:30 - 09:50	**Introduction to iPAAC** *by Dr. Tit Albreht, iPAAC Scientific Coordinator*
09:50 - 10:10	**Prevention and early detection of oral cancers in Hungary, challenges and future plans** *by Dr. Eva Remenár, National Institute of Oncology*
10:10 - 10:30	**Social inequalities and early diagnosis** *by Dr. Ana Molina, FISABIO*
10:30 - 11:00	*Coffee break*
11:00 - 11:15	**Barriers in early diagnosis - Presentation of the survey results** *by Dr. Clarissa Bingham, Cancer Society of Finland*
11:15 - 11:30	**Introduction to group work** *by Ms Satu Lipponen and Dr Ahti Anttila, Cancer Society of Finland*
11:30 - 12:30	**Barriers, cancer type and inequality - First round of group work**
12:30 - 13:30	*Lunch*
13:30 - 14:00	**Early detection and cancer burden in Europe** *by Dr. Isabelle Soerjomataram, IARC*
14:00 - 15:00	**5 things to know - Second round of group work**
15:00 - 15:15	*Coffee break*
15:15 - 16:15	**Setting priorities in early detection - Summary reports from the working groups**
16:15 - 16:45	**General discussion** *moderated by Dr. József Lövey, National Institute of Oncology, Medical Director*
16:45 - 17:15	**Closing remarks and next steps**

https://www.ipaac.eu/

EARLY DIAGNOSIS - 5 THINGS YOU NEED TO KNOW

First WP5 iPAAC Conference - Hosted by the National Institute of Oncology
20 May 2019 - National Institute of Oncology
NIO, Building 3, Rath György u. 7-9, Budapest, Hungary

Briefing for group members
Barriers, cancer type and inequality - First round of group work

There will be 2 rounds of group work. The aim of the 1st round (11:30 to 12:30) is to generate a discussion on the barriers, using provided questions to guide the discussions. The group has to identify the two most important solutions to two chosen barriers, along with strategies to overcome them. After this round, we will have a total of 14 solutions to barriers (7 tables x 2 solutions each).

The 2nd round of group work (14:00 to 15:00) aims to shortlist to only 5 solutions to barriers via Dotmocracy. Each group will make a 5-minute elevator pitch on why everyone should vote for their two solutions to barriers and strategies to overcome the barriers as among the Five Things to Know. Individuals are given five ballot sheets each to place on the solutions plus barriers of their choice. The votes will be tallied to decide on the most popular five barriers and the solutions.

After the coffee break at 15:15, groups are invited to give brief reports on their group work, and a moderated discussion will take place to set priority actions to overcome the final shortlisted five solutions and barriers.

General description and timetables:

1. One facilitator per group, responsible to give a report after the meeting

2. Each group receives a set of questions. The facilitator takes care of timetables and summaries

3. Reports from the group will be included in the conference report

4. Group members are incouraged to submit cases directly to WP5 or via submitting to Best practice contest

5. Each group decides 2 proposals for statements to be adopted by this conference

6. There will be a joint selection process of the five key proposals

7. There will be general discussion of the group work at the end of the day to enrich the findings

8. Outcomes of this meeting are included in the conference report

9. Your contributions will be circulated for comments

	Group Work Round 1 (discussion and identification of barriers and solutions) **11:30 – 12:30 (60 min.)**	
1.	Introduction by facilitators	**4 mins**
2.	*Identify solutions to the early detection of cancer type or barrier. Discussions led by facilitators*	**40 mins**
3.	*Identify the TWO most important barriers and solutions, and the strategies to overcome them.*	**15 mins**
4.	*Facilitator notes the two barriers/solutions on poster sheets for displaying on the walls (for voting by all in Round 2.) With 7 tables, there will be a total of 14 barriers and solutions. Only 5 barriers and solutions will win to be the Five Things to Know.*	**1 min**

	Group Work Round 2 (Identifying the Five Things to Know) **14:00 to 15:00 (60 min.)**	
1.	Each group makes a 5-minute elevator pitch on why everyone should vote on their two barriers and solutions to be among the Five Things to Know.	**7 x 5 = 35 mins**
2.	Dot-voting for dotmocracy: participants walk to vote by placing their 5 stickers on the wall posters with the barriers and solutions of their choice. They can only use one sticker per barrier/solution (i.e. using all 5 votes on one barrier/solution is not allowed). Dotmocracy Police will be monitoring the voting.	**10 mins**
3.	Tallying votes and announcing the Five Things to Know	**15 mins**

IPAAC WP5 **Working group tables**

Presentations

The Budapest conference presentations are available at ECL website
https://www.europeancancerleagues.org/wp-content/uploads/iPAAC_WP5-Conference_20_5_2019_Budapest_All-presentations-Reduced-pdf.pdf

WP6 Genomics and Cancer

Scope: Develop practical guidance for Member States on:

1) organizing the **societal debate** on ethical, legal and privacy issues on the use of genome information in healthcare
2) installing stratified screening by **genetic testing** of high-risk cancer patients
3) implementing **precision genomics** in medical care
4) how to deal with **'Direct to Consumer'** testing
5) **education and training** on genomics of health professionals, policy makers and the citizens

WP6 - Genomics and Cancer

- Task 6.1: Applying genome information in health care: a paradigm shift in healthcare
- Task 6.2: Concept for the implementation of risk-adjusted prevention: the breast cancer case
- Task 6.3: Requirements and prerequisites for implementation of 'omics' in routine molecular diagnosis in oncology
- Task 6.4: 'Direct to Consumer' genetic testing
- Task 6.5: Education and training on genomics for healthcare professionals

WP6 - Genomics and Cancer

Topics

1. Citizen participation methodologies
   - Citizen forum Belgium (case study)
   - French approach on genomics acceptance (case study)
   - *Sienna project results (research)*
   - *Wellcome Trust initiative (research)*
1. Roadbook genomics in HCS (Be, F, It) (case studies)
2. WGS in HCS (UK, F, 1M Genomes project) (case study)
3. DTC policy
4. Tool for education & training on genomics

WP 7 – Cancer information and registries

Task 7.1: Mapping data sources and state-of-art of integrated cancer information systems

Task 7.2: Piloting the integration of data on care pathways

Task 7.3: Piloting the integration of data on cancer costs

Task 7.4: Piloting the integration of data on long-term follow up of cancer survivors

Task 7.5: Piloting longitudinal integration of administrative health care records and centralised coding systems at national level

Task 7.6: Delivering informative epidemiological indicators on cancer prevalence and survivorship

Task 7.7: Support to the Road Map – cancer information and registries

WP 8 – Challenges in Cancer Care

Task 8.1: Definition of neglected cancers: the case for pancreatic cancer
- Preliminary list of core clinical variables for cancer registries in pancreatic cancer circulated (*March 2019*)
Report expected before June 2019

Task 8.2: Neglected cancers: proposal of criteria for reorganisation of treatment delivery
Task Leader: ICO, Participating Partners: SAM (VUHSK), WIV-ISP, IPHS
- Literature review carried out (March / April 2019) with a focus on policy measures to reorganize treatment delivery of pancreatic cancer.
- Workshop planned for discussion in September 2019, Bratislava; with scientific societies, patients representatives, experts and national cancer plans.
- Final report expected November 2019
- ECCO (subcontract): Essential requirements for pancreatic cancer. December 2019

Task 8.3: MDTs and potential impact of new technologies and systems. Assessment of the opportunities for improving integration of cancer care
Task Leader: ICO, Participating Partners: IPHS, BcSAS, NIJZ, SAM (VUHSK)
- Selection of care studies: ongoing whit the support of ECCO.
- Site – visits: expected for *May to June 2019*. Methodology approach: multiple-case study.
- *Report delivered in November 2019*

WP 8 – Challenges in Cancer Care

Task 8.4: Economics of cancer care
Task Leader: ISS, Participating Partners: ICO, SAM (VUHSK), NIJZ, NIPH (IPMN), ISS (MoH)

4.1: To review international experiences in promoting allocative efficiency and identifying low-value or inappropriate cancer care and to map the desirable characteristics of interventions targeted to health care providers for improving the level of appropriateness in clinical care.

- Survey prepared and circulating.
- *Meeting in September 2019*

4.2. To review the recent developments in reimbursement models and experiences in introducing innovative treatments in European health systems, with special focus on radiation oncology and complex cancer surgery as case studies

- Literature review for reimbursement in radiotherapy oncology (*expected May 2019*)
- Literature review for reimbursement in surgical oncology (*expected September 2019*)
- Workshop to review the pros and cons of each reimbursement model with scientific societies, patients representatives and experts (*January 2020*)
- *Report expected April 2020.*

WP 8 – Challenges in Cancer Care

Task 8.5: Pain management in the context of cancer care
Task Leader: ISS, Participating Partners: ICO, ISS, THL

- Literature review on pain prevalence, barries to adequate pain management eith focus survivors.

- *Report expected September 2020*

Task 8.6: Palliative care
Task Leader: ISS, Participating Partners: ICO, THL

- *Report expected September 2020*

WP 9 – Innovative Therapies in Cancer

French National Cancer Institute (INCa)

KEY HIGHLIGHTS OF THE PAST YEAR – Tasks 1 & 2

WP9 Kick-off meeting 02-03 July 2018 — Literature review — WP9 meeting task 1 02 Oct 2018 — Questionnaires — Analysis of results and writing of first deliverable (current activities) — Milestones: 1st draft for May 2019

Main results from lit. review:
- 120 CPG placing innovative immunotherapies (ITS)
- Off-label recommendations identified mainly for small target groups, rare cancers
- Place of innovative immunotherapies could differ between guidelines, especially when comparison data are missing
- Hard to keep updated GPC in this fast evolving field

Completion of 1st questionnaire by iPAAC partners

Main results from questionnaire:
- Only half of the EU countries have included innovative ITS in at least one CPG
- Comparison between countries and between therapeutic indications regarding access in terms of reimbursement and restrictions of uses
- Existing early access programs

WP 9 – Innovative Therapies in Cancer

French National Cancer Institute (INCa)

KEY HIGHLIGHTS OF THE PAST YEAR – Task 2 & 3 - Horizon scanning systems & Biomarkers

WP9 Kick-off meeting 02-03 July 2018 — WP9 meeting task 2 & 3 06 March 2019 - Bruxelles — WP9 Horizon scanning meeting November 2019 - INCa

Preparation of the task
- Literature review
- Meetings with Euroscan, IHSI

Presentation of methodology for retrospective analysis to evaluate the efficiency of HS in oncology

Review of existing Horizon scanning systems and organizations

Identification of key figures and issues associated with innovative cancer therapies

- Highlight methodological specificities needed in HS systems in the field of oncology, especially for
  - cell and gene therapies
  - Biomarkers
- Assessment of inequalities between European Countries

WP 9 – Innovative Therapies in Cancer

French National Cancer Institute (INCa)

PLANS FOR THE NEXT YEAR – Task 1 & 2

- Consolidation of the deliverable linked to task 1 to present results from literature review and questionnaires
- Review and validation of the deliverable by WP9 partners. Finalized version expected for September 2019
- Consolidate main fields of interests for the roadmap:
  - List of clinical practice guidelines providers in Europe in the field of oncology
  - Examples of fruitful collaborations for the production of CPG; and of endorsement methods
  - Examples of reimbursement models enabling fast access
  - Examples of frameworks enabling early access to innovative immunotherapies for an unauthorized indication
  - Innovative cancer therapies in clinical pratice guidelines: remaining challenges (acceptability of off-label recommandations, how to improve production and update of CPG, visibility?, need to create a public financing system to implement studies comparing several innovative therapies between them when no comparison data are available)
  - Remaining challenges: Link with ECL – European Fair Pricing Network (increase transparency of innovative therapies prices – joint negociations in EU)?
  - Remaining challenges for access to innovative therapies across Europe (including inequities)

WP 9 – Innovative Therapies in Cancer

French National Cancer Institute (INCa)

PLANS FOR THE NEXT YEAR – Task 2 & 3 – Horizon Scanning systems

- Conduction of the retrospective analysis with the help of the questionnaire
- Additional meeting will be organized in November 2019 to validate task 3 deliverables
- For the roadmap, the following points could be included:
  - Generalities on Horizon scanning systems: definition, purposes, main methodological steps to follow to implement an HSS
  - Present some existing European HSS in place
  - Present the main ongoing collaboration initiatives existing in Europe
  - Present specificities to be considered in the HS methodology for the oncology field with a focus on innovative immunotherapies, gene and cell therapies (with the example of CAR-T cells) and biomarkers
  - Highlight challenges related to the assessment of impact of innovative therapies in the field of oncology

PLANS FOR THE NEXT YEAR – Task 4 – Real-life monitoring of innovative immunotherapies

- Meeting dedicated to task 4 to be organized in February 2020

WP 10 – Governance of Integrated and Comprehensive Cancer Care

German Federal Ministry of Health (BMG) and German Cancer Society (DKG)

KEY HIGHLIGHTS OF THE PAST YEAR 2018/19

Goal: "….develop practical instruments (…) (to ensure) a standardized (…) comprehensive oncological care in all Member States that is tumour-specific and delivers (…) high-quality care to all patients. These instruments should be used by NCCPs for the governance of oncological care".

Task 1: Assess and review NCCPs; develop recommendations on how the results of tasks 10.2-10.5 could be included in updated NCCPs
- 1.1. Survey on National Cancer Control Programmes/Cancer Documents in EU (M12)
- 1.3. Preliminary literature research on the conceptual model of governance and stewardship of cancer care (M12)

Task 2: Review and assess existing models of oncological patient pathways; develop a generic patient pathway for CCCNs
- 2.1. Literature Review of existing models of oncological patient pathways (M12)
- 2.1. Agreement of definition of patient pathways (M12)

Task 3: Review and assess implemented QI; develop standardized methodology; develop set of general and tumour specific QI for CCCNs
- 3.1. Literature Review of already implemented Qis and their respective methodology which was used (M12) –

WP 10 – Governance of Integrated and Comprehensive Cancer Care

German Federal Ministry of Health (BMG) and German Cancer Society (DKG)

KEY HIGHLIGHTS OF THE PAST YEAR 2018/19 (cont.)

Task 4: Review and assess existing PROMs; develop a framework for the implementation and pilot the framework in CCCNs
- 4.1. Preliminary results of literature review of existing models of collecting PROMs (M18)

Task 5: Develop a set of generic and tumour-specific requirements (including PP, QI and PROMS) for the setup of CCCNs; develop framework to monitor the successful implementation of the set of requirements
- 5.3. Establishment of CCCN pilot sites: Charité Hospital, Berlin/Germany & Lower Silesian Oncology Centre, Wroclaw/Poland (M3)
- 5.1. Generic and tumour-specific requirements for the set-up of CCCN developed and agreed (M12)

Overall: Synergies between work packages identified
- Task 3 QI and WP 7.2 (= Piloting the integration of data on care pathways)
- Task 4 PROMs and WP8.1 (= Definition of neglected cancers: the case for pancreatic cancer)
- Task 5 CCCN and WP 8.2 + WP 7.2 (8.2 =Neglected cancers: proposal for criteria for reorganization of treatment delivery [of pancreatic cancer] ; 7.2 = with the goal to use the same key figures/quality indicators)

WP 10 – Governance of Integrated and Comprehensive Cancer Care

German Federal Ministry of Health (BMG) and German Cancer Society (DKG)

PLANS FOR NEXT YEAR 2020

Goal: "….develop practical instruments (…) (to ensure) a standardised (…) comprehensive oncological care in all Member States that is tumour-specific and delivers (…) high-quality care to all patients. These instruments should be used by NCCPs for the governance of oncological care".

Task 1: Assess and review NCCPs; develop recommendations on how the results of tasks 10.2-10.5 could be included in updated NCCPs

Task 2: Review and assess existing models of oncological patient pathways; develop a generic patient pathway for CCCNs

Task 3: Review and assess implemented QI; develop standardized methodology; develop set of general and tumour specific QI for CCCNs

Task 4: Review and assess PROMs; develop a framework for the implementation and pilot the framework in CCCNs

Task 5: Develop a set of generic and tumour-specific requirements (including PP, QI and PROMS) for the setup of CCCNs; develop framework to monitor the successful implementation of the set of requirements

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Social inequalities and Early Diagnosis of Cancer

Ana Molina-Barceló

First WP5 iPAAC Conference

Monday, 20 May 2019
National Institute of Oncology, Budapest, Hungary

FISABIO-Public Health

Cancer and Public Health Unit

Presence, characteristics and equity of access to breast cancer screening programmes in 27 European countries in 2010 and 2014. Results from an international survey. Deandrea S, Molina-Barceló A, et al. Prev Med. 2016 Oct;91:250-263

European Guide on Quality Improvement in Comprehensive Cancer Control

Policy Paper on Tackling Social Inequalities in Cancer Prevention and Control for the European Population

1. Strategies for early detection of cancer
2. Effective solutions for population-based screening programmes
3. Cancer prevention & health promotion: implementation of the European Code Against Cancer

WP5 main tasks

Inequality a **cross-cutting** theme integrated in above mentioned tasks

CONTEST OF BEST PRACTICES TACKLING SOCIAL INEQUALITIES IN CANCER PREVENTION

Deadline for submission is 10th August 2019

https://www.ipaac.eu/news-detail/en/23-contest-of-best-practices-tackling-social-inequalities-in-cancer-prevention/

SOCIAL INEQUALITIES IN HEALTH
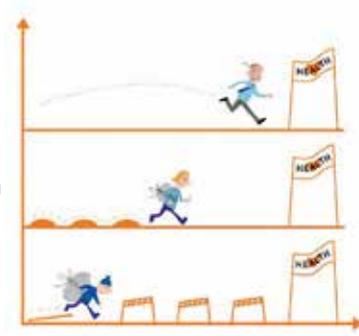
Systematic and socially produced

Unfair and avoidable

From: Norwegian Ministry of health and care services. National strategy to reduce social inequalities in health. Report No. 20 (2006–2007).

Social inequalities in cancer refer to health inequalities spanning the full cancer continuum across the life course (Krieger, 2005).

Risk Factors — Secondary prevention — Health care services — Rehab, survival → Inequalities in cancer incidence, and mortality

SOCIAL DETERMINANTS OF HEALTH MODEL (WHO, 2010)

Source: World Health Organization (2010). A conceptual framework for action on the social determinants of health. Social Determinants of Health discussion paper 2. Geneva: World Health Organization

Inequalities between countries

Cancer **incidence** higher is in Northern and Western European countries

Cancer **mortality** higher is in Eastern and Southern ones.

Cancer incidence and mortality patterns in Europe: Estimates for 40 countries and 25 major cancers in 2018.
Ferlay J, et al. Eur J Cancer. 2018;103:356-387

Inequalities within countries

Socioeconomic inequalities in cancer survival in England after the NHS cancer plan.
Rachet B, et al. Br J Cancer. 2010 Aug 10;103(4):446-53

SURVIVAL AND STAGE OF DIAGNOSIS

TEN-YEAR SURVIVAL FOR EIGHT TYPES OF CANCER COMBINED

EQUITY IN EARLY DIAGNOSIS

Socio-economic inequalities in breast and cervical cancer screening practices in Europe: influence of the type of screening program.
Palencia et al. Int J Epidemiol. 2010 Jun;39(3):757-65.

CANCER SCREENING vs EARLY DIAGNOSIS

Guide to cancer early diagnosis.
World Health Organization (WHO); 2017. ISBN 978-92-4-151194-0

COMMON BARRIERS TO EARLY DIAGNOSIS

Guide to cancer early diagnosis.
World Health Organization (WHO); 2017. ISBN 978-92-4-151194-0

Breast cancer awareness and barriers to symptomatic presentation among women from different ethnic groups in East London.
Forbes LJ, et al. Br J Cancer. 2011 Nov 8;105(10):1474-9

Step 2

Socio-demographic inequalities in stage of cancer diagnosis: evidence from patients with female breast, lung, colon, rectal, prostate, renal, bladder, melanoma, ovarian and endometrial cancer.
Lyratzopoulos G, et al. Ann Oncol. 2013 Mar;24(3):843-50.

Step 3

2-3 hours

1 hour

Figure 5: Mean travel time to nearest treatment centre for each socioeconomic deprivation quintile by 1-year

Socioeconomic disparities in head and neck cancer patients' access to cancer treatment centers.
Walker BB, et al. Rural Remote Health. 2017 Jul-Sep;17(3):4210

WHAT CAN WE DO TO REDUCE INEQUALITIES?

Population   **Targeted**   **Proportional Universalism**

Whole population   Socially vulnerable people   Proportionate efforts to the level of disadvantage

Fair Society, Healthy Lives: The Marmot Review.
Marmot M. London: Strategic Review of Health Inequalities in England post-2010; 2010.

Population

CanCon

Population

Targeted

Feasibility and acceptability of a cancer symptom awareness intervention for adults living in socioeconomically deprived communities.
Smith P, et al. BMC Public Health. 2018 Jun 5;18(1):695

CONCLUSIONS

- Social inequalities in early diagnosis of cancer exist between countries and within countries by social groups.

- It´s important to identify not only the barriers to early diagnosis of cancer, but also the impact of such barriers on inequalities

- It is recommended to include an equity perspective in the early diagnosis strategies, based on a proportional universalism approach in order to reduce social inequalities in cancer.

Thank you very much for your attention

Ana Molina-Barceló
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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
- Initally, the survey was planned to include 4-6 countries but was enlarged to the whole European level

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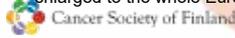
Background

- 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)

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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

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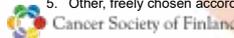
Barriers

- 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.

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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.

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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

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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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Materials

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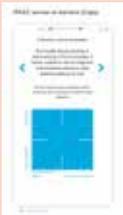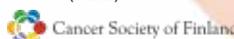
Invitations

- 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 socities, 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 send 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

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Respondents

	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**

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Connection of respondent to survey (N=147)

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

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Professional affiliations
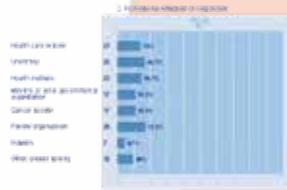
Other affiliations:
- Research
- Cancer registries
- Private health care professionals

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Expert knowledge

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Professional background
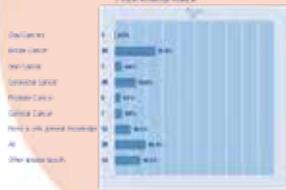
Cancer Society of Finland
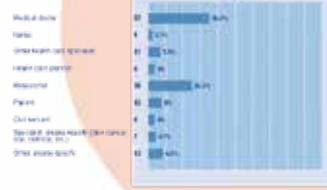
Respondents by country (N=140)

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, Luxembург, 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

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Cancer type (n=329)

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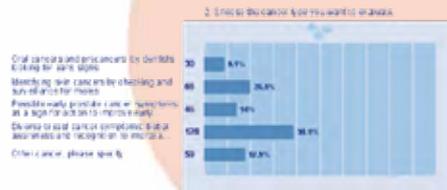
Other cancers:

- 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

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Oral cancers

- 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

- 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)

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Breast cancer

- 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)

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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

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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

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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

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Discussion

- The number of respondents decreased significantly bewteen 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 hte 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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- 1. World Health Organization (WHO). Guide to cancer early diagnosis. World Health Organization, 2017 (ISBN 978-92-4-151194-0)
- 2. European Committee for standardization (CEN). Health care services - Quality criteria for health checks. Collaborative Workshop Agreement (CWA) 16642:2013 (E).
- 3. International Agency for Research on Cancer (IARC). Breast cancer screening. IARC Handbooks of cancer prevention, vol. 15. IARC, Lyon 2016.
- 4. Zanetti R, Sacchetto L, Coebergh JW, Rosso S. To accelerate cancer prevention in Europe: Challenges for cancer registries. Eur J Cancer 2018;104:151-159.
- 5. Roland M, Neal D, Buckley R. What should doctors say to men asking for a PSA test? BMJ 2018;362:k3702 doi: 10.1136/bmj.k3702 (an editorial).

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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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Burden and trend of Cancer in Europe: First step towards Earlier Detection

International Agency for Research on Cancer
Lyon, France

Isabelle Soerjomataram

Budapest – 20 May 2019

Early Detection: Recommendation

Early Detection: Recommendation

Burden of Cancer in Europe

Cancer incidence: European Regions

Source: GLOBOCAN 2018
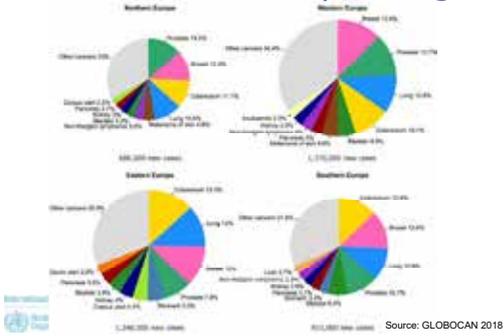
Cancer mortality: European Regions

Source: GLOBOCAN 2018
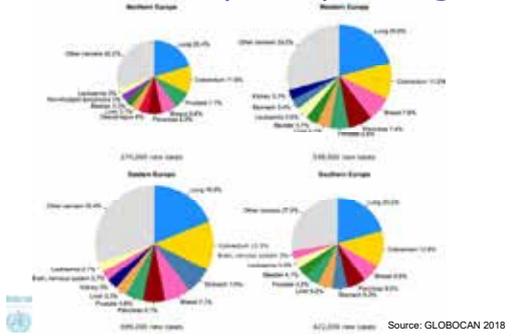
Melanoma of the Skin

Incidence & Mortality Melanoma

Source: GLOBOCAN 2018

Melanoma of skin

Source: ECIS

Incidence of Melanoma

Source: GLOBOCAN 2018

Mortality of Melanoma

Source: GLOBOCAN 2018

Incidence & Mortality Melanoma, E

Source: GLOBOCAN 2018

Trend incidence of Melanoma

* regional registries

Source: CI5plus

Trend mortality of Melanoma

Source: WHO mortality

Incidence & Mortality – by age

Source: CI5plus, WHO mortality
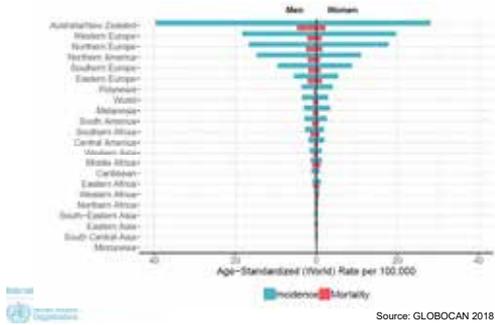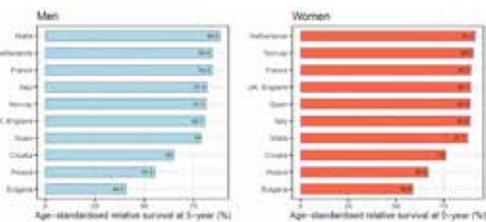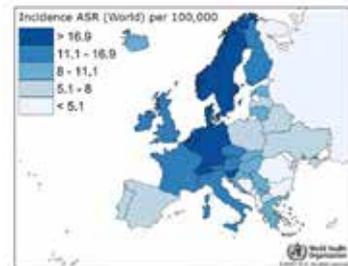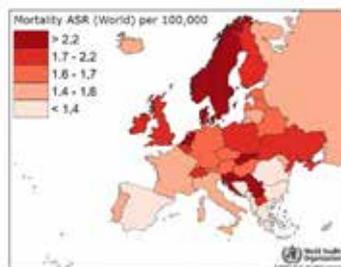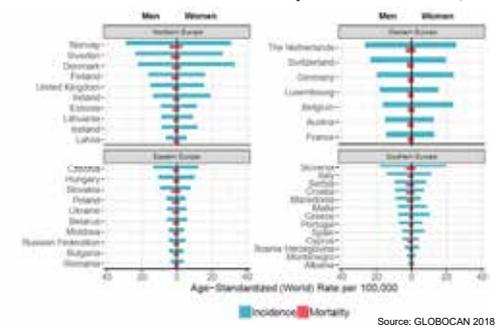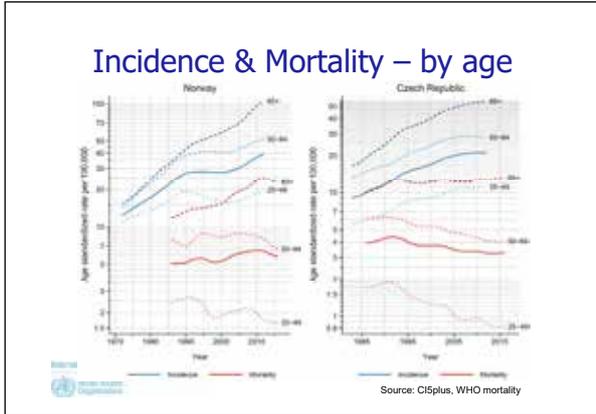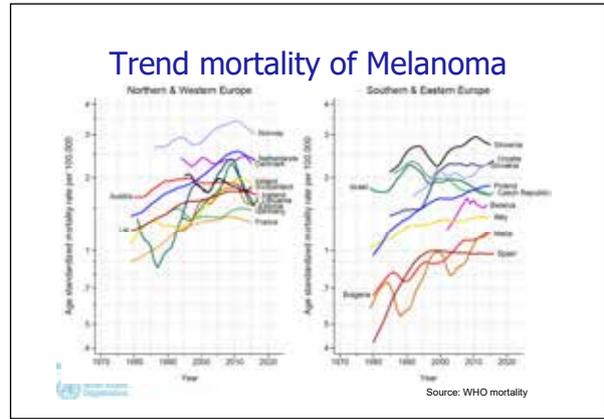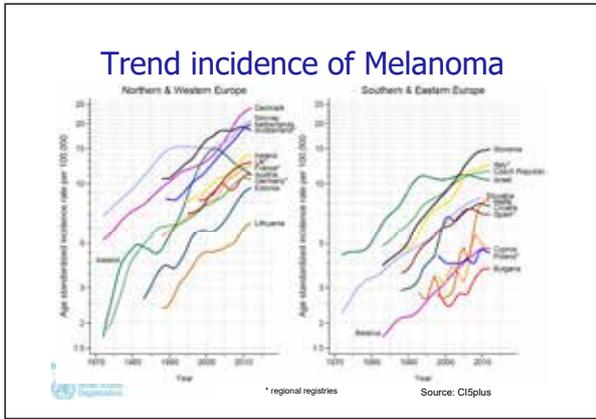
Success in Prevention of Melanoma

- SunSmart since 1980
- Secular changes
- 'Population dilution'
Mortality reduction
- Better treatment and follow-up
- Early detection

Oral Cavity Cancer

Incidence & Mortality from oral cavity cancer, world

Source: GLOBOCAN 2018

Incidence of Oral Cavity cancer

Source: GLOBOCAN 2018, incl. lip

Mortality of Oral Cavity cancer

Source: GLOBOCAN 2018, incl. lip
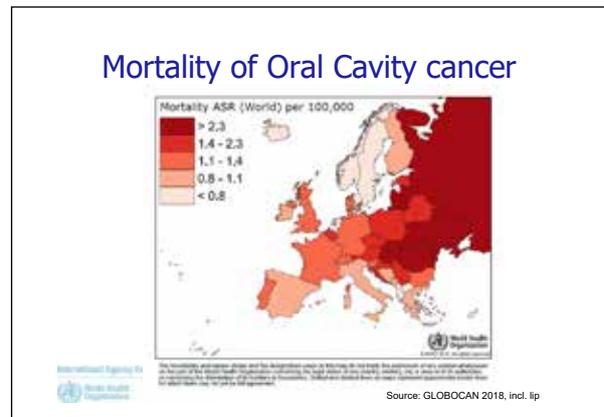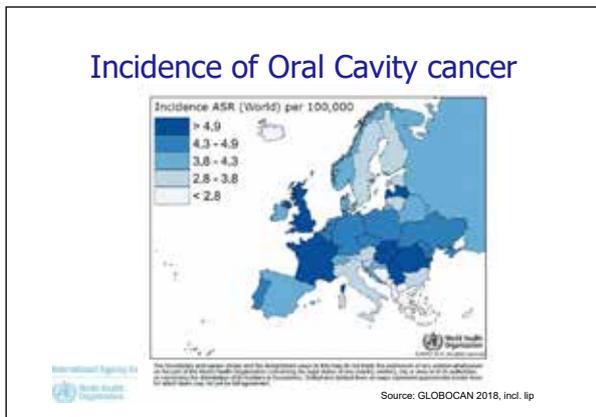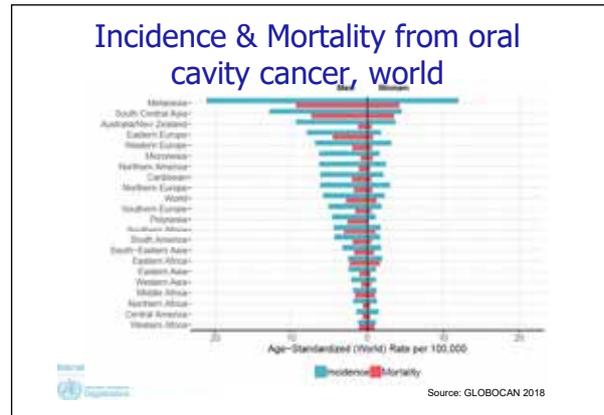
Incidence & Mortality from oral cavity cancer
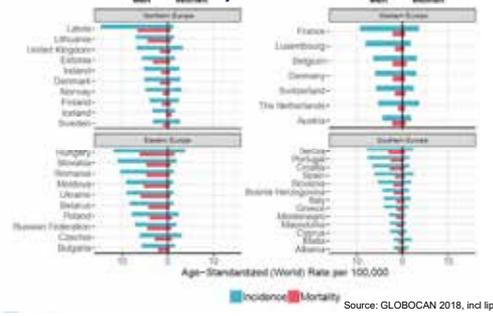
Source: GLOBOCAN 2018, incl lip

Survival from Oral cavity Cancer
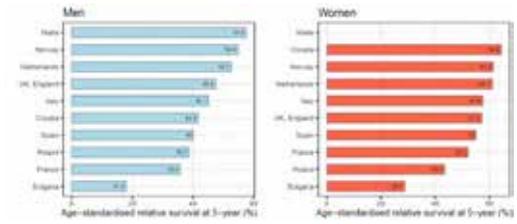
Source: ECIS

Lip, oral cavity and pharynx
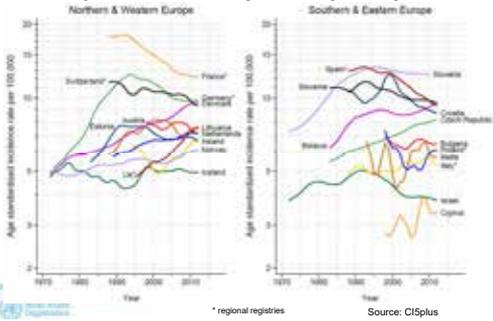
* regional registries   Source: CI5plus

Lip, oral cavity
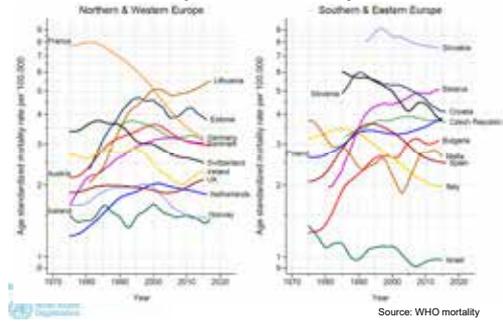
Source: WHO mortality

Prevention - Oral Cavity

- Separate w Lip Cancer!
- Primary prevention
- Screening – visual & physical examination for Oral Potential Malignant disorders
- Early detection – GP and dentists
  - Smokers & alcohol drinkers

Breast Cancer

Breast cancer screening: status

Basu et al 2018

Incidence, Mortality of Breast cancer
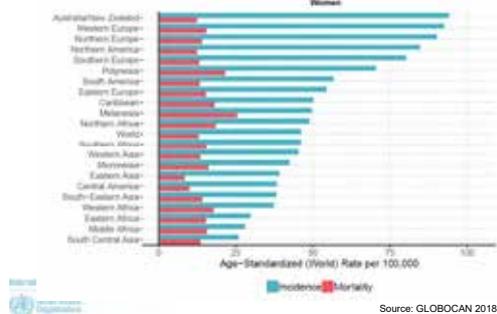
Source: GLOBOCAN 2018

Survival from Breast cancer
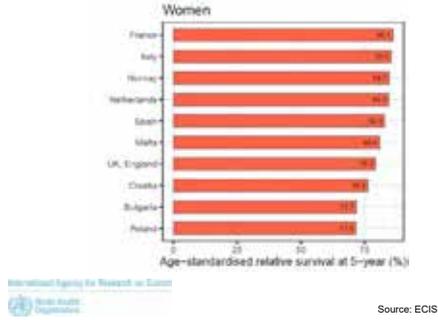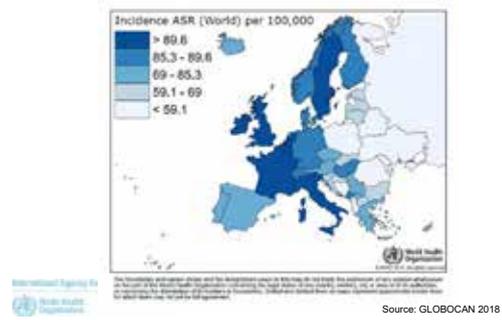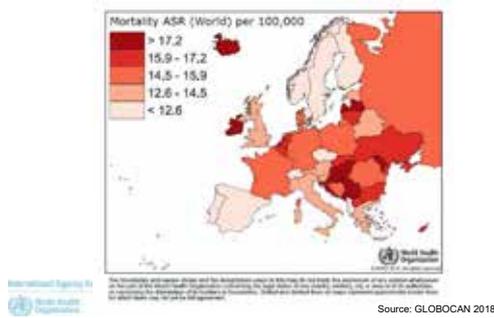
Source: ECIS

Incidence of Breast cancer

Source: GLOBOCAN 2018

Mortality of Breast cancer

Source: GLOBOCAN 2018

Incidence, mortality of Breast cancer

Source: GLOBOCAN 2018

Trend incidence of Breast cancer

* regional registries   Source: CI5plus
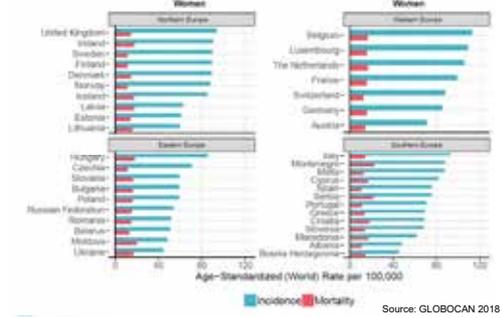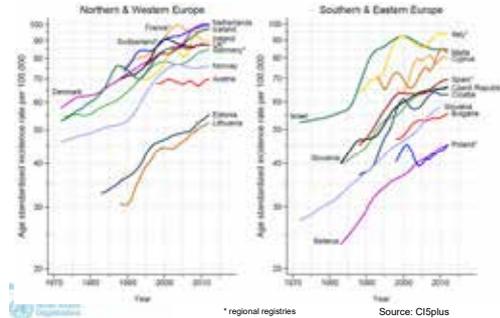
Trend mortality of Breast cancer

Source: WHO mortality

Trend incidence – by age

Source: CI5plus, WHO mortality
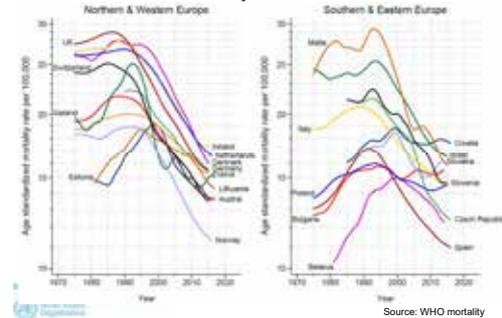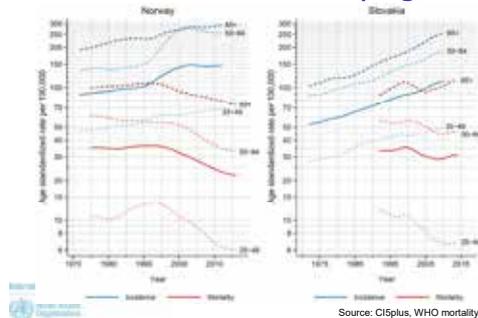
Breast Cancer Prevention

- Primary prevention
- Screening
- Early detection
  - Clinical Breast Examination – sufficient evidence for stage shift but not mortality reduction
 - Self Breast Examination – inadequate evidence to reduce mortality even if done correctly

Colorectal cancer

Incidence, mortality of CRC

Source: GLOBOCAN 2018

Incidence of Colorectum cancer

Source: GLOBOCAN 2018

Mortality of Colorectum cancer

Source: GLOBOCAN 2018
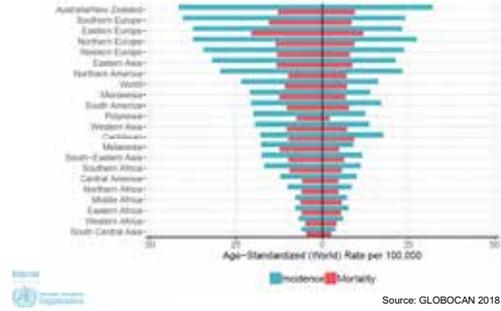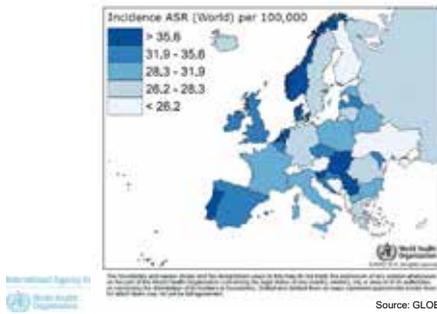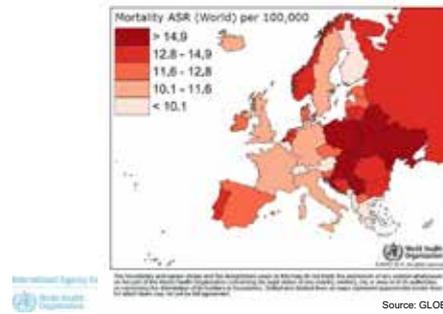
I & M of Colorectum cancer

Source: GLOBOCAN 2018
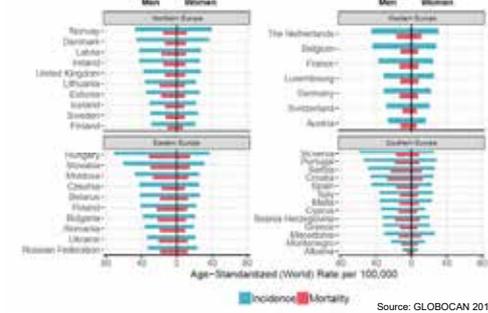
Survival from Colorectum Cancer

Source: ECIS
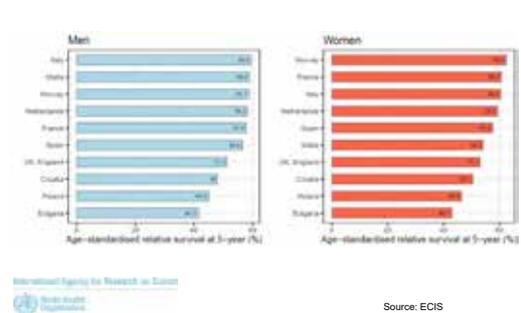
Trend incidence of Colorectum cancer

* regional registries   Source: CI5plus
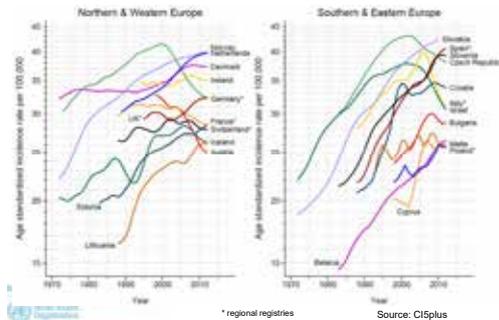
Trend mortality of Colorectum cancer

Source: WHO mortality
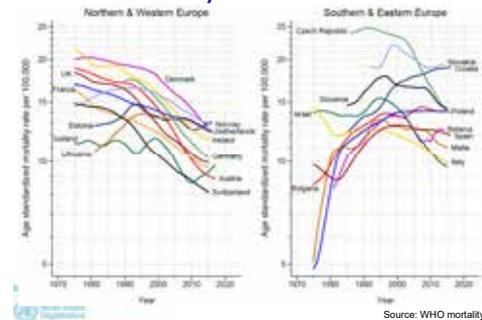
Increasing rates in young adults

Araghi et al 2019

Colorectal cancer screening: status

Basu et al 2018
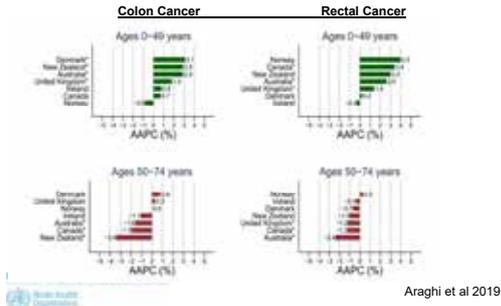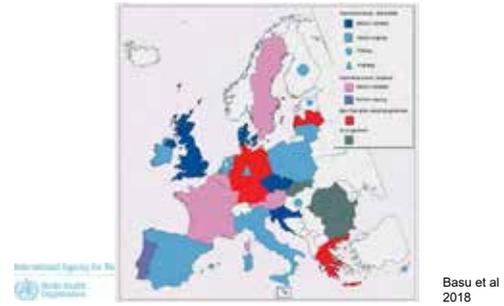
Colorectal Cancer Prevention

- Primary prevention
- Better screening (implementation & quality control)
- Early detection?

Conclusion

- Great variation in Europe
- Examples based on best practice
- Early detection
  - Determine burden
  - Scope for early detection
  - Implementation
  - Quality assurance

Acknowledgement

- Cancer registries – Cancer incidence
- Jerome Vignat
- Organisors

Prostate cancer

Prostate Cancer Incidence

Source: GLOBOCAN 2018
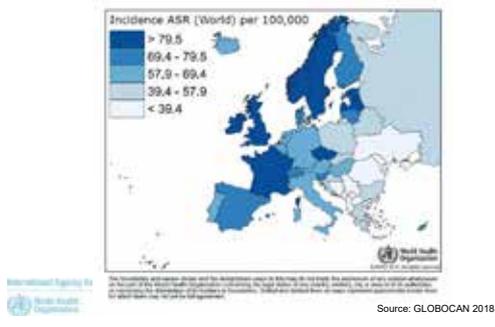
Prostate cancer mortality

Source: GLOBOCAN 2018
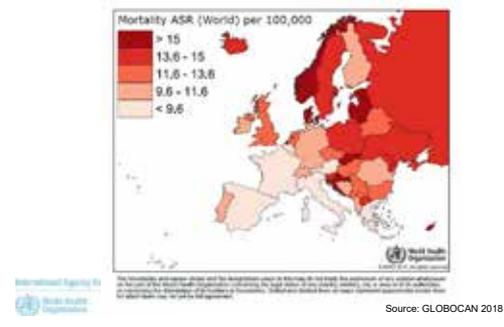
Incidence, mortality - global
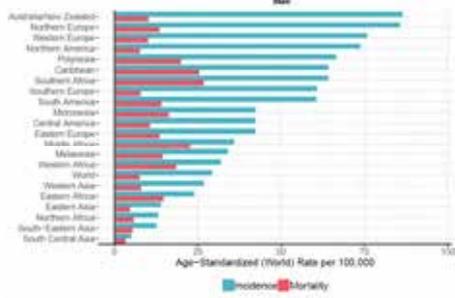
Incidence, mortality – Europe
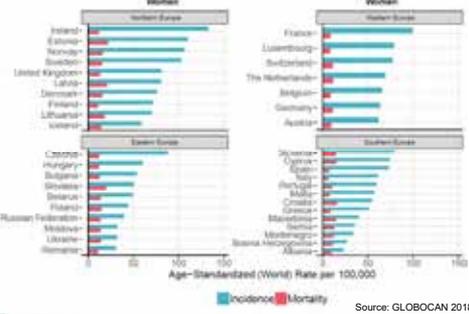
Trend incidence: Prostate cancer
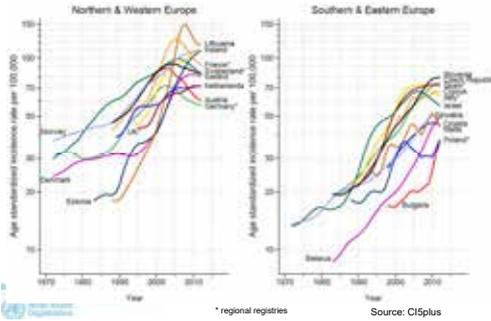
Trend Mortality: Prostate cancer
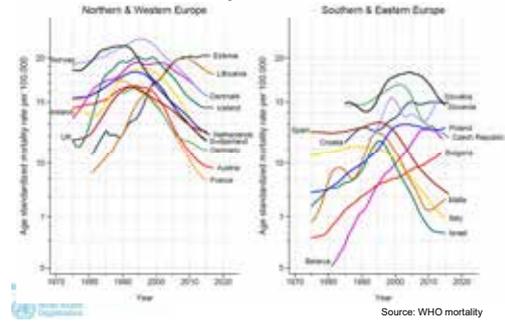
Prostate cancer trend – by age
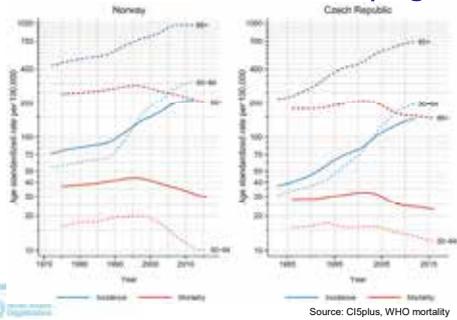
Survival from Prostate cancer
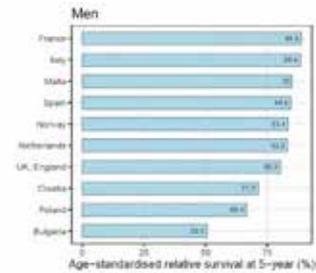
PRESS RELEASE

Embargoed 20 May 2019

Lack of Awareness is a Major Barrier to Early Cancer Detection

Budapest, 20 May 2019 - Cancer experts across Europe declare that there are still significant barriers to detecting cancer early. Over 150 experts from over 30 countries responded to the survey of the EU co-funded Joint Action iPAAC (innovative Partnership for Action Against Cancer). The results were announced in Budapest today.

Lack of awareness was identified as an important barrier to the early diagnosis of cancer. But the recognition of symptoms is not enough. Other issues are delays, access to primary care and socioeconomic inequalities. Early detection can also produce more harm than benefit, so more knowledge is needed to avoid unnecessary medical treatments.

The iPAAC survey explored some of the most common cancers in Europe: breast, prostate, skin and oral cancers. Six barriers in the survey ranged from lack of evidence to cancer stigma and poorly organized patient path.

The most common cancer among women in Europe is breast cancer, yet women are unfamiliar with the diverse early symptoms. The need is therefore urgent for better information and on the advantages of early detection.

Among men, prostate is among the most common cancers, but unfortunately, it is very difficult to detect early. There are no clear warning signs for aggressive types of prostate cancer and more research is needed. The lack of evidence was also very high among barriers mentioned.

Unequal access to primary care is another major barrier. There are populations who cannot afford to seek health care services, or cannot travel the distances required. It may also be that services simply do not exist.

The results of the European survey will be discussed at an international expert meeting today in Budapest. For Hungary, the focus will be especially on head and neck cancers. More than 60 experts are attending this meeting to advance European cancer control. They represent governmental agencies, health ministries, European societies, health care professionals, research institutes and patient advocacy organisations.

The aim of the meeting is to prioritize the most important findings of the survey for European policy-makers. There will be another conference in December 2019 in Helsinki about screening programmes where early detection will be tackled at the population level. Currently, EU recommends three population-based screening programmes: cervical, colorectal and breast cancer.

The iPAAC conference is organized by the Hungarian Institute of Oncology, the Association of European Cancer Leagues (ECL), the International Agency for Research on Cancer (IARC) and the Cancer Society of Finland.

iPAAC is a consortium of 44 organisations from 24 countries. This EU Joint Action is led by the Slovenian Institute of Public Health. It will run until April 2021. More on the Joint Action is at www.ipaac.eu and @ipaac_project on Twitter.

For more information: Dr. Clarissa Bingham, Clarissa.Bingham@cancer.fi

Annex: FACT SHEET: Main findings from the survey

FACT SHEET: Main findings from the survey

1. Early diagnosis relates to **the recognition of symptomatic cancer** in patients (definition source WHO)
2. The objective is to identify cancer 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.
3. For prostate cancer, the most important barrier is lack of evidence. There are no clear signs for early detection.
4. For breast cancer, the most important barrier to early diagnosis is lack of awareness.
5. At the patient-level, financial reasons are the most important barrier to the early diagnosis of oral cancers.
6. For skin cancer, the main barrier to early diagnosis is lack of awareness.
7. For most cancers, lack of awareness is still the most important barrier in Europe, experts say.
8. Cancer stigma does not play the most important role as a barrier to early diagnosis in Europe, experts estimate.
9. For both breast and prostate cancers, poor patient pathway is an important barrier to early diagnosis in Europe.
10. Limited access to primary care produces inequity in European cancer control.
11. New information of diagnosing cancer early: several significant barriers still exist.
12. The European survey examined four cancer types (oral, skin, breast and prostate), and found variations according to cancer types found in early diagnosis.

Source: Survey on perceptions of attitudes of barriers to early detection, iPAAC Joint Action, May 20, 2019

#ipaac #survey #cancer @ipaac_project

www.ipaac.eu

MAGYARORSZÁG KORMÁNYA

KORMÁNYZAT   DOKUMENTUMOK   A MAGYAR ÁLLAM

Emberi Erőforrások Minisztériuma

Dr. Kásler Miklós
az emberi erőforrások minisztere

**EMBERI ERŐFORRÁSOK
MINISZTÉRIUMA**

Hírek

Miniszter

Miniszteri biztosok

Helyettes államtitkárok

Háttérintézmények

Közérdekű adatok

Társadalmi egyeztetés

Elérhetőségek

ÁLLAMTITKÁRSÁGOK

Közigazgatási Államtitkárság

Parlamenti Államtitkárság

Család- és Ifjúságügyért Felelős
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Fejlesztéspolitikáért Felelős
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Sportért Felelős Államtitkárság

Szociális Ügyekért Felelős
Államtitkárság

A tájékozatlanság komoly akadálya a rák korai felismerésének

2019. május 21. 16:20

 Ajánlom 62

A tájékozatlanság még mindig jelentős akadálya a daganatos megbetegedések korai felismerésének – állapította meg az az európai felmérés, amelynek eredményeit az Országos Onkológiai Intézetben (OOI) rendezett Korai Diagnózis Konferencián hoztak nyilvánosságra.

Az egészségügyi minisztériumok, európai kutató intézmények és civil szervezetek részvételével zajlott találkozón felmerült egy hazai pilot program indításának lehetősége is, amely a fogorvosok és a háziorvosok bevonásával a szájüregi daganatok korai szűrését célozná meg. A program részleteit a későbbiekben dolgozzák ki a szakemberek.

A 30 ország több mint 150 szakemberének részvételével zajlott vizsgálat kérdőívét az „Innovatív Együttes Fellépés a Daganatos Megbetegedések Ellen (iPAAC JA)" uniós projekt keretében fejlesztették ki. A projekthez az Országos Onkológiai Intézet Prof. Dr. Kásler Miklós akkori főigazgató vezetésével csatlakozott, amelyet Prof. Polgár Csaba jelenlegi főigazgató visz tovább. Megbízásukra a szakmai és tudományos munkát Prof. Nagy Péter, az OOI tudományos igazgatója koordinálja.

A felmérés az Európában leggyakrabban előforduló daganatos megbetegedések közül a mell-, a prosztata- és a bőrrák, valamint a szájüregi daganatokat vizsgálta. A kutatás hat akadályozó tényezőt azonosított, a bizonyítékok hiányától kezdve a daganatos megbetegedéseket övező stigmán át, a rosszul megszervezett betegutakig.

A felmérés megállapította, hogy bár az európai nők körében a mellrák az egyik leggyakoribb rosszindulatú elváltozás, az érintettek számára továbbra is ismeretlenek a korai tünetek, így kiemelten szükséges a betegségről szóló hatékonyabb felvilágosítás. A férfiak körében a prosztatarák az egyik leggyakoribb daganatos megbetegedés, amit sajnálatos módon nehéz a korai szakaszban felismerni, így ez esetben akadályt jelent a bizonyítékok hiánya, valamint további kutatások szükségesek az egyértelmű figyelmeztető jelek felismerésére.

Magyarországon jelenleg a Nemzeti Rákellenes Program kiemelt része a felvilágosítás, a megelőzés, valamint, hogy a rizikócsoport tagjai részt vegyenek a szűrővizsgálatokon. Hazánkban ma három daganatos betegség esetében nyílik lehetőség a népesség szintű szűrésre. A méhnyakszűrés 1994-es bevezetését 2002-ben – az első Orbán-kormány idején – az emlőszűrés követte, majd a negyedik Orbán-kormány ideje alatt, 2018 novemberében a vastag- és végbélszűrés bevezetése új korszakot nyitott a betegség elleni küzdelemben. Április végéig az ország valamennyi megyéjében és a fővárosban is elindult a program, amelynek keretében eddig már több mint 220 ezren kaptak meghívólevelet.

(EMMI)

ESEMÉNYEK

2019.
okt.
28.

A mai napon nincs kiemelt esemény.

→ *Eseménynaptár*

VIDEÓK

Több mint 50 ezren igényelték a családvédelmi akcióterv valamelyik formáját

1 2 3 4

→ *további videók*

FOTÓK

A legszelídebb motorosok felvonulása

1 2 3 4

→ *további fotók*

BŐVÜLT
AZ ADÓKEDVEZMÉNYRE JOGOSÍTÓ
BETEGSÉGEK LISTÁJA!

→ *Adókedvezmények*

**CSALÁDI
OTTHONTEREMTÉSI
KEDVEZMÉNY**

→ *Családi Otthonteremtési
Kedvezmény (CSOK)*

Facilitator´s report, József Lövey, Natioal Institute of Oncology, Hungary

„5 things you need to know about early detection"

Setting priorities in early detection

20 May 2019, 15:15-16:45

The aim of the facilitated discussion was to identify the most important barriers and strategies to overcome them in the field of early detection.

The participants joined groups forming 7 tables in defined topics. The tables were; Prostate, Breast Cancer, Head and neck cancer, Health literacy, Awareness 1 and 2, Evidence and Access.

Group work has been started earlier in two rounds:

> The 1st round (11:30 to 12:30) generated a discussion on the solutions/barriers, using provided questions to guide the discussions. The groups identified the two most important solutions/barriers, along with strategies to overcome them. A total of 14 solutions/barriers (7 tables x 2 barriers each) have been identified at the end.

> The 2nd round of group work (14:00 to 15:00) shortlisted only 5 barriers via Dotmocracy. Each group made a 5-minute elevator pitch on why everyone should vote for their two barriers and strategies as among the Five Things to Know. Individuals were given five ballot sheets each to place on the solutions/barriers of their choice. The votes have been counted and the most popular five solutions/barriers identified.

During group-work the most important barriers receiving the most votes were:
1. **lack of awareness**
2. **low level of health literacy of the population**
3. **misinformation (gained mostly from the internet)**
4. **low level of multidisciplinary collaboration**
5. **inadequate funding**

For strategies to overcome them the propositions were:
1. **education programs for patients (and for professionals)**
2. **elevate (through courses, information-material and media) the health literacy of the people**
3. **controlled internet sites – or highly recommended web-sites, certified by authentic organizations**
4. **strengthen the multidisciplinary collaboration (governmental responsibility)**
5. **early detection programs for targeted population (governmental responsibility)**

Following the announcing the votes a free discussion has been started discussing the possible ways of implementing the solutions. This included education of adults and young people; Use of modern information channels e.g. social media; to compete efficiently with those sources who spread false information; Areas of responsibility of governments, civil groups and the individuals; Financial problems and the possible harmful interference of financial interests.

Evaluation

ECL sent a questionnaire directly after the conference to the attendees. Results are presented below.

Table 1. Evaluation of conference sessions

Please tell us what you thought of the sessions	Excellent	Good	Satisfactory	Poor
Welcome & Introductions	14	14	5	0
Introduction to iPAAC	15	15	2	0
Prevention and early detection of oral cancers in Hungary	15	13	7	0
Social ineaqualities and early diagnosis	23	14	0	0
Barriers in early diagnosis - Presentation of survey results	14	19	2	1
Introduction to group work	14	18	4	0
Barriers, cancer type and inequality – 1st round of group work	14	11	6	0
Early detection and cancer burden in Europe	20	7	1	0
5 things you need to know – 2nd round of group work	13	15	1	0
Setting priorities in early detection – Summary report of WG	14	10	1	1
Closing remarks and next steps	9	12	0	0
Total	165	148	29	2

Table 2. Evaluation of use of time in conference

The time allocated to the sessions was	Too short	Right length	Too long
Presentations in general	0	33	0
Facilitated iscussions	5	27	0
Participants presentations	1	33	0
Hands-on workshop	6	25	0
Overall length of the workshop	3	30	0
Total	15	148	0

Table 3. Evaluation of group work

Please evaluate the group work	Agree	No opinion	Disagree
Background documents sent in advance was helpful	21	9	0
Facilitation of group work was good	22	7	0
I was able to contribute in the group work	27	4	0
The propsals and summary reflected the group's discussion	22	4	0
Voting was a good idea	19	12	0
Total	111	36	0

EARLY DIAGNOSIS - 5 THINGS YOU NEED TO KNOW
First WP5 iPAAC Conference - Hosted by the National Institute of Oncology

Monday, 20 May 2019 - National Institute of Oncology
NIO, Building 3, Rath György u. 7-9, Budapest, Hungary

iPAAC
INNOVATIVE PARTNERSHIP
FOR ACTION AGAINST CANCER

Ahti Anttila	Finland	Research Director	Mass Screening Registry, Finnish Cancer Registry
Akos Juhasz	Hungary	Pharmacist	ESOP European Society of Oncology Pharmacits
Ana Molina Barceló	Spain	Phd	FISABIO
Andreas Charalambous	Cyprus	Nurse – Nurse Researcher – EONS President Elect	European Oncology Nursing Society
Balázs Rozványi	Hungary	President	Hungarian League Against Cancer
Borbély Katalin	Hungary	National Institute of Oncology	National Institute of Oncology, Budapest
Carmen Ungurean	Romania	coordonator of cancer screening a prohrammes	National Institute of Public Health
Clarissa Bingham	Finland	Senior Specialist	Cancer Society of Finland
Csaba Polgár	Hungary	Director General	National Institute of Oncology
David Ritchie	Belgium	Senior Cancer Control Officer	ECL
Edit Marosi	Hungary	International Relations Coordinator	National Institute of Oncology
Elisabeth Dupont	Belgium	Operations Coordinator	ECL
Emma Woodford	Belgium	Chief Operating Officer	EONS
Erzsébet Podmaniczky	Hungary	Department Head, International Relations Department	National Institute of Oncology
Éva Remenár	Hungary	Head Physician	National Institute of Oncology
Frédéric de Bels	France	Head o the National screening Department	French National Cancer Institute (INCA)
Gordan Sarajlić	Croatia	epidemiology resident	Croatian institute of public health
Gordan Sarajlić	Croatia		Croatian Institute of Public Health
Hendrik van Poppel	Belgium	Prof. Dr. MD., PhD.,	European Association Urology (EAU)
Ilana White	Switzerland	Assoc. Director, Oncology Policy	MSD
Imre Gaál	Hungary	Vice President	Hungarian League Against Cancer
Inga Cechanoviciene	Lithuania	Head of Specialized health care department	Ministry of Health of the Republic of Lithuania
Isabel Portillo	Spain	SCREENING COORDINATOR	The Basque Health Service
Isabelle Soerjomataram	France		IARC
Jakub Gregor	Czech Republic	editor, photographer	Masaryk University, Faculty of Medicine
Janne Villemoes Bigaard	Denmark	Head of early detection and vaccination	Danish Cancer Society
Jon Kirknes	Norway	Head of Prevention	Norwegian Cancer Soceity
Jörn Knöpnadel	Denmark	Expert Health Technology Assessment	National Association of Statutory Health Insurance Physicians
Kazda Tünde	Hungary	Patient Engagement Specialist	Pfizer Gyógyszerkereskedelmi Kft.

Kimmo Järvinen	Finland	CEO	Propo the Finnish Prostate Cancer Association
Magyar Henrietta	Hungary	Public Affairs and Communications Lead	Pfizer Gyógyszerkereskedelmi Kft.
Marc Van Den Bulcke	Belgium	head cancer center	sciensano
Mari Nygård	Norway	Senior Medical Advisor	OUS/Cancer Registry of Norway
Maria Dalmas	Malta		Ministry for Health
Maria Godeny	Hungary	Dr	National Institute of Oncology
Marta Hernández García	Spain	Researcher on cancer prevention	Fundación FISABIO
Mercédes Sára Fraunberger	Hungary	Youth Ambassador	Hungarian Cancer league
Miljana Stojanovska		Youth Ambassador for the European Code Against Cancer	European Cancer Leagues – ECL
Mirela Strandzheva	Bulgaria	Senior Researcher	National Center of Public Health and Analyses, Sofia
Müller Cecília	Hungary	országos tisztifőorvos	Nemzeti Népegészségügyi Központ
Nataša Antoljak	Hungary	national coordinator of colorectal cancer screening programme	Croatian institute of public health and University Zagreb Medical school
Ondrej Majek	Czech Republic	Department Head	Institute of Health Information and Statistics of the Czech Republic
Ondrej Ngo	Czech Republic	Biostatistician	Institute of Health Information and Statistics of the Czech Republic
Pekka Jousilahti	Finland	Research Professor	National Institute for Health and Welfare
Péter Nagy	Hungary	Scientific Director	National Institute of Oncology
Réka Felhő	Hungary	International Relations Coordinator	National Institute of Oncology
Sándor Kadarkai	Hungary	Medical Advisor	Pfizer Hungaria
Sarah Collen	Belgium	European Association of Urology – adviser	European Association of Urology
Sarolta Gundy	Hungary	scientist	Hungarian League Against Cancer
Satu Lipponen	Finland	Director, strategy and foresight	Cancer Society of Finland
Sebastian Schmidt	Germany	Head of Strategy and Medical Affairs CT	Siemens Healthcare GmbH
Sten Zelle	The Netherlands	Advisor monitoring & evaluation	National Institute for Health and the Environment – Centre for population screening Netherlands
Susanne Weg-Remers	Germany	Dr. med.	German Cancer Research Center
Svetlana Vrga	Serbia	International Cooperation	Institute of Public Health of Serbia
Tit Albreht	Slovenia		National Institute of Public Health
Vojtěch Bulhart	Czech Republic	graphic designer, cameraman	Faculty of Medicine, Masaryk University
Wendy Yared	Belgium	Director	ECL
Winkler Violetta	Hungary		Hungarian League Against Cancer
Zsuzsanna Ferbert	Hungary	International Relations Coordinator	National Institute of Oncology
Zsuzsanna Lénárt	Hungary	Administrator	National Institute of Oncology