iPAAC WP5, task 5.1.

EARLY DIAGNOSIS OF CANCER IN CANCER CONTROL STRATEGIES

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1. Defining early diagnosis

In the recent WHO Guide (1), 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. In addition there may be other patient finding approaches, based on surveillance or counselling of particular high-risk groups, where early diagnosis or prevention of cancer has been targeted (2). The WHO guide is meant for exploring the importance of early diagnosis in comprehensive cancer control. Therefore it is useful to adopt the above definitions for the task 5.1. of the iPAAC, so that the task will deal mainly with the above definition of early diagnosis of cancer, with possible further specifications relevant for early diagnosis to be developed during the course of the activity.

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 detected 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 access to diagnostic tests and pathology; poor follow-up and coordination; inaccessible high-quality, timely treatment; and, e.g., financial obstacles. Of note, when considering early diagnosis within individual patient perspective (without a programmatic view such as population-based cancer screening), there are additional barriers such as in individuals not having 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 the screening service. With an awareness/information campaign the population at risk, respectively, cannot be reached with a similar coverage.

One important suggestion in the WHO guide is that in 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.

Discussion points on the above:

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 on health checks (CEN/CWA) (7), health checks are defined as services that offer examinations for presumably healthy people/clients 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 to the health check and which affects to the contents of the health check. Therefore, 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 also with early diagnosis of cancer.

2. What services will be included in the task 5.1. on early diagnosis of cancer?

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).
- UV: Activities on early diagnosis of skin cancers based on inspection and surveillance of moles; can include also detection of pre-cancers, see the experiences of campaign on UV early cancer detection and prevention in the Cancon. 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 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 so 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.

Patient-level examples

Awareness and access to services based on symptoms for breast, cervix, prostate, mouth, larynx, 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. It would be, however, very difficult to deal with a large number of individual cancer sites and symptoms within the task. It is possible to focus just to few selected cancer sites. To select those depends largely upon what sites are of interest within the work group.

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**.**

3. Balances of benefits and harm in relation with early diagnosis

Early diagnosis and cancer burden

Major contributions in accurately measuring cancer burden in relation with early diagnosis consists of a range of indicators (incidence, survival and prevalence, mortality; taking into account e.g. prevalence of risk factors) at the population level and stage of diagnosis. Survival when used alone is not appropriate. 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 cancers or precancers (or other such conditions) by screening, which would not have been otherwise detected and which would not cause harm or symptoms (8, 9). For early diagnosis of cancers in symptomatic, the above definition is not accurate; here overdiagnosis of cancer mean rather detection of cancers that would not have affected mortality nor serious adverse effects (9). There can be, respectively, uncertainties on the eventual prognosis. Overdiagnosis can be also a result from increased diagnostic activity and widening of the diagnostic criteria to define a condition requiring an intervention (12).

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: the worry associated with a cancer diagnosis and some complications of the therapy. On the other hand small indolent tumors may 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).

Over-diagnosis 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 system. 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 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 can be 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 Europe-wide recommendation to avoid spontaneous screening, valid also for prostate cancer; however, spontaneous screening also of asymptomatic men is apparently very common and benefits and harms are still largely unstudied.

4. Social inequalities and inequities 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). Equitable access to early diagnosis of cancer is crucial to improve equity in cancer survival. 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 former have also been identified (30).

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 us 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 some recommendations have been suggested in the context of the previous Joint Action of the European Commission Cancer Control (36). These include a number of

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).

5. Further aspects for discussion within the Work Package

One interesting angle for the iPAAC Conference on early diagnosis can also be the 'grey' area of testing in order to diagnose early, or otherwise prevent cancer incidence or mortality, in activities which are between the systematic, population-based cancer screening programmes, and care for symptomatic cancer patients; such as seeking for care among high-risk populations within the various clinical settings. This can deal a woman seeking for a mammography referral due to breast cancer diagnosed recently in a close relative, or concern of prostate cancer due to disease diagnosed in close relatives as an indication for asking for a referral to PSA test. The current practice can vary between health care providers and, on the other hand, systematic evidence has not been available on all the benefits and harms: Under which indications such tests are to be done in the domain of early diagnosis? How this compares to tailoring of population-based cancer screening programmes (links with Task 5.2. of the WP5)? And how this compares with genetic tests/counselling as an indication to have the test?

One task planned for the task 5.1. is on issues in health literacy on genetics and risk-adjusted prevention through information services using breast cancer as an example will be placed within the current task (38). There are important links with this activity e.g. on the health literacy/illiteracy aspects and other such barriers in relation with social inequalities. Improvement of health literacy can be a step to improve the information available for patients in any condition (also in other patient groups that those coming from a high-risk group). Also, links with the task 6.2. of the iPAAC are possible.

We suggest some further literature searches from PubMed, using selected cancer sites as examples, for the group works in the conference. This will become possible after the group work topics for the Conference have been decided.

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Annex: Some objectives and recommendations from the earlier published documents

(1) WHO Guide

Step 1: Awareness and accessing care. The first step, “awareness and accessing care” consists of two key components: (i) symptom appraisal (period from detecting a bodily change to perceiving a reason to discuss the symptoms with a health-care practitioner); and (ii) health-seeking behaviour (period from perceiving a need to discuss the symptoms with a health-care practitioner to reaching the health facility for an assessment).

Patients must be aware of specific cancer symptoms, understand the urgency of these symptoms, overcome fear or stigma associated with cancer and be able to access primary care. Thus, awareness has to be translated into appropriate health-seeking behaviour, and the health care they seek has to be accessible, affordable and culturally and gender appropriate.

Step 2: Clinical evaluation, diagnosis and staging. The second step, “clinical evaluation, diagnosis and staging” can be classified into three components: accurate clinical diagnosis; diagnostic testing and staging; and referral for treatment. This step is also known as the diagnostic interval (Table 2).

Step 3: Access to treatment. In the third step, “access to treatment”, the patient with cancer needs to be able to access high-quality, affordable treatment in a timely manner. Effective management of cancer requires a multi-disciplinary approach and the development of a treatment plan that is documented and informed by a team of trained providers. The goal is to ensure that as many patients as possible initiate treatment within one month of the diagnosis being confirmed (5).

The three steps of early diagnosis, from symptom onset to initiation of treatment should generally be less than 90 days to reduce delays in care, avoid loss to follow-up and optimize the effectiveness of treatment (5). The exact target duration may vary between health system capacity and cancer type. In all settings, however, it is important that cancer care is delivered in a time-sensitive manner.

Further action to achieve early diagnosis:

Awareness and access to care

- Empower and engage people and communities
- Improve health literacy and reduce cancer stigma
- Facilitate access to primary care

Clinical evaluation, diagnosis and staging

- Improve provider capacity at first contact point
- Strengthen diagnostic and pathology services
- Develop referral mechanisms and integrated care
- Provide supportive counselling and people-centred care

Accessing treatment

- Improve access to treatment by reducing financial, geographic, logistical and sociocultural barriers

Developing a monitoring and evaluation framework: A robust monitoring and evaluation framework is critical to improve cancer early diagnosis services. Indicators can be collected at the community, facility and/or national levels and focus on structure, input, process or outcome measures (Table 6). The core

indicators for early diagnosis are: (i) duration of patient, diagnostic and treatment intervals (Table 2); and (ii) stage distribution at disease diagnosis. Targets should be developed based on a valid, current situation analysis focusing on prioritized metrics and according to the national and local context. Wherever possible, data should be analysed by sex, geographic location, ethnicity and socioeconomic status to allow inequalities in cancer care to be detected and addressed. A system for monitoring and evaluation is needed at the facility, community and national levels.

Population-based cancer registries are important at the national and subnational levels for collecting cancer data and in order to compute incidence and mortality rates among residents of a well-defined geographic region. Data are also needed to track the accessibility and quality of care, timeliness of referral and coordination between levels of care and budgeting of resources. Participation in and support of a population-based cancer registry benefits not only the community, but also national and international cancer control programmes (53).

To strengthen capacity for early diagnosis, a situation analysis should be performed to identify barriers and deficits in services and prioritize interventions. Financial, geographic, logistical and sociocultural barriers must be considered and addressed as per national context to improve access to timely cancer treatment.

A coordinated approach to building early diagnosis capacity should include empowerment and engagement linked to integrated, people-centred services at all levels of care.

(2) CEN/CWA Quality criteria for health checks

Quality criteria for health checks aim:

— to allow clients to make informed choices about health checks,

— to improve beneficence in prevention and early detection of health risks and disease,

— to protect individuals against potential adverse consequences (maleficence) of health checks and

— to ensure the quality of the health checks.

Patient/client information

The provider shall provide information that is understandable, timely, verifiable, accurate, complete, truthful and not misleading.

The provider shall provide information on the aim, benefits and harms and potential adverse consequences of the health check, the prevalence and incidence of the condition or risk factor searched for, the target population for the health check, the potential positive and negative results and options, costs and consequences of follow up of the health check offered.

The provider shall provide information on any (clusters of) parallel findings that might occur as a (direct or indirect) result of the health check, including their benefits and harms, prevalence and incidence.

The information should enable the client to ascertain the presence or absence of balance between benefits and harms of the health check for target or age group and make an informed choice about the personal usefulness of the health check.

Other areas included in the recommendations:

Communication

Condition/target population

Test procedure

Clinical validity

Results

Follow-up

Quality and safety management and legal environment