Do we know what patients need?

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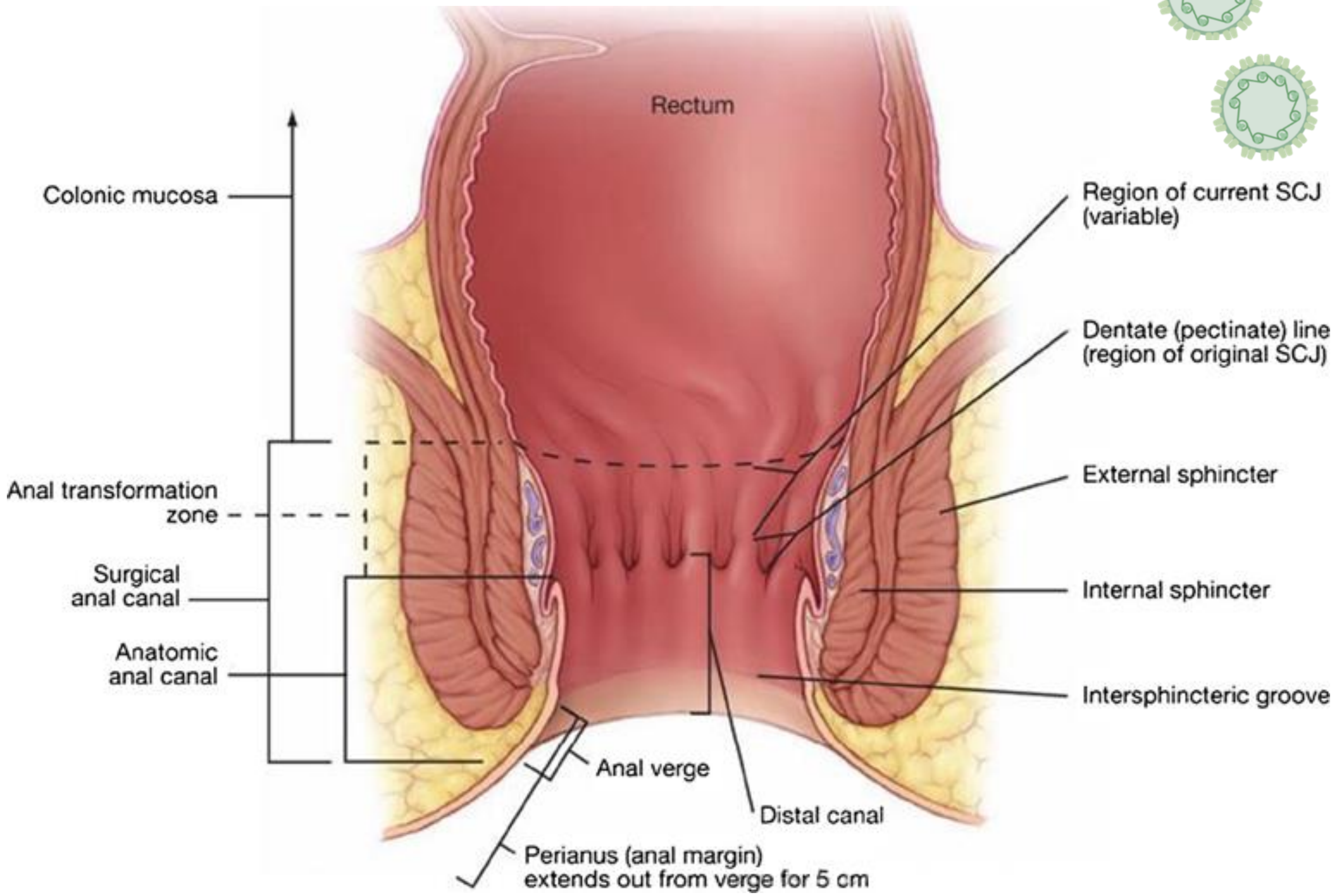
Anal cancer Awareness

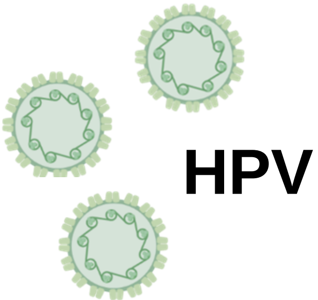
Patient responses

“I have anal cancer—so it is taboo to talk about it. It would have been easier for me to say that I had breast cancer. There is another perception of that. The problem is that the word ‘anal’ precedes the word cancer.” (48-year-old woman) [1]

‘Although I was always overtly treated with dignity and respect, there was an underlying sense of judgment. I felt the stigma associated with my HPV-related cancer from family, friends, and health care providers alike. I felt responsible for somehow causing my cancer. ‘ [2]

What is analcancer?





Numbers of analcancer in the Netherlands

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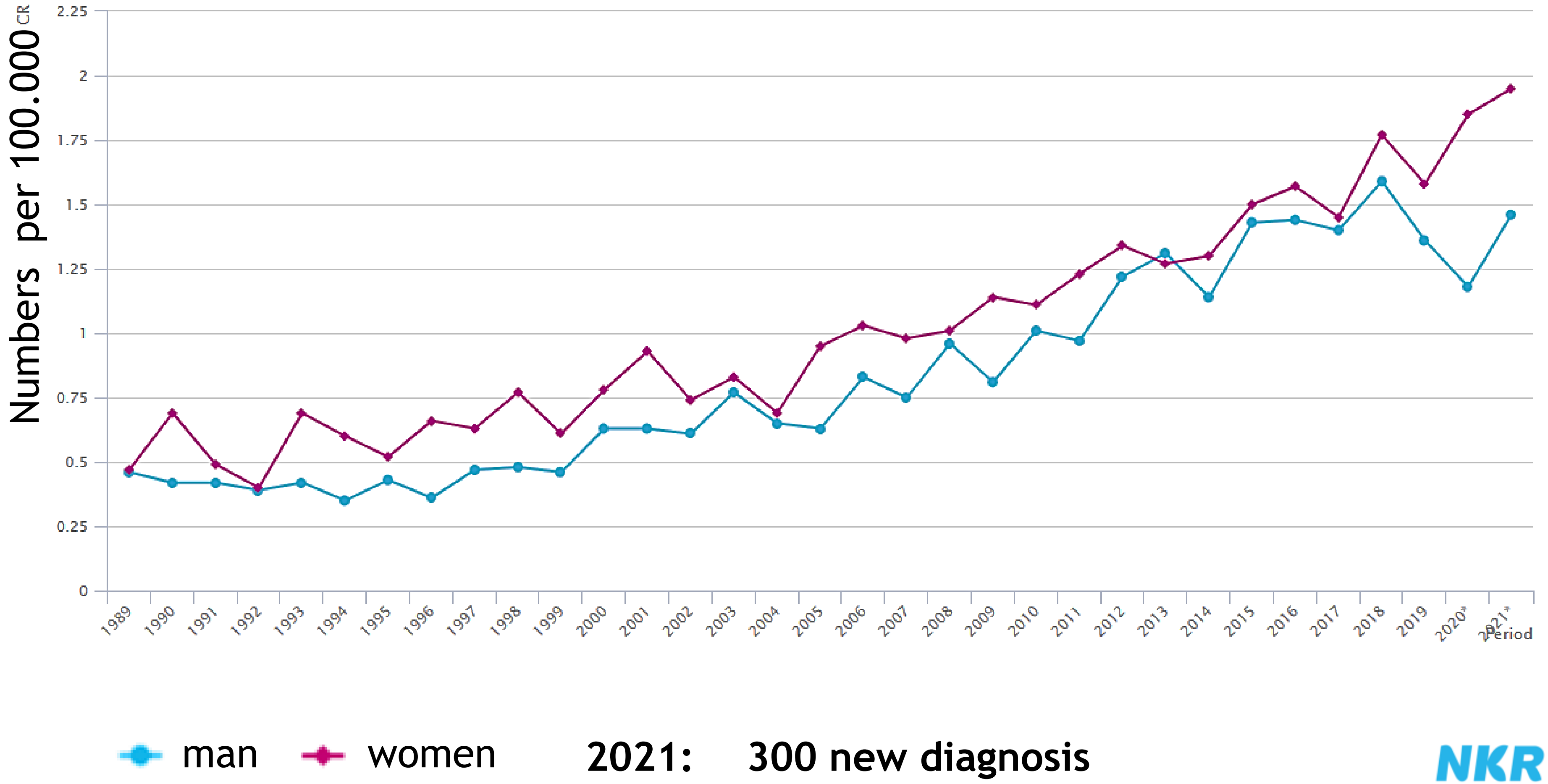
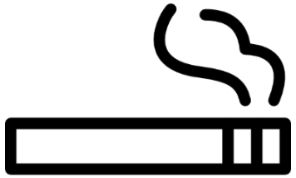
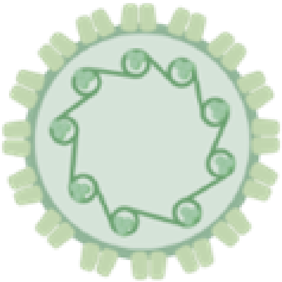


2021: 300 new diagnosis
60 deaths

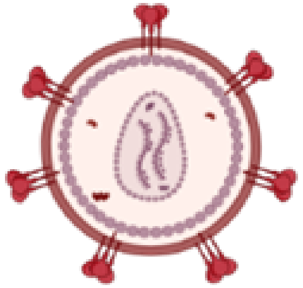
NKR
Source: NKR-cijfers / IKNL

Riskfactors





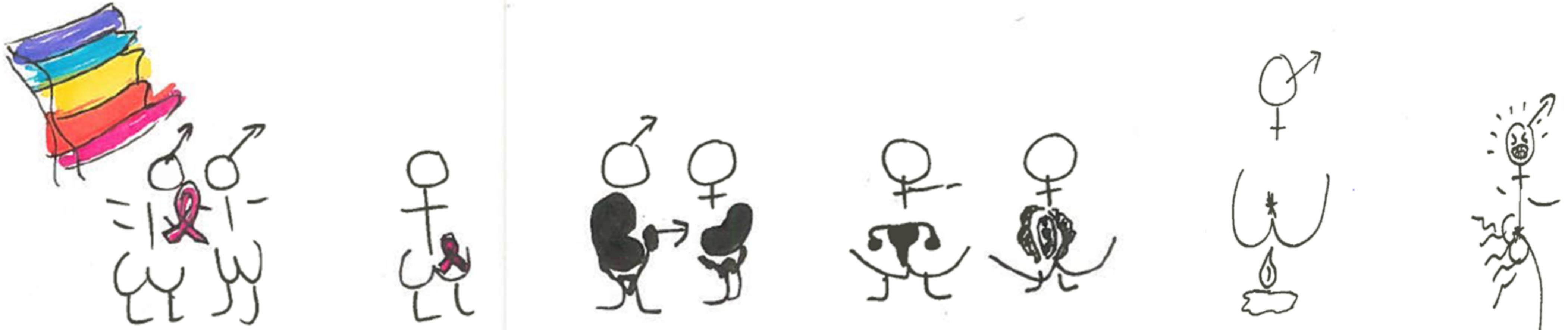
HPV



hiv

hiv+ MSM

Alarmbel



HIV+ MSM | HIV + vrouw | Transplantatie | cericale carcinomen | vulvaire carcinomen | Rectale bloedverlies | anale pijn

HPV and Cancer

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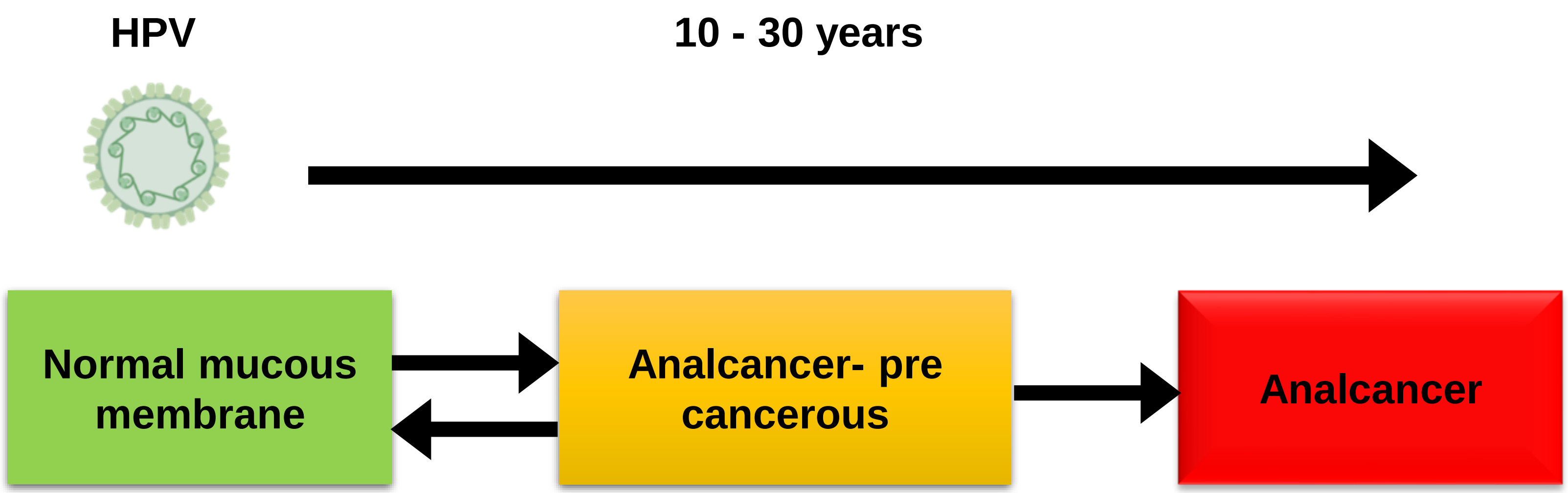
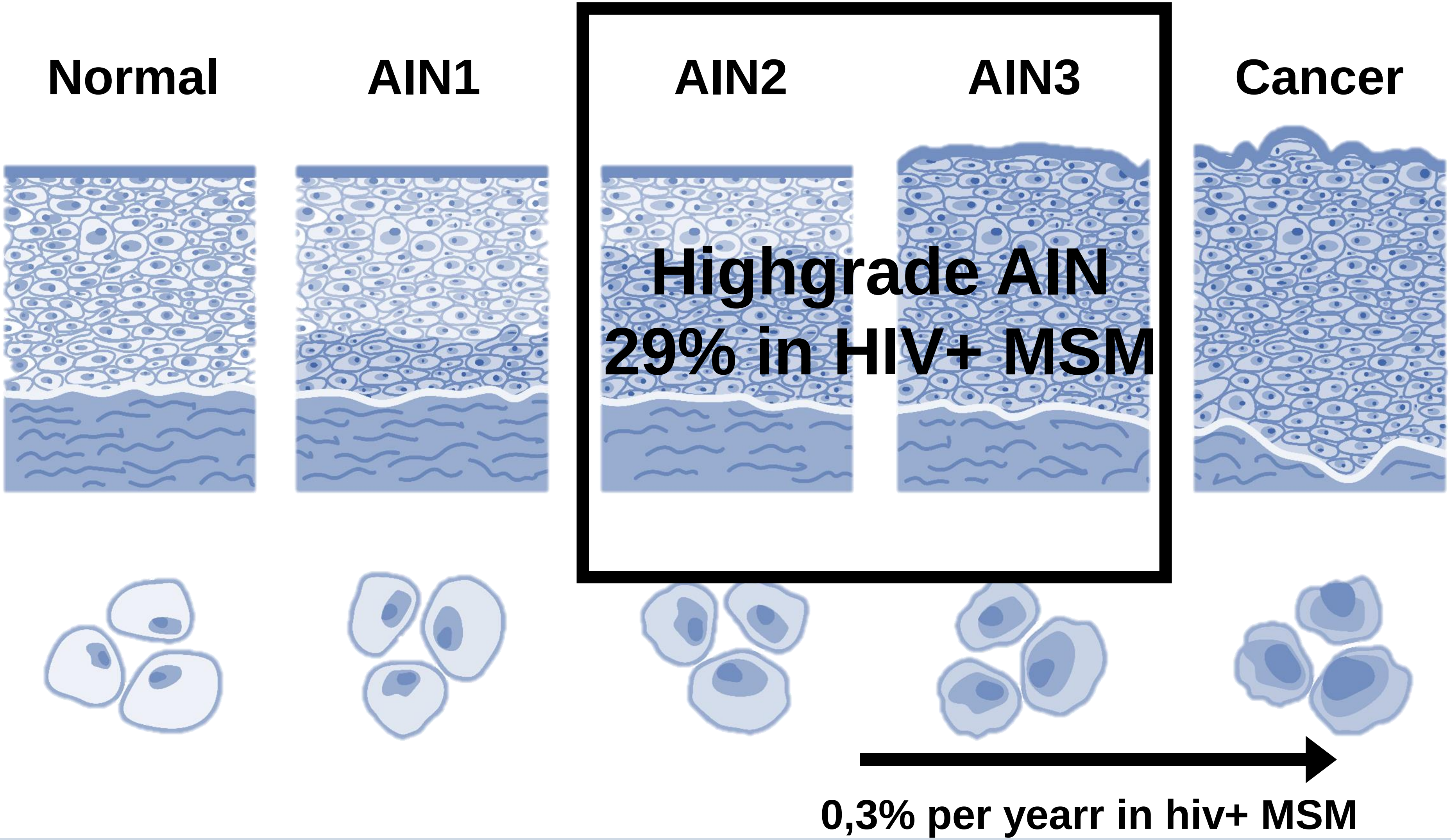


Anal intra-epithelial neoplasia
AIN

Anale intra-epithelial neoplasia



Machalek *et al.* Lancet Oncol. 2012

New anal cancer diagnoses among people with HIV in the Netherlands

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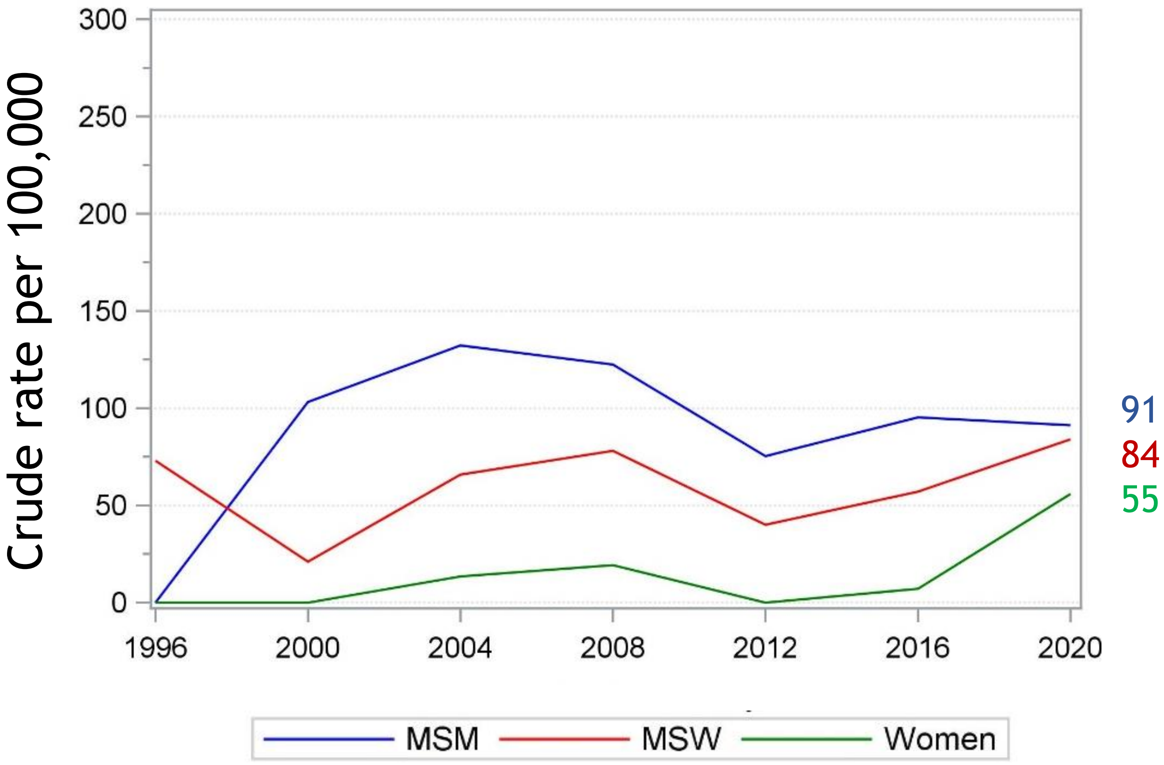

Van der Zee, Wit, et al. Lancet HIV

Analcancer prevention

- Early prevention of cancer

Digital anal rectal examination

- Primary prevention

HPV vaccination

- Secondary prevention

Screening and treatment of AIN

HRA/AIN screening

High-resolution anoscopy (HRA) with biopsies
- Currently possible for HIV+ MSM aged 35 and older

- Burdensome procedure
- Difficult to implement and time-consuming
- Too little screening capacity

Treatment of HGAIN

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Ablation therapy (electrocoagulation)
Painful
High risk of recurrence (50% in 18 months)

NEW

Scientific evidence for screening

Who to screen?

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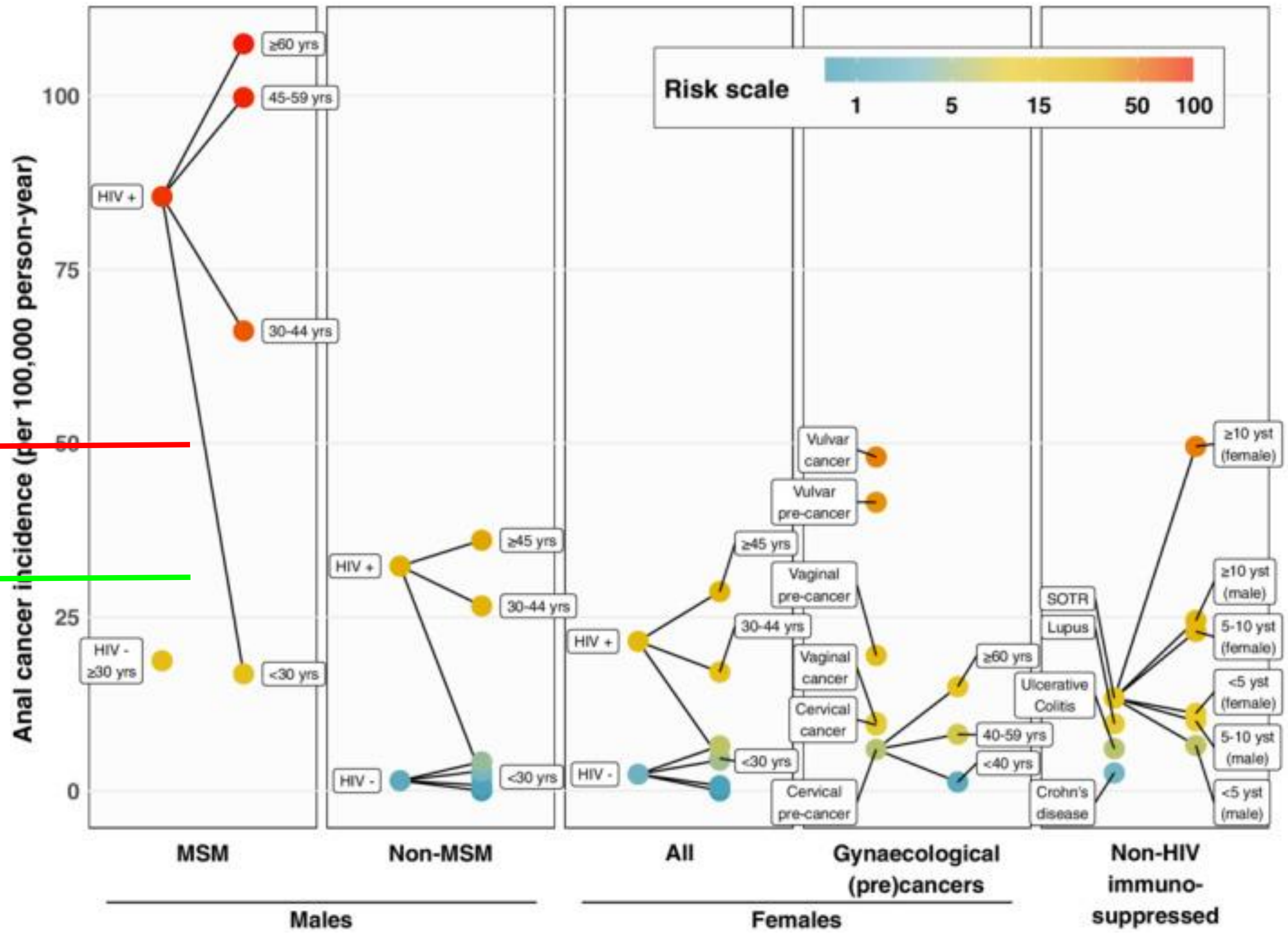
Colorectal screening

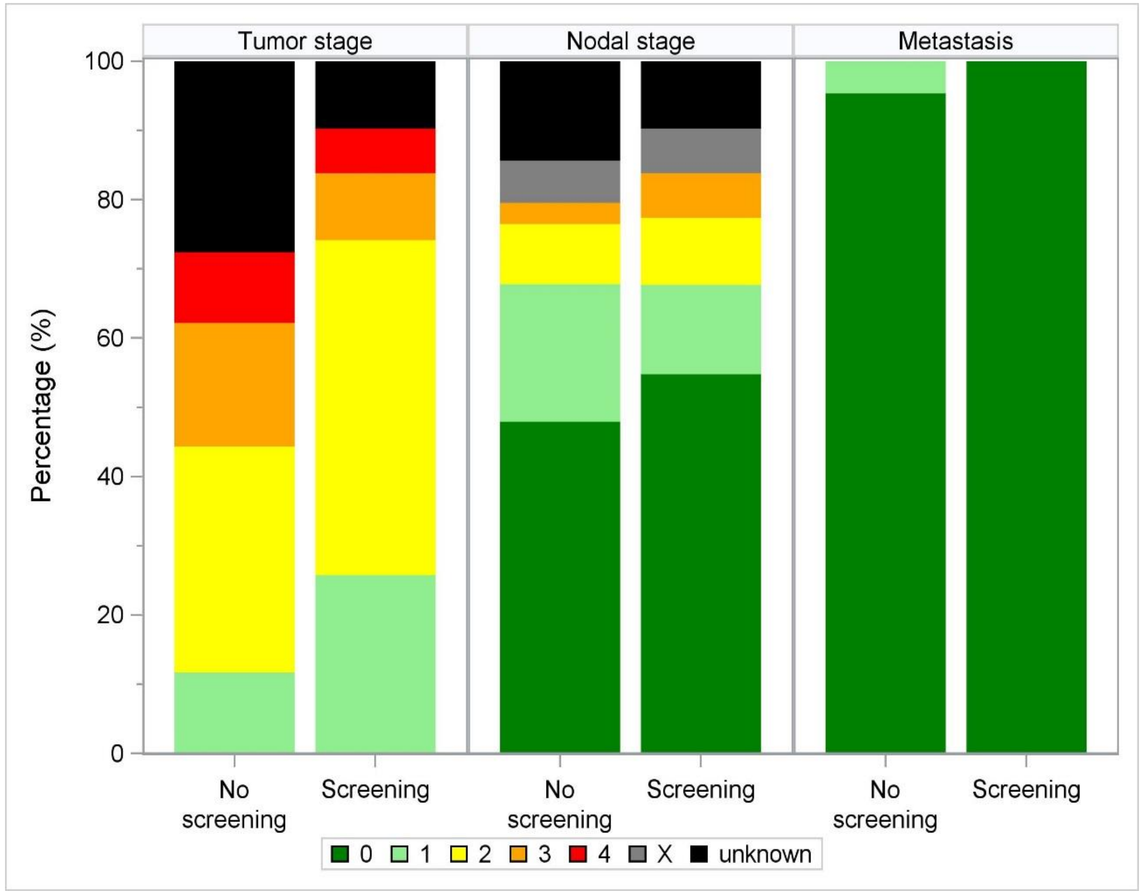
Cervical screening



Clifford *et al*. Int J Cancer. 2021

Why screen?

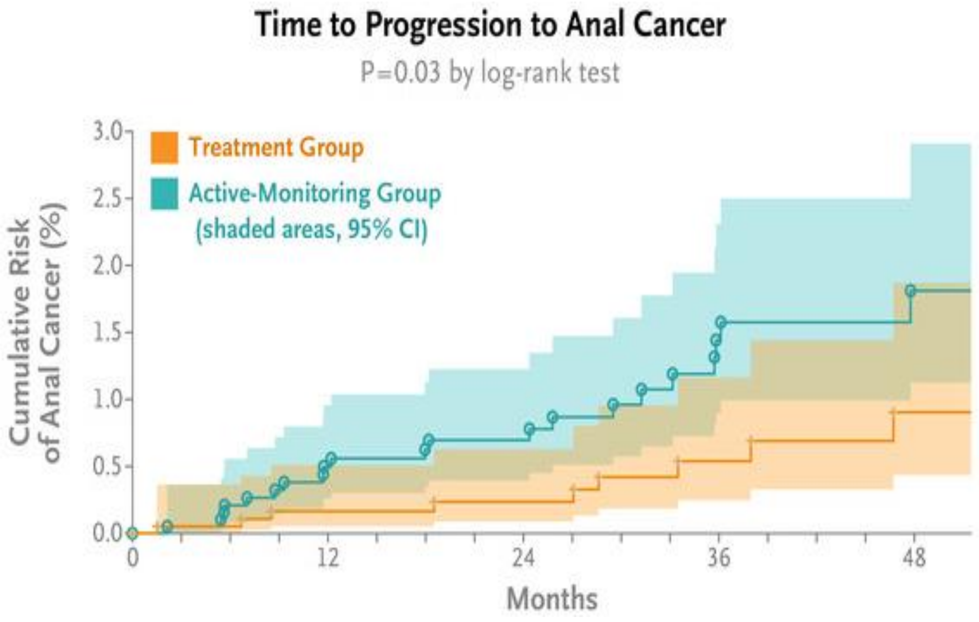
1. More diagnoses made (RR = 2.4)
2. Diagnosis made earlier, better prognosis

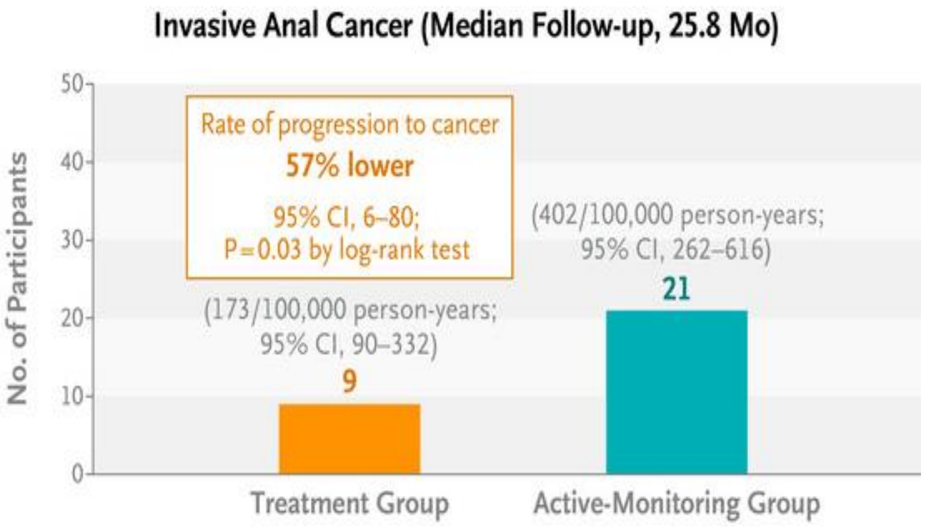


Van der Zee, Wit, *et al.* Lancet HIV

Why treat?

- •   1. Prevention of analcancer

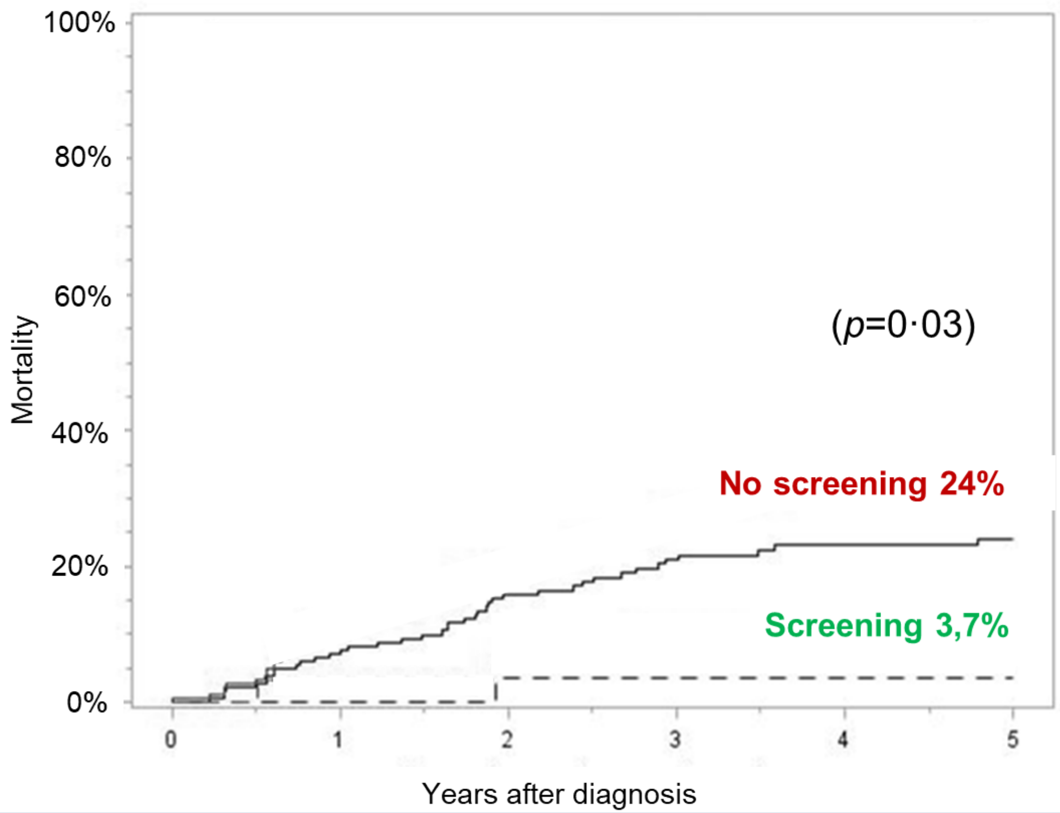




Palefsky *et al*. N Engl J Med. 2022

Why treat?

- Prevention of anal cancer
- Lower mortality.



Van der Zee, Wit, *et al*. Lancet HIV

And now?

There are (yet) no guidelines that recommend screening

- Too little capacity for HRA prioritise

Alternative screening methods:

- Anal cytology on smear?
  Self-collection of smear?

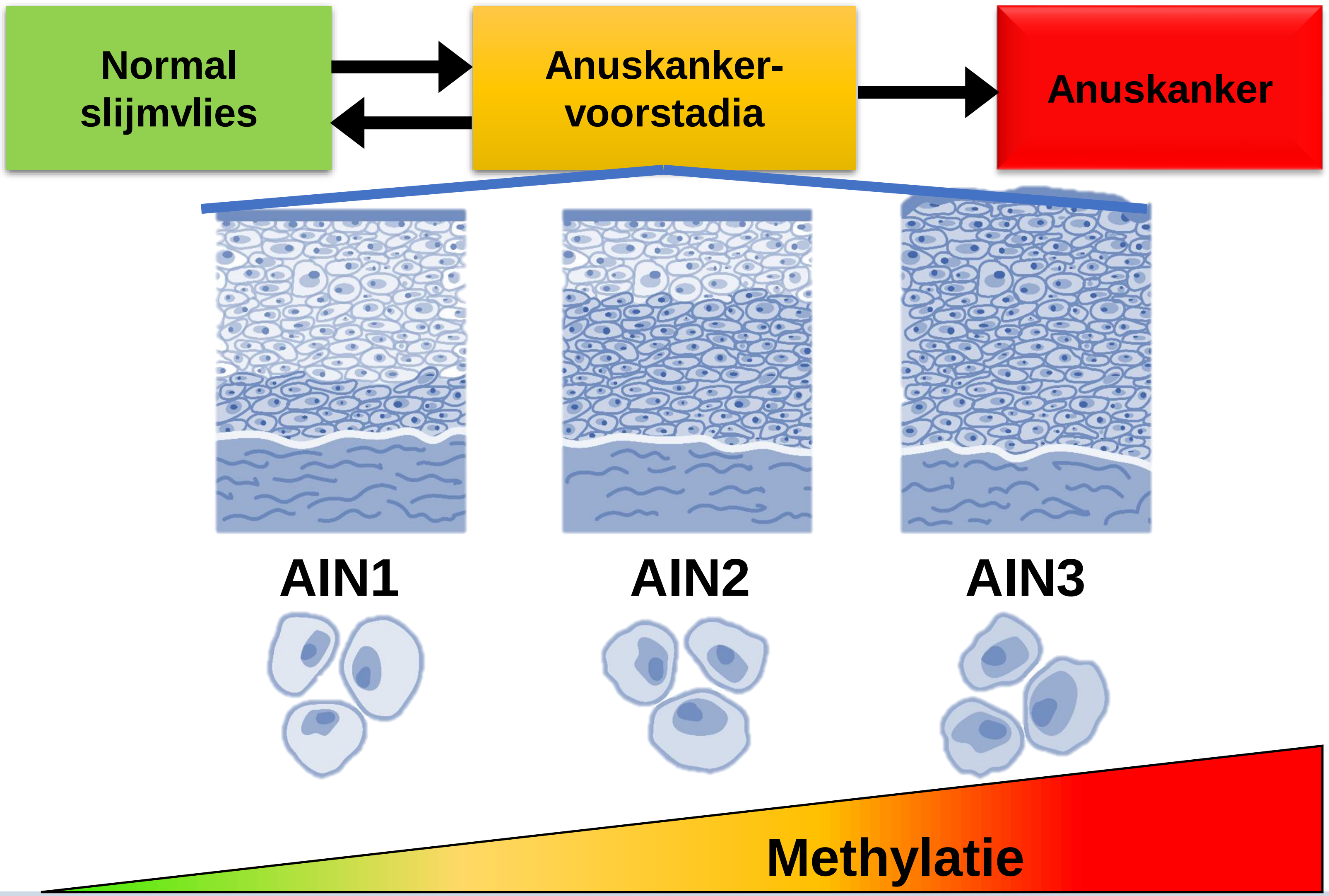
HPV vaccination!

Who has an indication for screening?	Who gets screend?	In the future?
Hiv + MSM	From 35 jr	not all is included yet….
Suspicion of analcarcinoom	All suspicions	We should…
Hiv + PLWH fron 35/45 jr	Not yet	We should…
Vaginal carcinoom in patient history	Not yet	yes
Anal cancer in history treated with surgical treatments only	Not yet	yes
10 year post transplantation	Not yet	yes
HIV + transplantation	Not yet	yes
Penis/cervix/oropharyngeale cancers in patient history	Not yet	Especially if there is a history of HPV-related cancer, you should at least ask Dare and complaints...

part II:
Future perspectives

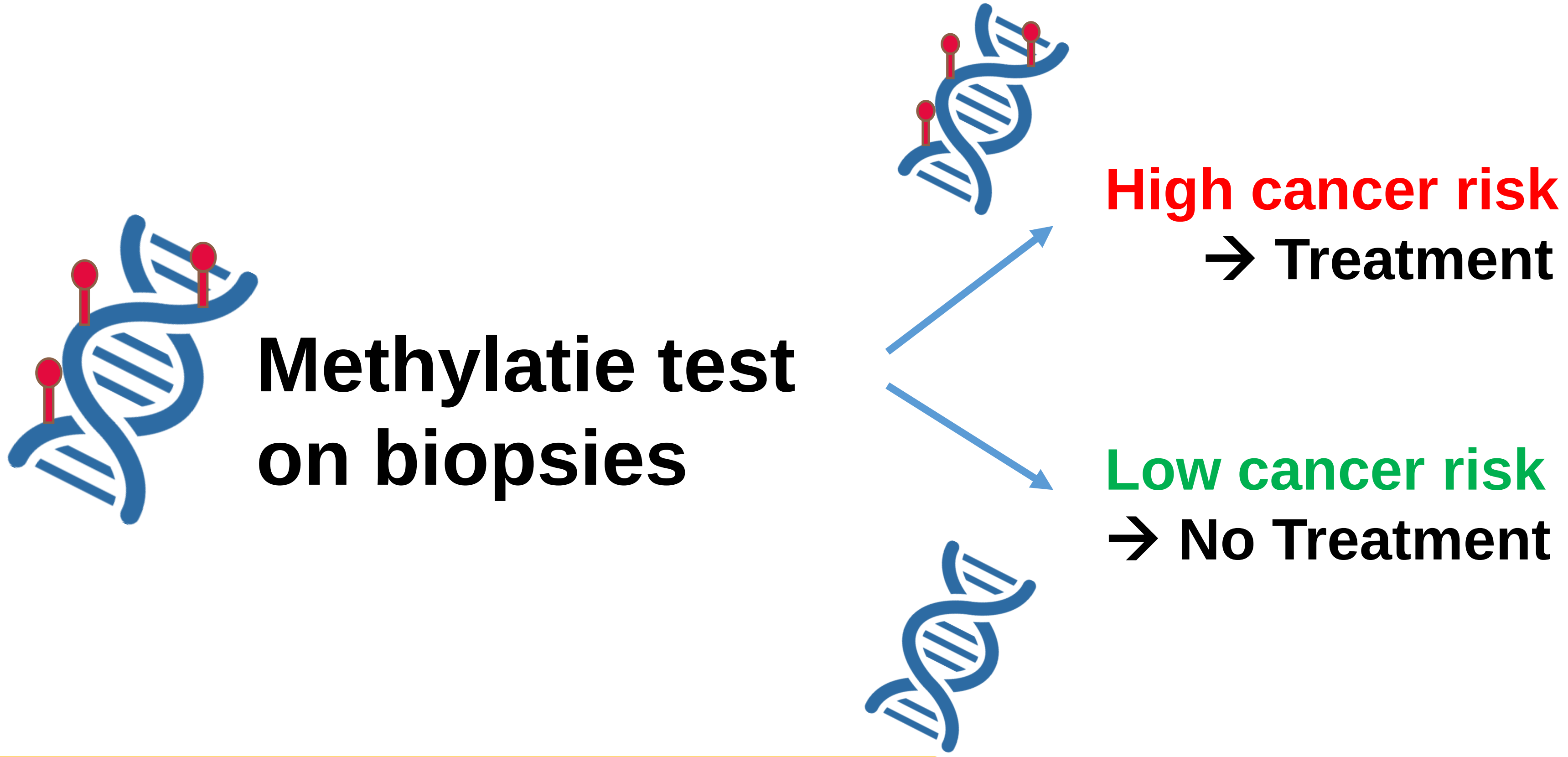
NEW

Targeted screening with biomarkers



Van der Zee *et al.* Clin Infect Dis. 2021

Treatment decision with methylation



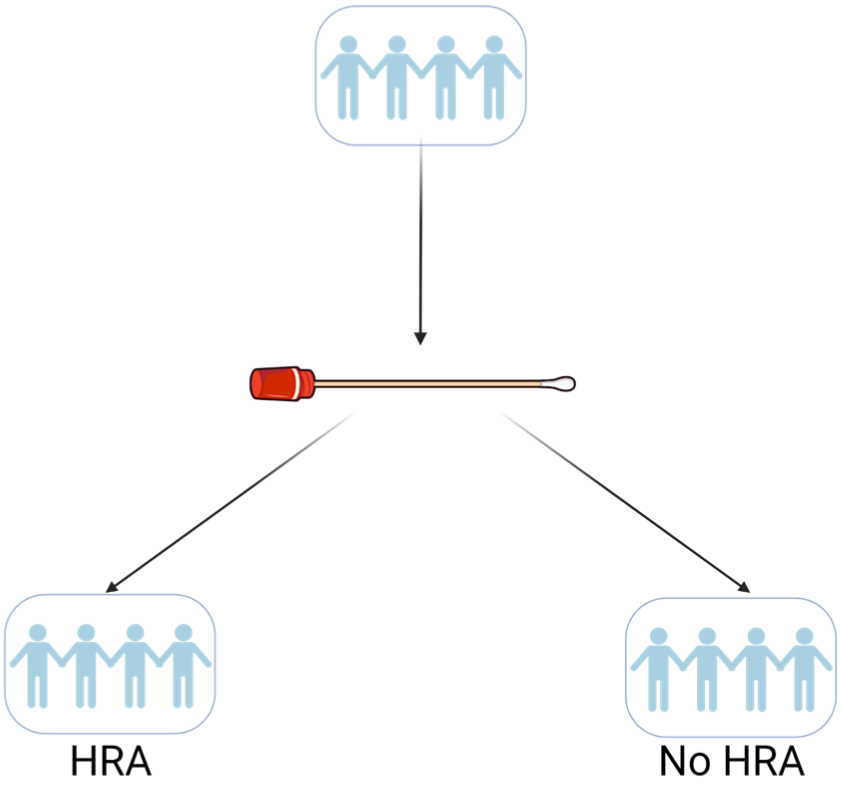
→ Prevention of over treatment

Van der Zee *et al.* Clin Infect Dis. 2021

Triage for HRA

Methylation test on analswab

Triage



→ Targetted use of HRA capacity


HPV
HRA SCREENING
MRI

Sexuality: More than nice to have!

Disturbances in **sexual function** and in **intimacy** are common consequences of **cancer** and its **treatment**. For a variety of populations and of cancer and treatment types, estimates of such disturbances range from **20% to 100%** and involve both **physical and psycho-social causes.**

Physical effects on sexual function include loss of libido through anti-hormonal therapy, chemotherapy or radiotherapy; impaired physical arousal (reduced lubrication, erectile dysfunction, sensory limitations) through surgical, chemotherapeutic or radio-oncological therapies; incontinence or stoma; loss of fertility; fatigue.

Psychological effects on sexual experience such as distress and depression, anxiety, insecurity and issues with gender identity, body image change, feelings of shame, self-esteem reduction, withdrawal and development of avoidance strategies in body interaction / sexuality.

Social effects such as withdrawal from body contact with others, mutual protection behavior, seclusion and loneliness, increased relationship conflicts due to dissatisfaction in the relationship and general social withdrawal e.g., due to change in excretory function.

Sexual problems caused by common cancer treatments can lead to **regret**, **depression**, **relationship problems**, etc., and, thus, to a considerable reduction in **quality of life**. It is therefore necessary to **address** the negative consequences of treatment on sexuality and to **support** patients in dealing with it.

Talk to your patient about sexuality!

Sexuality often is a taboo topic for both patients and healthcare professionals (HCPs). Intimacy and sexual difficulties are typically glossed over by cancer patients - as the vast majority of them and their partners do not feel at ease to bring up such a sensitive topic. Yet, after a consultation, they might regret missing the opportunity to talk about their sexual difficulties and concerns. Hence, HCPs should always introduce the topic and offer advice and support - as they are regarded as experts in the eyes of the patient and patients may expect them to initiate the discussion.

Displaying brochures and informational material on cancer and sexuality in the consultation room, for instance, would certainly convey the importance and relevance of the topic.

Keep in mind that it may very well be the first time that the patient opens up about cancer-related sexual dysfunction and that talking may be a great sense of relief to them. Do not rush to the "giving advice" phase of the conversation as active listening is key!

How do you start a conversation about sexual issues with your patients?

PREPARE THE CONSULTATION

Bear in mind that conversations about private and intimate issues may take time. Therefore, plan your consultation and schedule ahead in order to allow enough time to have a thorough discussion, or refer the patient to an appropriate colleague. Ensure that the consultation takes place in a comfortable and enclosed space to guarantee privacy and encourage patients to open up about their sexual issues.

Always use neutral and inclusive terms such as 'partner' and pose your questions in a non-judgmental manner. Avoid making assumptions about your patient based on age, appearance, marital status, or any other demographic factor. In particular, unless the person shares more information with you, refrain from making assumptions based on the person's sexual orientation, behaviors, gender identity or cultural background.

In order to build rapport with your patients, start off the conversation with general, medical topics, before addressing personal and intimate issues. At the end of the session/consultation, offer the patient to invite and bring their partner(s) to the appointment or the session when you plan to discuss these issues.

EXPLAIN WHY SEXUALITY ISSUES ARE COMMON PROBLEMS

Addressing sexuality issues can be firstly done by emphasizing that sexual complaints are frequent among cancer patients, and the patient is not in a unique or rare situation:

"We know that many patients with comparable therapies notice effects on their sexuality - do you also feel burdened by changes in your sexuality?"

If so: '**We would be happy to support you in dealing with this - what is your concern in this context?**'
If not: '**Very well, feel free to contact us if a similar problem arises in the future. Maybe we can find a solution for it**'

You can also explain that you, as a specialist, are concerned with quality-of-life issues and you know from other patients that the impact of cancer treatment on relationships and sexuality may be significant. Although you may not be able to answer all questions, you will create a safe space where patients feel comfortable talking about their sexual concerns.

ASK PERMISSION

Given the diverse cultural and religious backgrounds, gender, and age of cancer patients, it might be a good strategy to ask the patient for an explicit permission to talk about sexual issues such as:

'Is it OK for you to discuss these issues in more detail?' or
'Would you like to talk about it now or later on?'

Avoid making any prejudiced assumptions about how the person relates to sexual issues.

- If the patient agrees, this stimulates a sense of ownership and control to explore this intimate domain of life.
- If not, let the patient know you are always available to discuss his/her questions and worries anytime.

ENCOURAGE PATIENTS TO TALK ABOUT THEIR WORRIES AND EXPERIENCES

Start with an open-ended question, such as: '**Have you experienced sexual or intimacy troubles since your cancer diagnosis / since your treatment started?**'

Then ask more specific questions (including when? where? what? how?) to elicit precise and clear answers, such as: '**During your last sexual intercourse, did you feel any pain or experience other troubles?**' and '**Did you experience troubles before? How do you feel about them? What is your partner's reaction?**' Try to avoid yes/no-questions.

Ensure that you and your patient share an understanding of the terms being used to avoid confusion. If you are not familiar with a term your patient used, ask for an explanation. If you are not sure the patient has the same understanding of specific terms, be prepared to explain them. If the patient feels uncomfortable to open up about certain topics, respect them and suggest possible discussion during the next visit or with a specialist

EDUCATE THE PATIENT

Provide concise and clear information to educate the patient about anatomy, physiology, sexual response, the possible side-effects of cancer treatment, and other aspects that may be relevant to their experience.

SUMMARISE AND REPEAT PATIENT'S CONCERNS

Summarise what the patient has said about his complaint(s) and double check whether you have understood them correctly. This helps to validate the patient's experience.

PROVIDE PATIENTS MORE EXPERTS ADVICE AND REFERRAL

Provide practical suggestions and recommendations to help the patient to deal with their complaint(s). Plan a new consultation for further treatment/therapy or advise the patient to seek help from another HCP, such as a psycho-sexual therapist, physical therapist, couple counselor, cognitive-behavioral therapists, etc.). Do not forget to explain why a consultation with that particular HCP would be beneficial. You might also refer your patients to a specialist of the same gender – as this might facilitate discussions regarding sex, sexuality and intimacy.

If you are not comfortable discussing sexual issues with your patients, feel free to refer them to a colleague who feels safer in this area. In addition, tell patients where they can find reliable information on the internet.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