



**The voice of patient: Strategies for  
patient's empowerment and quality of  
life.**

**THE BCN HPV  
COURSE**

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# Conflicts of interest

- Subjectivity

*Since a subject is a person, subjectivity refers to how a person's own uniqueness influences their perceptions.*

*All knowledge – even if it is objective – goes through a process of subjectivation.*

- *Humour and coffee*

# Index

- The Voice of the Patient – Barriers and facilitators
  - Qualitative studies
    - MSM with HSIL history (Apaydin KZ et al. Sex Health. 2018)
    - Community-based health advocates (Newman PA et al. J Gay Lesbian Soc Serv. 2008)
    - MSM with HIV (Koskan AM et al. Cancer Control. 2016) (Grace D et al. Plos One. 2018)
  - Talk with two friends
- Quality of life
  - Quantitative studies

# Prior Knowledge about HPV

<50% MSM know about HPV related cancer.  
10% MSM report concern about anal cancer.  
Vaccine related to vaginas.

Racial and ethnic groups

Younger people

<35

HCP reluctance and  
misperceptions

“ [anus] It’s an area that most physicians are not  
real comfortable with”

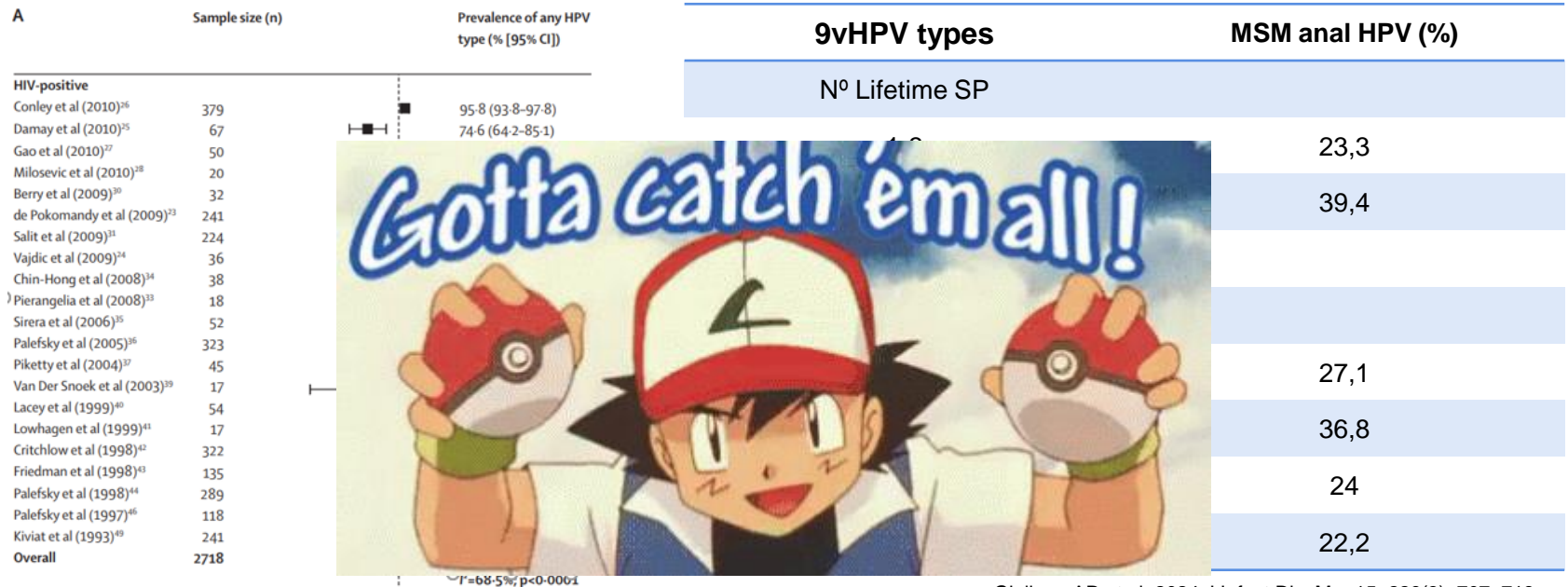
“Physicians hate, hate to check your anus!”

Weak recommendation for vaccine.

HSIL patient. [Crying] “My HIV doctor told me to  
come back asap because I have cancer”.



# What can we really do with HPV info?



Machaleck DA et al. Lancet Oncol 2012; 13: 487-500

Giuliano AR et al. 2024 J Infect Dis. Mar 15; 229(3): 707-718

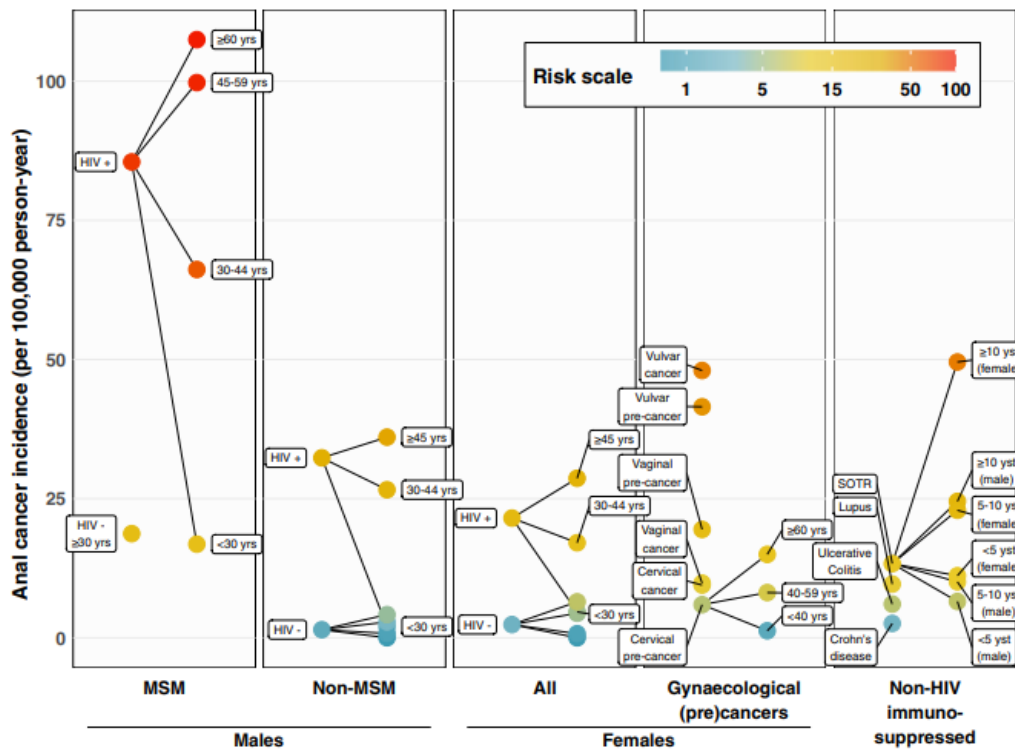
Infection is universal  
Skin to skin transmission  
Condom controversial

THERE IS VACCINE

Frightening people  
Advising to "take care"  
Insisting in condom use

# Positive encouragement

## WHAT WE KNOW?



Clifford GM et al. Int J Cancer. 2021 Jan 1;148(1):38-47

Incidence 7-12/10.000p-y  
 HSIL to cancer <1%/year  
 ¿High or Low?

1/20.000

Death Falling from a ladder

1/6.250

Reached by a lightning

1/10.000

Finding a four leaf clover

1/117

Flying with a drunk pilot

Our passion and commitment as physicians can make us lose perspective

# Positive encouragement

“Fear is an incompetent teacher.”

Jean-Luc Picard

Reassuring HRA results and a familiarity with HRA as an anal cancer **prevention tool** facilitated adherence.

*“You know there is some fear too. Like, not having symptoms put it out of me. That’s classic me.”*

## Fear as motivation

Not effective  
Not realistic  
Produces distress

## Positive encouragement

Assertive info  
Being healthy  
Improvement



# Stigma (internalised)

*“You know frankly, I would be embarrassed if I got it, because I feel like I brought it upon myself by sexual behaviour.”*

*“There is a stigma that being a “bottom” is being dominated. Take the power away from as being a male.”*

*“It’s kind of... dynamic of women not knowing there vaginas. Nobody sits over a mirror and says, Hey what’s that there?”*

## **Having HPV**

Previous stigma HIV  
Social opinion about STI

## **Receptive anal sex**

Previous stigma MSM  
Bottom->Camp->Femininity  
Misogynist society

## **Anus as Hidden**

Intimate part of body  
Not recognised  
Not discussed



# Stigma (societal)

*“There’s less of a stigma to have breast cancer than to have anal cancer... it still is reminiscent of, in a way... you’re morally deficient, and you deserve it.”*



Breast



Cervix

**Religious moralism**  
**Patriarchal system**  
**LGBT phobia**  
**Monogamous society**



**STIGMA**  
**on**  
**any Deviant sexual practise**



# Gender trouble

*“I don’t see men really thinking any kind of health issue. It is about this macho attitude...[being] the breadwinner.”*

Traditional BINARY gender roles affect medicine:  
Women: attend but ignored / Men: not even attend

Specially racial communities with marked gender roles

Self identified Gay men may be more willing to seek health care.

## Once under HRA...

*“It feels invasive, uncomfortable, sort of, **emotionally**, and extremely uncomfortable physically. And then there’s the aftermath.”*

*“It is a very **submissive** situation, even being gay.”*

*“...it is the emasculation, and perhaps the **cleanliness**”*

*“...they gotta worry about if they’ve douched or not because they’re embarrassed.”*

**Cleanliness**

**Submission**

**Physical discomfort**

# Cleanliness

*"In now way I would go to HRA without a rectal douche before. Actually I do take two loperamide also".*

## Box: Performing an Anal Cytology Test

- Perform an anal cytology test before
- A moistened nylon or polyester gauze pad is used for the collection instruction  
– See [University of California](#) detailed instructions.
- Instruct patients to refrain from sexual activity involving the anus for 24 hours before collection.

**NO RECTAL DOUCHE MAY MEAN NO HRA  
DO NOT CONFRONT**

**PATIENT GOES FIRST**

In case of repeatedly not valid citology, evaluate only HRA

os no conversation!

hygiene



caras, sin conversación!

**worry, Pure for Men**

Here's an adult gay film st

What should

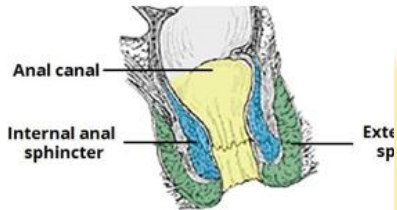
How do you douche using a rectal  
enema?

How do you stay 'clean' for bottoming for  
hours?



# Physical discomfort

## Anuscopy technique



1<sup>st</sup> and 2<sup>nd</sup> barriers  
Patience



## TCA vs ECA

### EFICACIA

	ECA grupo (n=227)
<b>Respuesta</b>	<b>61.7 %</b>
Completa	30 %
Parcial	31.7 %

### TOLERANCIA

- La **duración** de efectos adversos fue de 4 días con ECA y 3 días con TCA (p<.001).

	ECA grupo (n=204)	TCA grupo (n=143)	P
Discomfort anal	85.8 %	79 %	.111
Dolor anal	31.4 %	21 %	.037
Sangrado	26 %	16.8 %	.049
Prurito anal	2.9 %	17.6 %	<.001

## Sinecat vs Cidof

Sinecat. (n=36)	Cidofovir (n=28)	P
51.1 %	82.3 %	.18

para la electrocoagulación, 27.8% (n=16).

graves, ni alteraciones analíticas

destacables.

	ECA (n=35)	Sinecat. (n=36)	P (ECA vs Sin)	Cidofovir (n=28)	P (ECA vs Cid)
Dolor anal	60 %	6 %	<.01	25%	.01
Picor anal	26 %	6 %	.02	46 %	.09
Sangrado anal	69 %	3 %	<.01	21 %	<.01
Inflamación peri-anal	6%	14 %	.14	50 %	<.01
<b>Duración</b> (días, DE)	7 (10)	10 (9)	.22	27 (9)	<.01

# What about us...?

*“Think about it, if you happen to have a **gay physician** who’s very popular, gay men may not want him to be the one checking their anus.”*

Ask if they are comfortable  
It is going to be a long-term relationship  
Be absolutely clear this is CONFIDENTIAL

Knowledge and expertise  
Clear statements  
Being previously informed!  
Anti-anxiety meds preprocedural

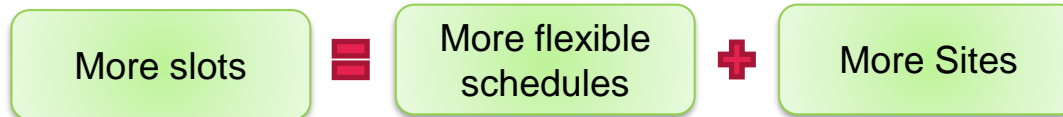
Not harmonious collab  
between staff  
Excessive talkativeness  
Careful while teaching

# And our health system...?

*"The schedule had not been moved... go book to London a year from now... The appointment isn't booked."*



**DO NOT ATTEND**



Mobile medical units  
Festivals, Gay Pride, Saunas

Take care of the space



## If you share with gyne

Anal dysplasia info  
Posters  
Decoration, music  
Air freshener

**Make it kind**

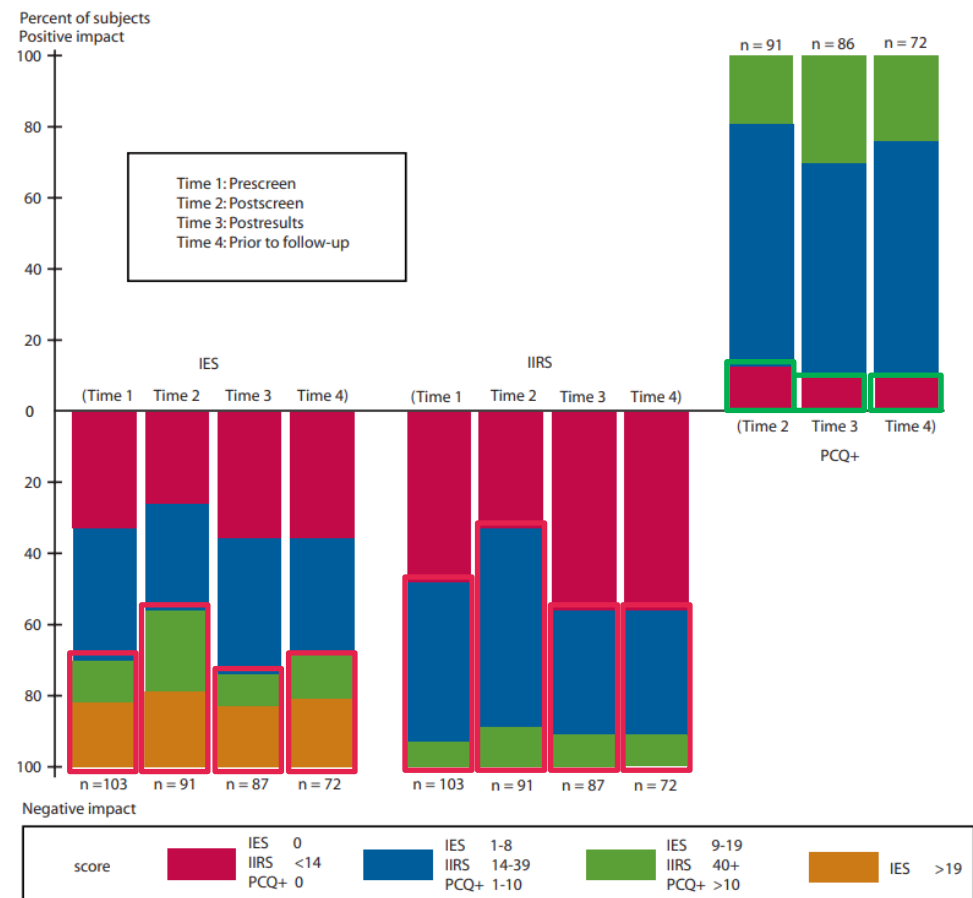
Chemotherapy patient and VR user



# Quality of life

Time 1: 1 wk before visit  
 Time 2: 1 wk after visit  
 Time 3: 1 wk after results  
 Time 4: 1 wk before follow-up

<b>IES</b>	Impact of recent stressful life events
<b>IRRS</b>	Assesses the psychosocial impact of chronic disease
<b>PCQ</b>	Originally developed for patients having screening mammography (positive aspects)



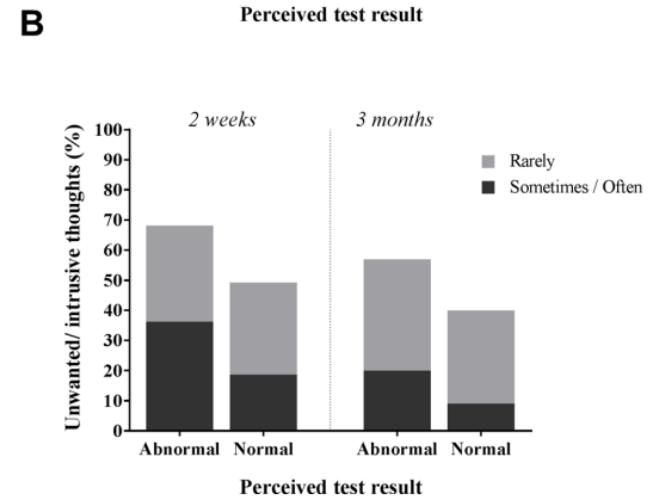
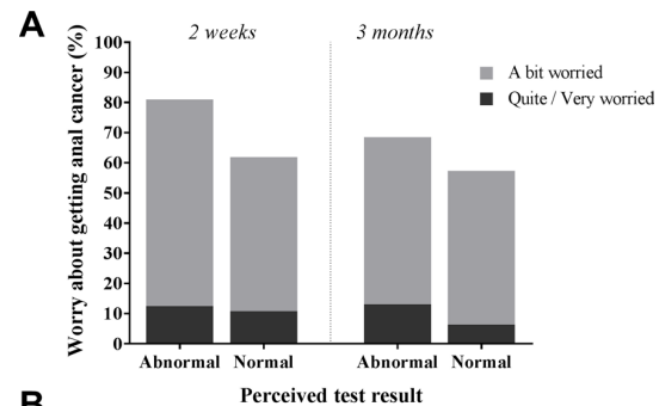
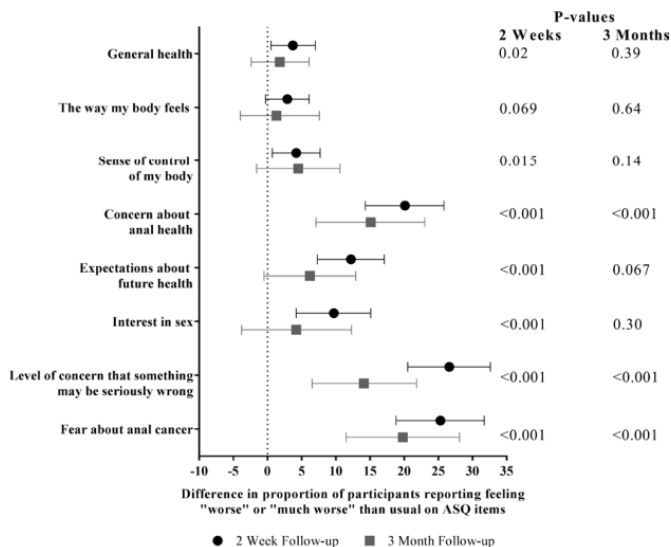


# Quality of life (results)

SPANC Cohort

Mental component score (MCS)  
from SF-36

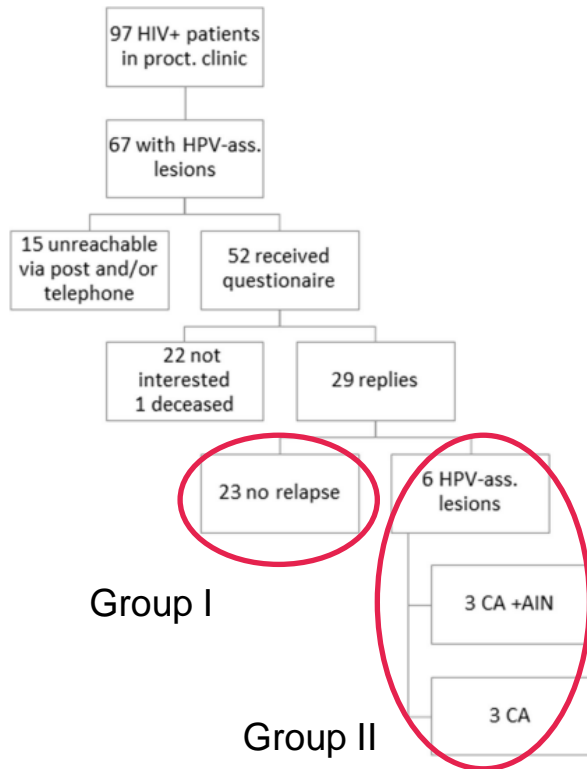
Anal Screening Questionnaire  
(modified from Cervical)



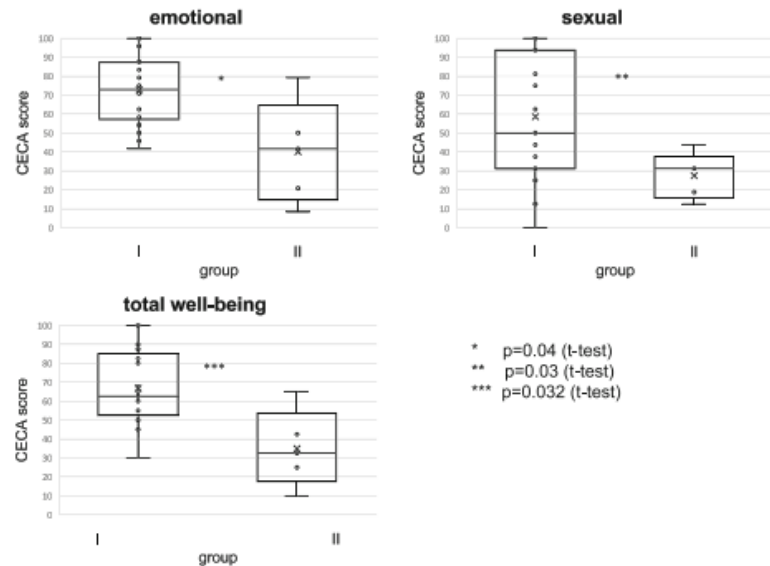
# Quality of life (treat or not)

## SF-36

The evaluation revealed no significant differences in the QoL between the groups



## Modified CECA



# Quality of life (treatments)

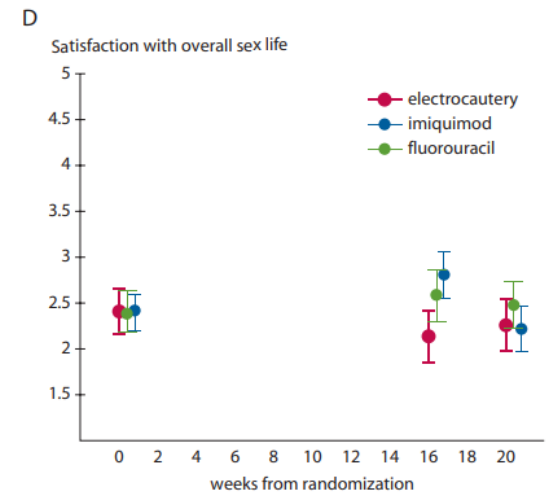
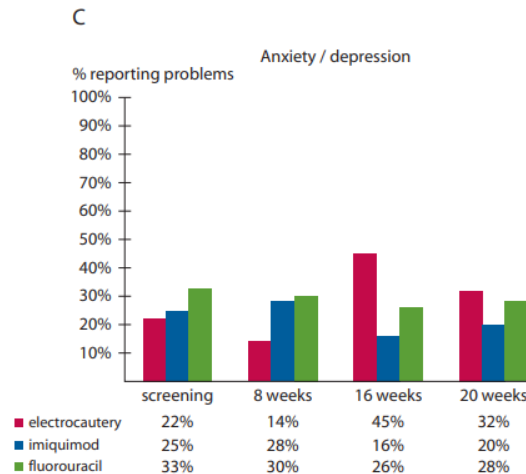
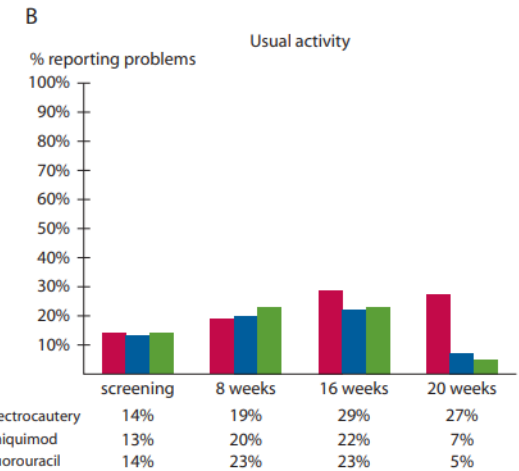
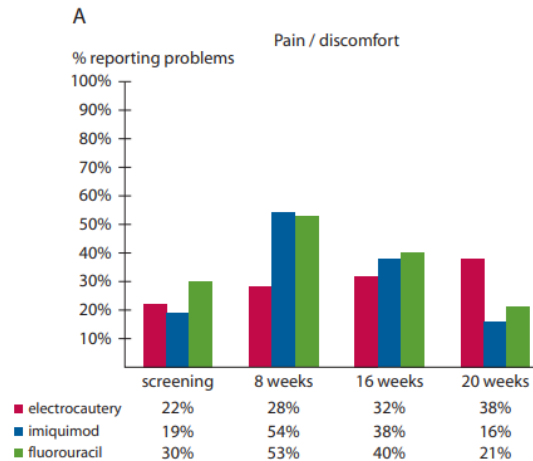
EQ5D: generic HRQL

SF: “International Index of Erectile function” and “Female sexual function Index”

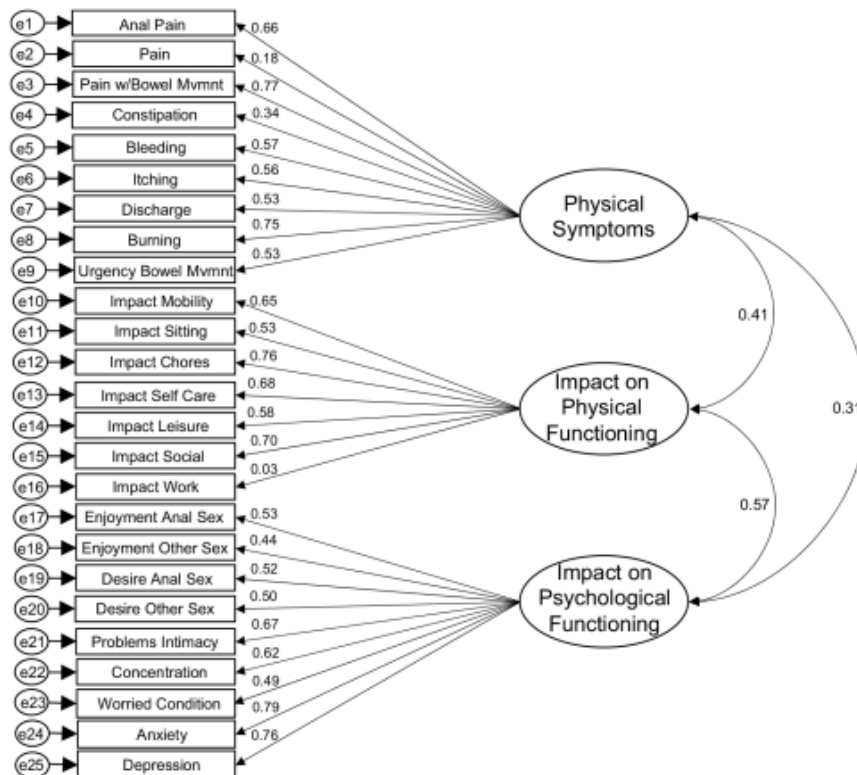
ECA: monthly 16 wks

Imiquimod: 3/wk 16wks

Fluoracil: 2/wk 16wks



## Anchor-Health related symptoms index



**Fig. 2.** Confirmatory factor model for the three-factor solution

### SHORT REPORT

Open Access



## Linguistic validation of the Spanish version of the Anal Cancer High-Grade squamous intraepithelial lesions outcomes Research Health-Related Symptom Index (A-HRSI): AMC-A04

### Physical Impacts

I have problems taking care of myself (e.g., bathing, dressing, shaving)

I have problems with my physical ability to move around

Tengo problemas con mis deberes personales diarios (por ej., bañándome, vistiéndome, afeitándome)

Tengo problemas con mi capacidad física para movilizarme

Problemas con mi arreglo personal

Tengo problemas con mi capacidad física para moverme

### Psychological Symptoms

I have a decreased enjoyment of anal sexual activity

I have a decreased enjoyment for any form of sexual activity other than anal sexual activity

Me ha disminuido el placer de la actividad sexual anal

Me ha disminuido el placer de cualquier forma de actividad sexual diferente a la actividad sexual anal

Me ha disminuido el disfrute de la actividad sexual anal

Me ha disminuido el disfrute de cualquier forma de actividad sexual diferente a la actividad sexual anal



## ***Take home messages***

There is a need for improvement HPV knowledge in the population.

Change one's mind – Change one's advice.

Understanding what our patients are going through is key for a good attendance.

Secondary effects related to treatments should be as important as efficacy.

We need to standardize how we collect QoL measures. A-HSRI

## *Some little advice from my friend*



**Greg**  
a patient

**My first visit to a clinic was very stressful,**