21-22 September 2019 • Rome, Italy

HOSTED BY:

IN PARTNERSHIP WITH:

ANAC
Association of Nurses in AIDS Care

‘Zero, No Risk, Can’t pass it On’

U=U: A Multidisciplinary Approach

Shaun Watson, Clinical Nurse Specialist (HIV Community)

Declarations

I have undertaken paid work and received scholarships from

ViiV, Gilead, MSD & Pfizer.

U=U

PrEP

U=U
UNDETECTABLE EQUALS UNTRANSMITTABLE

U=U*
UNDETECTABLE
viral load means HIV IS
UNTRANSMITTABLE

ntahc
northern territory AIDS & hepatitis council

U
UNDETECTABLE
UNDENIABLE
UNDESTROYABLE
UNDEFEATABLE
UNDETERRABLE
UNTRANSMITTABLE

Understanding U=U for women living with HIV
U=U

thewellproject

U=U
UNDETECTABLE=UNTRANSMITTABLE:
Building Hope and Ending HIV Stigma

Why are we discussing U=U?

- **Not everyone is onboard as messages differ from ‘zero risk’ ‘virtually no risk’ ‘negligible’ this can be confusing.**
- “I have a patient who…”
- **What about viral load is it >200 >50 >20?**
- ”I just don’t understand the science….”

The Evidence

Swiss Statement	Expert opinion and evidence review of >25 smaller studies looking at impact of ART on risk factors for HIV transmission.	Concluded that transmission would not occur undetectable with viral load.	2008	Vernazza P et al. [7]
HPTN 052	1763 serodifferent heterosexual couples randomised to immediate or deferred ART. Although condom use was high the impact of ART was highly significant.	All infections occurred in people with detectable viral load: n=17 in the deferred ART group and one early infection in the ART group before VL was undetectable. Follow-up reported out to four years.	2011	Cohen M et al. [8, 9]

“an HIV positive person on effective HIV treatment (ART) cannot transmit HIV through sexual contact”

- on ART and adherent
- undetectable VL
- no STIs
- risk <1 in 100,000 (<0.001%)

The Evidence

PARTNER	Prospective observational European study in ~900 serodifferent couples who were not using condoms.	Final results reported zero transmissions after more than 58,000 times couples had sex without condoms when viral load was undetectable <200 copies/mL.	2014 (interim). 2016 (final)	Rodgers A et al. [10, 11]
Opposites Attract	Prospective observational study in 358 serodifferent gay male couples in Australia, Thailand and Brazil.	Zero transmissions when viral load was undetectable <200 copies/mL.	2017	Grulich A et al. [12]
PARTNER2	Extension of PARTNER study to collect additional follow-up in gay male couples.	Study is fully recruited and still ongoing (2014–2017).	Expected 2018.	[13]

PARTNER 2

- **900 gay couples only (March 2014 to May 2018)**
- **Aim - to provide a similar level of confidence for gay men to PARTNER**
- **The PARTNER study recruited HIV couples (one partner positive, one negative) at 75 clinical sites in 14 European countries. They tested the HIV-negative partners every six to 12 months for HIV, and tested viral load in the HIV-positive partners. Both partners also completed behavioural surveys. In cases of HIV infection in the negative partners, their HIV was genetically analysed to see if it came from their regular partner.**
- **The study found no transmissions between gay couples where the HIV-positive partner had a viral load under 200 copies/ml – even though there were nearly 77,000 acts of condomless sex between them.**

Risk of HIV transmission through condomless sex in serodifferent gay couples with the HIV-positive partner taking suppressive antiretroviral therapy (PARTNER): final results of a multicentre, prospective, observational study. Rodger, Alison JColl, Pep et al (2019) The Lancet , Volume 0 , Issue 0

Partner 2 at AIDS2018

Q: What would you say to HIV information providers who are withholding this [U=U] information from people with HIV?

A: "It is very, very clear that the risk is zero. If you are on suppressive ART you are sexually non-infectious. *THE TIME FOR EXCUSES IS OVER*."

Dr. Alison Rodger, lead author of PARTNER2 at the International AIDS Conference - AIDS 2018 presentation (July, 2018)

This means…

In absence of evidence, having an opinion against U=U is either out-of-date or just prejudice - Simon Collins (i-Base)

- If you are HIV positive and undetectable you cannot pass the virus on to sexual partners.
- The challenge since 2008 is whether HIV transmission can occur – so far this not been proven.

There is no evidence, anywhere, that anyone has transmitted HIV when they have an undetectable viral load

It's a fact

U=U

Undetectable equals untransmittable

BHIVA

prevention access campaign

The British HIV Association is proud to support the #UequalsU consensus statement of the Prevention Access Campaign

The Campaign

That's Amazing But....

- **This is not a campaign to promote unprotected sex.**
- **We still need studies on breastfeeding and blood transmission.**
- **There are people living with HIV who despite everything cannot get to undetectable.**
- Globally there are people living with HIV who cannot access ART.
- **There are people living with HIV who decide not to take treatment (intentional non-adherence)**

What Can We Do?

- It's a multidisciplinary team approach – we should all be passing on the same information.
- **Reiterate - talk to people living with HIV about the necessity of staying undetectable for U=U to be applicable.**
- Adherence management – discuss the importance of taking ART as prescribed to maintain health and prevent onward transmission.
- **Encourage engagement – ensure people living with HIV attend appointments and are fully engaged with their care and have knowledge of their viral load status. This means also discussing issues that may effect their adherence and engagement. What else is going on for them, life style, home, finances etc.**

THE NATIONAL HIV NURSES ASSOCIATION SUPPORTS

U=U

THE RISK OF ACQUIRING HIV SEXUALLY FROM A PERSON WITH HIV WHO IS UNDETECTABLE ON ANTIRETROVIRAL TREATMENT IS ZERO #UEQUALSU

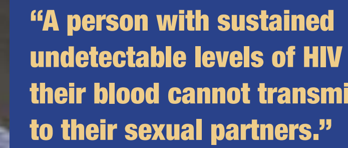
PREVENTIONACCESS.ORG

U=U*

UNDETECTABLE viral load means HIV IS UNTRANSMITTABLE

www.i-Base.info/u-equals-u

Michelle Ross, cliniQ



Angelina Namiba, Salamander Trust

"A person with sustained undetectable levels of HIV in their blood cannot transmit HIV to their sexual partners."

Simon Collins, HIV i-Base

Chloe Orkin, Chair, British HIV Association (BHIVA)

* Undetectable = Untransmittable

Poster produced by HIV i-Base for Kobler@CWH (July 2018)

U=U
UNDETECTABLE viral load means HIV IS UNTRANSMITTABLE

In PARTNER 1, couples (both straight and gay) had sex more than 58,000 times without condoms.

In PARTNER 2, in gay men only, couples had sex more than 77,000 times without condoms.

There were no linked transmissions in either study.

Other research includes the Rakai, HPTN 052 and Opposites Attract studies. It also includes the Swiss Statement that first published information about the risk being zero in 2008.

These and other studies are discussed in this online article.

The evidence for U=U: why negligible risk is zero risk

www.i-base.info/htb/32308

Does U=U apply to breastfeeding?

Although an undetectable viral load on ART also reduces the risk from breastfeeding, it doesn't reduce this risk to zero.

The have been cases where babies have become HIV positive from breastfeeding, even when the mother had an undetectable viral load.

Further information

The international U=U campaign raises awareness about this benefit from ART.

Currently, more than 720 organisations have joined from over 90 countries.

www.preventionaccess.org

i-Base has more information on U=U, including a longer version of this factsheet.

www.i-base.info/u-equals-u

U=U

Undetectable = Untransmittable

Did you know that having an undetectable viral load on HIV treatment (ART) stops HIV transmission?

ART is not only good for your health – it also protects your partners.

U=U means that you don't need to use condoms if you were only using them to stop HIV transmission.

Leading UK doctors and researchers strongly support the U=U statement.

"There should be no doubt that a person with sustained, undetectable levels of HIV in their blood cannot transmit HIV to their sexual partners."

Professor Chloe Orkin,
Chair, British HIV Association

UK guidelines state that HIV doctors should talk to all their patients about how ART stops transmission.

What is U=U?

U=U stands for:

Undetectable = Untransmittable

It means that someone with an undetectable HIV viral load on ART cannot transmit HIV, even without using condoms or PrEP.

What does U=U involve?

This protection from ART depends on:

- Taking ART every day.
- Having undetectable viral load for at least 6 months.
- Continuing to take your meds every day.

How can U=U not be a risk?

The quick answer is when HIV viral load is undetectable there is too little virus in sexual fluids for an infection to occur.

Any risk of sexual HIV transmission relates to viral load and being undetectable reduces this risk to zero.

Does U=U work with all HIV drugs?

Yes. Any ART that makes viral load undetectable will mean U=U.

Does U=U work for everyone?

Yes. The PARTNER studies included both gay and straight couples.

In straight couples sometimes the man was positive and in others the woman was positive.

Does U=U work for all types of sex?

Yes. The PARTNER studies collected information about the numbers of times people had oral, vaginal or anal sex. It also asked whether the negative partner was active or passive and whether there was ejaculation.

PARTNER reported zero transmissions for all situations.

Does this mean I can stop using condoms?

Whether you use condoms is a personal choice. Or a mutual choice with your partner.

Condoms reduce the risk of many STIs and they can effectively prevent pregnancy.

But if HIV is the only concern, then in the context of U=U, there is no reason to continue to use condoms.

My partner still wants to use condoms?

Whether your partner is HIV positive or HIV negative, they have to decide what is right for them.

They might want to use condoms for other reasons, or they might still worry about HIV transmission.

Sometimes it takes time for someone to accept new evidence, especially after using condoms for many years.

Do STIs affect U=U?

Based on the PARTNER study, U=U still works if, without realising it, one or both partners has an STI.

It is important to monitor and treat STIs, but they are unlikely to affect U=U.

Is U=U widely accepted?

Yes, most leading HIV scientists and doctors now agree with the U=U statement.

This includes the British HIV Association (BHIVA), the International AIDS Society (IAS) and the US Center for Disease Control (CDC).

Will my doctor know about U=U?

Hopefully, yes. U=U has been headline news for at least two years. U=U is included in the BHIVA Standards for HIV Care (2018).

If your doctor doesn't tell you about U=U, then ask them.

How long does viral load need to be undetectable?

Guidelines recommend having an undetectable viral load for six months before relying on 100% protection from U=U.

This cautious approach is why guidelines refer to being on stable ART.

What if I miss my meds?

Missing your meds once will not change U=U.

But missing meds for 2-3 days might be enough with some combinations for viral load to become detectable.

Good adherence is essential for U=U.

What about viral load blips?

Sometimes viral load can "blip" just above 50 copies/mL.

Blips that stayed below 200 copies/mL did not affect the PARTNER results.

How do we know U=U is so effective?

Researchers have known for over 20 years that ART reduces all transmission risks. But it is only recently that the zero risk has been proved.

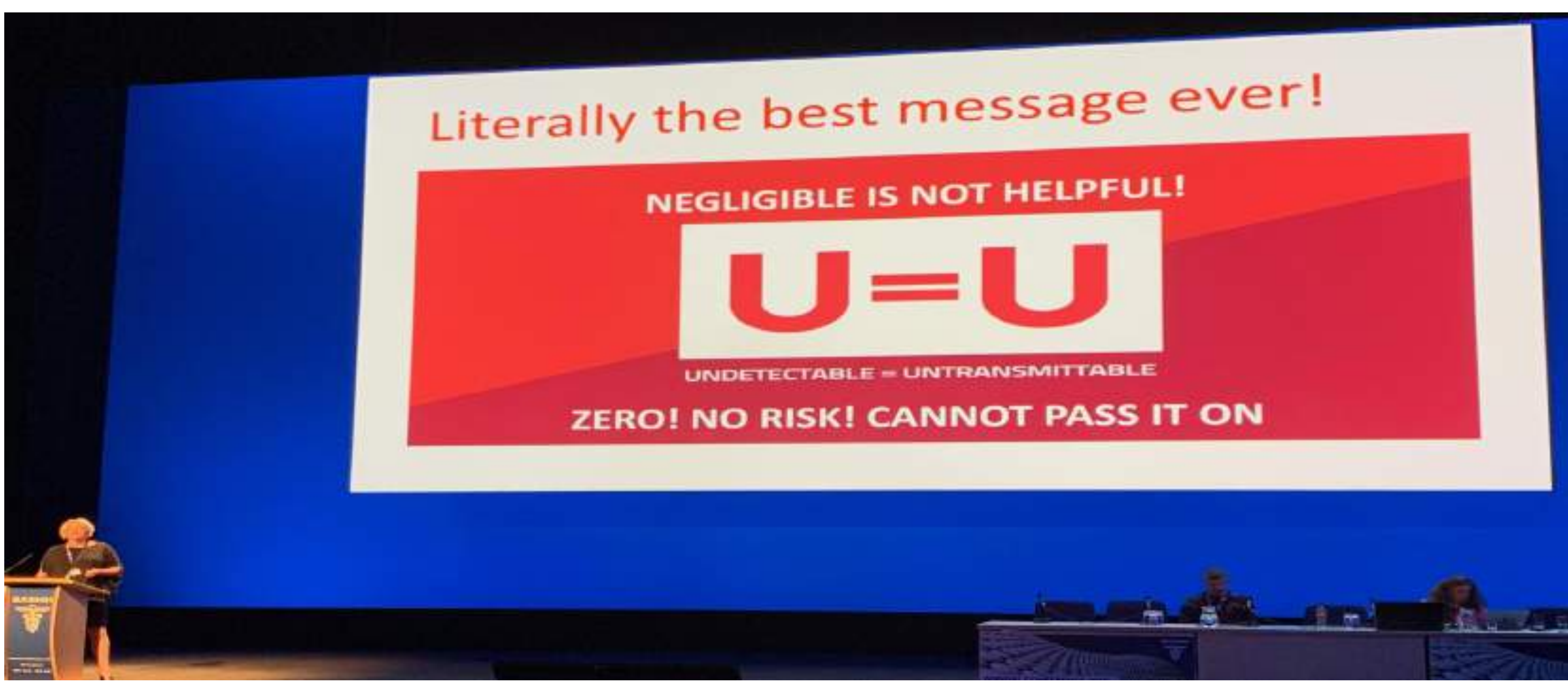
The PARTNER studies included couples where one partner was HIV positive on ART and the other HIV negative.

The positive partner needed to have an undetectable viral load and the couple needed to be having sex without condoms.

Organisations endorsing BHIVA's position on U=U to date include:

Organisations wanting to endorse BHIVA's statement please contact Jo Josh at jo@commsbiz.com

I'll leave the final word to Laura Waters…



Resources

- https://www.preventionaccess.org – equal access to the HIV prevention revolution based on #ScienceNotStigma. All people living with HIV have a right to accurate and meaningful information about their social, sexual and reproductive health.
- http://positiveseries.org – offers downloadable and customizable social marketing campaigns to educate about U=U and encourage engagement in care.
- http://i-base.info/u-equals-u/ - clear concise information.

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21-22 September 2019 • Rome, Italy

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Sexual Health Counselling for people living with HIV

Shaun Watson
Clinical Nurse Specialist (HIV Community)
Chair of the National HIV Nurses Association

Disclosures

- I have undertaken paid advisory work and speaking invitations for:

  ViiV, MSD, Gilead and Pfizer

What is Sexual Health?

Sexual satisfaction is an important element of sexual health and is associated with overall well-being. According to the World Health Organization's definition, sexual health is

"...not merely the absence of disease, dysfunction or infirmity. Sexual health requires a positive and respectful approach to sexuality and sexual relationships, as well as the possibility of having pleasurable and safe sexual experiences, free of coercion, discrimination and violence"

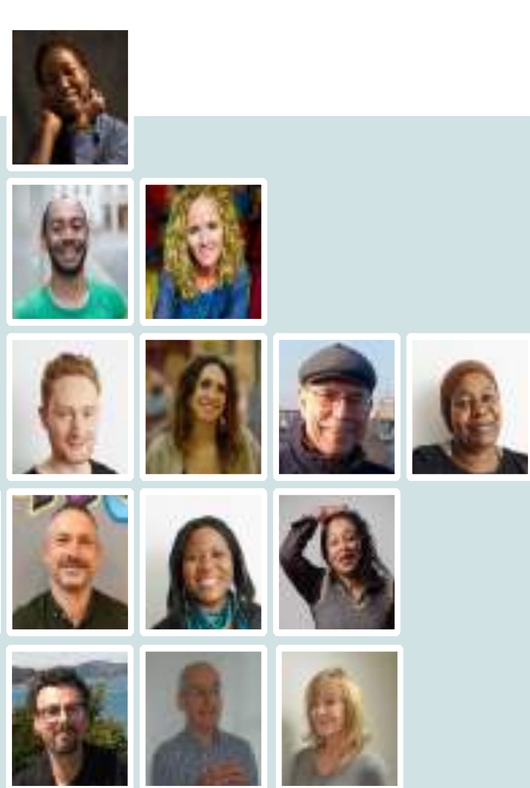
Annual health review for people living with HIV

A good practice guide

Funded by

Standards of Care

for People Living with HIV 2018



GUIDELINES

Version 9.1
October 2018

English

What Does EACS Say?

European AIDS Clinical Society state that 'sexual history should be taken on diagnosis and every 6-12 months'. Most of the guidance looks at sexual dysfunction recommending psychosexual counselling around:

1. Desire (lack of sexual desire or libido; desire discrepancy with partner; aversion to sexual activity)

2. Arousal (difficulties with physical and/or subjective sexual arousal; difficulties or inability to achieve or sustain an erection of sufficient rigidity for sexual intercourse i.e. erectile dysfunction; lack or impaired nocturnal erections ; difficulties lubricating; difficulties sustaining arousal)

3. Orgasm (difficulties experiencing orgasm)

4. Pain (pain with sexual activity; difficulties with vaginal/anal penetration–anxiety, muscle tension; lack of sexual satisfaction and pleasure)

What About the BHIVA Standards?

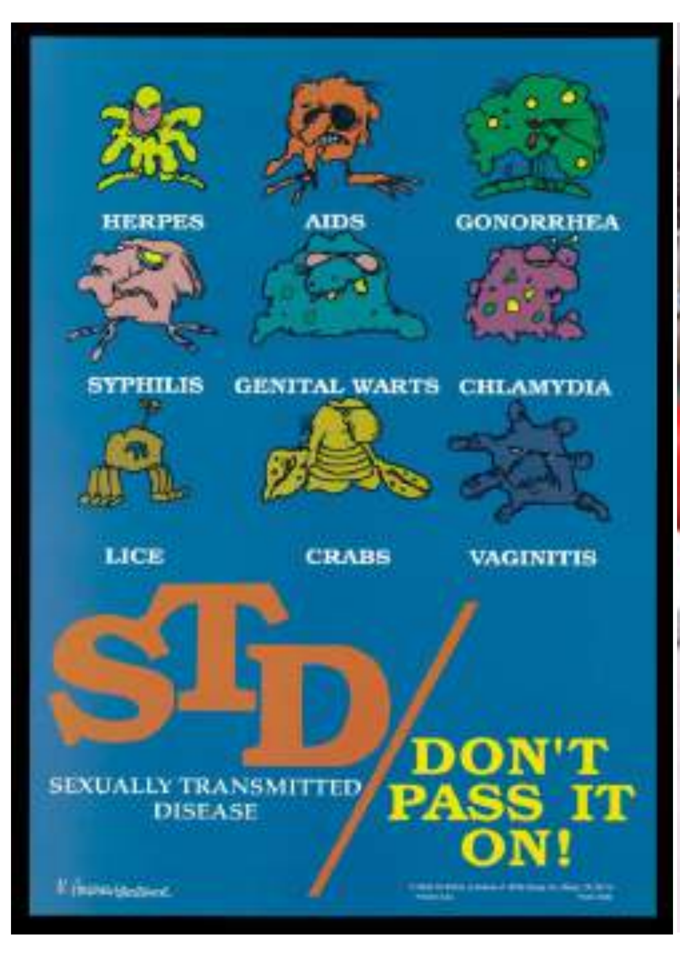
- **Good sexual health is part of good overall health.**
- The impact of living with HIV, a potentially stigmatizing sexually transmissible infection….should not be underestimated, and is **associated with sexual dysfunction and psychosexual morbidity.**
- **People living with HIV and their partners require access to appropriate, culturally sensitive and effective information and support about sexual behaviour and minimizing transmission risks.**
- Practitioners need **knowledge and expertise to be able to sensitively discuss sex and sexuality, safer sexual practices, HIV transmission risk in the context of effective therapy and preventative therapy for contacts, HIV disclosure and fear of criminalization.**

NHIVNA Annual Health Review

Standard 4: Sexual and reproductive health and psychosexual wellbeing

- All people living with HIV should be regularly screened for all sexually transmitted infections and have access to preventative interventions
- All people living with HIV should be supported in establishing and maintaining health and enjoyable sexual lives for themselves and their partners should they want
- All people living with HIV should have access to safe, effective and acceptable methods of contraception

It’s Not Just All About…



Sexual Health & HIV: What are the issues?

- The role of embarrassment, shame and fear - STIGMA
- **Sharing HIV status with others**
- **Fear of Criminalisation in the age of U=U**
- Ageing HIV population
- The moral responsibility – most research looks at safer sex
- **Lack of confidence**
- Change of body Image – weight loss/gain/neuropathy/rashes
- **The condom talk!**
- Lack of pleasure – rarely researched!

Research says…

- Some HIV-positive people may need more intensive client-centred counselling from professionals to address personality (e.g., sexual compulsiveness, impulsiveness), emotional (anger), and attributional (blaming others for one's HIV infection) dynamics underlying sexual risk behaviour (Crepaz & Marks, 2002)
- The prevalence of sexual dissatisfaction is high in both men and women living with HIV. It underscores the importance of a positive response instead of silence in clinical and social work encounters. Staff should initiate a dialogue and offer counselling related to sexual satisfaction (Schönnesson et al, 2018)

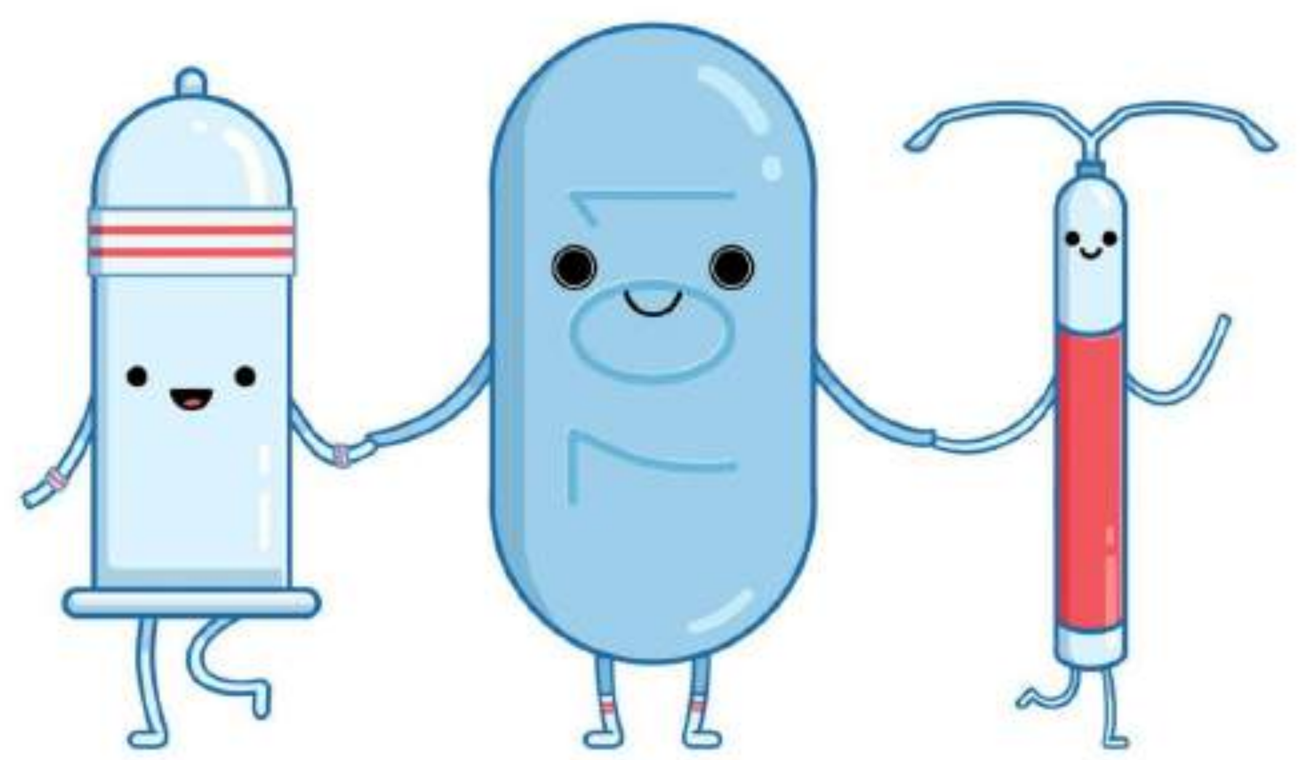
HIV-Stigma

- HIV-stigma can draw upon prejudicial and other negative attitudes to sex and sexuality; where attitudes prevail that identify certain sexual acts as normal, and others as abnormal or perverse, certain sexualities as normal and others as abnormal or perverse, the latter become stigmatised.
- **HIV-stigma might even be related to attitudes about the appropriate amount of sex or number of sexual partners an individual should have, and perhaps this in turn invokes further gendered prejudice (Hutchinson & Dhairyawan, 2017)**
- Patients may delay their presentation because of embarrassment, fear of stigmatisation, or ignorance regarding the seriousness of their symptoms (Spears et al, 1995)

Role of Shame in HIV

- **Shame can prevent an individual from disclosing all the relevant facts about their sexual history.**
- Shame can serve as a barrier to engaging with or being retained in care.
- **Shame can prevent individuals presenting at clinics for STI and HIV testing.**
- Shame can prevent an individual from disclosing their HIV (or STI) status to new sexual partners.
- **Shame makes people want to hide and withdraw from the world and others, it therefore makes the task of living with HIV a far more negative experience than it should, or needs to be (Hutchinson & Dhairyawan, 2017)**

let's talk



about sex

Why Isn't Sexual Health Discussed?

- It's not important
- **Assumption that the person with HIV isn't having sex (age, gender)**
- Presence of a third person in the appointment (partner, interpreter, child)
- **Person living with HIV don't want to discuss it/don't initiate discussion**
- Familiarity – they didn't want to talk about sex previously so it never gets raised again
- **Too embarrassed**
- Not enough time

What my patients say

- “Chance would be a fine thing!”
- “I’ve not had sex in years”
- “I don’t want to have sex since becoming positive”
- “I can’t get an erection and if I do I can’t cum”
- “I’ve got syphilis!”

Older Women and Sexual Health

- **One study among women living with HIV found that fear of stigma, discrimination and disclosure resulted in some self-imposing restrictions on expressions of sexuality and sexual desire (Gurevich et al, 2007)**
- HIV limited older women's ability to experience sexuality and intimacy, resulting in perceptions of "damaged sexuality" and "constrained intimacy" due to stigma and fears of rejection and violence after sharing their HIV status (Nevedal & Sankar, 2015)
- **Being HIV positive is associated with lower sexual function and a higher prevalence of sexual problems,. Almost twice as many women living with HIV reported low sexual function, with two-thirds of women with HIV also reporting at least one sexual problem in the previous year.**
- Postmenopausal status was associated with sexual dysfunction in women with HIV, an association that was not observed in HIV-negative women (Toorabally, 2019)

Older Women and HIV

Taylor et al (2017) highlighted the following characteristics:

1) sexual pleasure increases with age

2) sexual freedom from the fear of pregnancy and traditional gender norms

3) less pleasure due to partner and relationship characteristics

4) changes in sexual abilities - less stamina, flexibility

5) sexual risk behaviors

6) ageist assumptions about their sex lives and serostatus

In My Experience…

- Gay men feel more open to talk about sex to a gay nurse (or maybe it's just me).
- **What are they not telling you?**
- Be honest about boundaries – what are you willing to discuss, what are your limits?
- **Vigilance when visiting someone's home - lube, condoms, poppers, medications, partner(s)**
- Recognize that everyone has sexual needs and wants to discuss it from ages 18 to 88!

What Can We Do?

- **Has U=U been discussed? How has undetectability effected their sex life**
- Be sensitive, non-judgmental, think about body language.
- **Initiate the conversation – get over the embarrassment. If you can't, refer to someone who can. Don't ignore the need to talk about sex.**
- Think about the environment – curtains around a bed offer no privacy
- **Make time or refer to someone who has time (usually a nurse!)**
- Don't focus on what's wrong, talk about what's right, problem solve.
- **Unless it's illegal, talk about it!**

Examples of Questions to Ask

Are you having sex?
Are you having consensual sex?
Is it a good relationship?
Do you have pleasurable sex?
How easy do you find it to talk about HIV with new sexual partners?
Do you understand U=U?
When was the last time you had sex without (drugs/name of drug(s)if discussed)?
Do you have concerns about the kind of sex you have when taking (drugs/name of drug(s) if discussed)

Are you able to sustain an erection? Are you able to ejaculate?

What contraception do you use?
Was your last smear OK?
Do you have any pain/regular bleeding/spotting?

In Conclusion

- While some of the determinants of sexual dissatisfaction are beyond the control of the clinician, other responses such as raising the issue, demonstrating concern, and sex-positive interaction may reduce the client’s sense of hopelessness and feelings of sexual isolation.
- The ultimate goal should be to maximize an individual’s possibility to recognize herself/himself as a sexual human being who has the right to sexual well-being (Schönnesson et al, 2018)

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Thank you for inviting me to speak

Shaun.watson@nhs.net

Sexual health counselling in HIV-care

Suzanne de Munnik
Nurse practitioner

Sexual health counselling in HIV-care

INTERDISCIPLINARY TEAM

SCIENCE IN SEXUALITY
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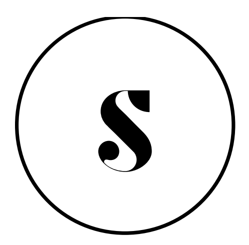


SCIENCE IN SEXUALITY

Suzanne de Munnik
Nurse practitioner infectious disease MSc
Catharinahospital – Netherlands
Total bed partners: 5
Current sex life: B+

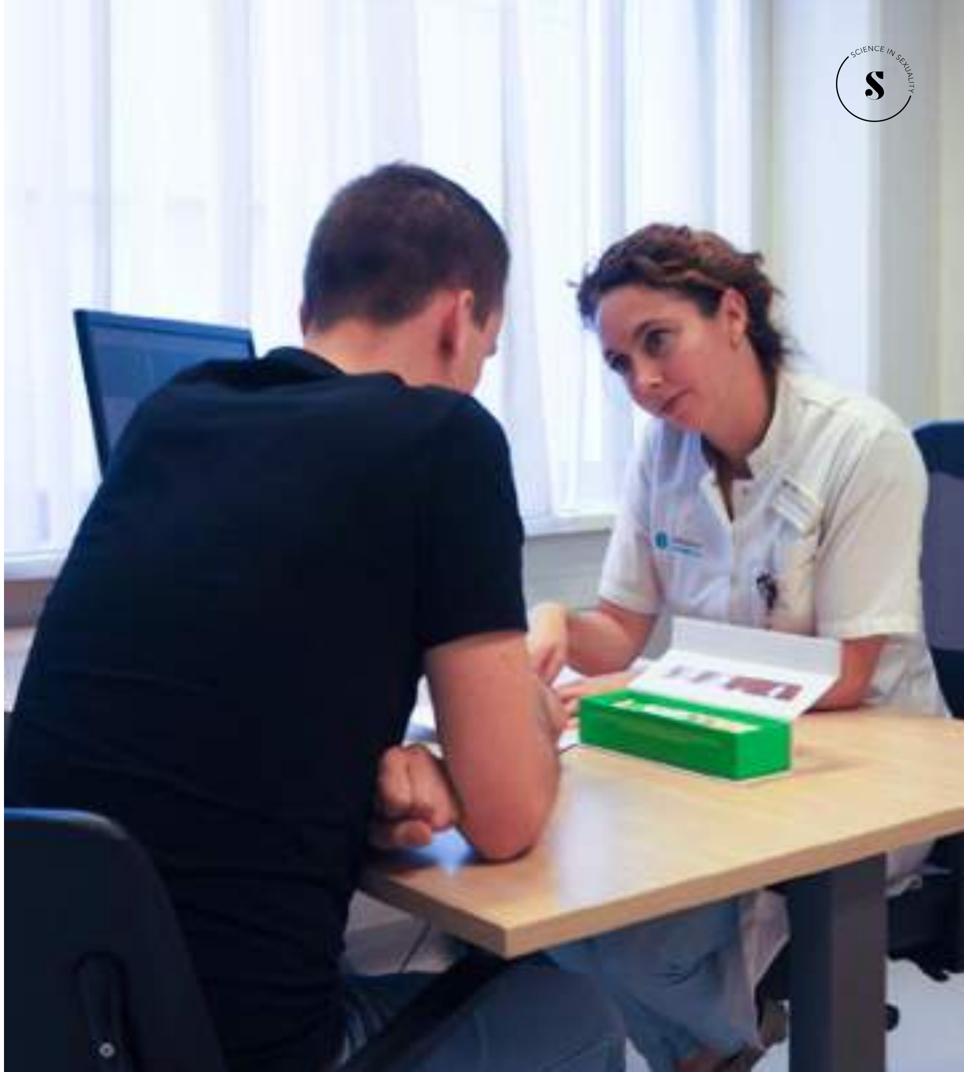
HIV-care Netherlands

INTERDISCIPLINARY TEAM

- Internist-infectiologist
- HIV-nurse/ nurse practitioner
- Consultation (psychologist, social worker i.e)
- National patient organisations, HIV association i.e.

POSITIVE HEALTH

- Quality of life
  - Sexuality



SCIENCE IN SEXUALITY

S

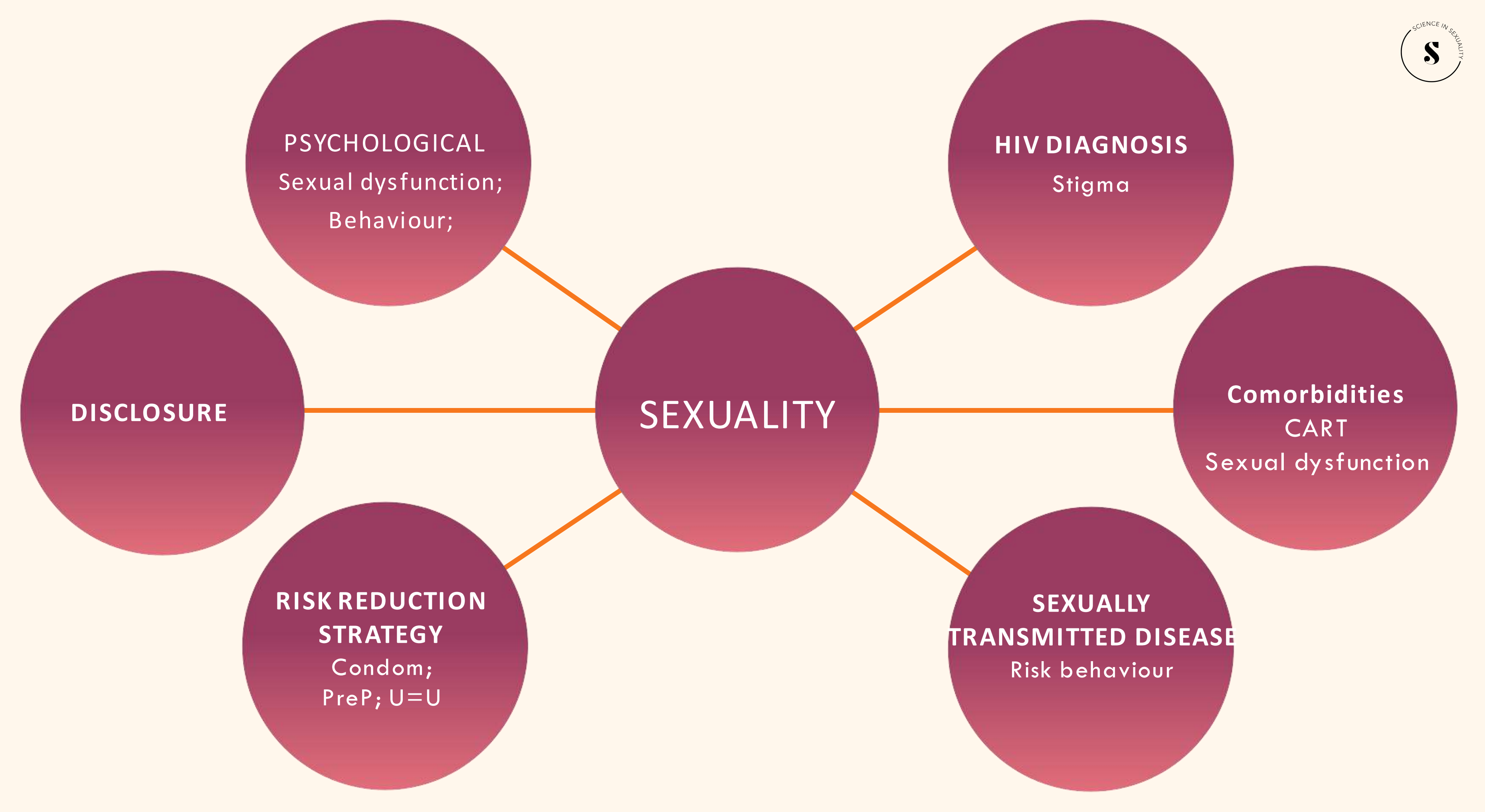
HIV and sexual health

1. STD detection rate: **36.6%** among people known to be living with HIV

2. **70.5%** of HIV-positive MSM experience one or more sexual problems < 1 yr after diagnosis.

2. **Netherlands**: national plan STD, HIV and sexual health 2017-2022

3. National guideline HIV nurses sexual health **2008**



SCIENCE IN SEXUALITY
S
PSYCHOLOGICAL
Sexual dysfunction;
Behaviour;
HIV DIAGNOSIS
Stigma
DISCLOSURE
SEXUALITY
Comorbidities
CART
Sexual dysfunction
RISK REDUCTION STRATEGY
Condom;
PreP; U=U
SEXUALLY TRANSMITTED DISEASE
Risk behaviour

International Journal of Nursing Studies
Volume 76, November 2017, Pages 55-61

Let's talk about sex: A qualitative study exploring the experiences of HIV nurses when discussing sexual risk behaviours with HIV-positive men who have sex with men

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ORIGINAL RESEARCH:
EMPIRICAL RESEARCH – QUANTITATIVE

WILEY JAN

From intention to STI prevention: An online questionnaire on barriers and facilitators for discussing sexual risk behaviour among HIV nurses

Suzanne de Munnik[1,2] | Sigrid C.J.M. Vervoort[3] | Heidi S.M. Ammerlaan[1] | Gerjo Kok[4] | Chantal den Daas[2,5]

PRESENT RESEARCH

The aim of the present study was to investigate to what extent sexual health counselling is incorporated into routine Dutch HIV care

METHODS

A cross-sectional survey among physicians and nurses in The Netherlands

2017 - 2018

The questionnaire consisting of 40 questions

- Demographic characteristics
- Self-perceived knowledge
- Competent
- Responsible
- Providing sexual health counseling
- Barriers
- Sexual health topics

IBM SPSS statistics 23

Physician (N=59)

	GENDER	KNOWLEDGE	DISCUSSING
Physician (N=59)	47%	34%	14%
Nurses (N=48)	77%	58%	63%

VS

Nurses (N=48)

Physician (N=59)

Barriers

	Insufficient time	Presence of a third party	Patients do not initiate
Physician (N=59)	61%	55%	85%
Nurses (N=48)	23%	60%	15%

INSUFFICIENT TIME

PRESENCE OF A THIRD PARTY

PATIENTS DO NOT INITIATE

Nurses (N=48)

sexual health counselling topics

	PHYSICIAN	NURSES
Fatigue	23%	50.0%
Lack of experienced pleasure	45%	88%
Inability to reach orgasm	13%	29%
Altered self image	38%	67%
HIV stigma	66%	85%

SCIENCE IN SEXUALITY

Frequently

Sexual health counselling

	KNOWLEDGE	BARRIER>2	RESPONSIBLE
Frequently	66%	61%	97%
Infrequently	33.3%	87%	80%

Infrequently

Discussion

Sexual health counselling

- Responsible
- Third person

Sexual health counselling multifaceted

- who/which topic

Overcoming barriers

SCIENCE IN SEXUALITY

Conclusion

Researchteam "talking about sex"

Prof. Dr. J. (John) de Wit

Mw. Dr. H.S.M. (Heide) Ammerlaan

Mw. Dr. C. (Chantal) den Daas

Mw. Dr. S.J.C. (Sigrid) Vervoort

Dr. H.W. (Henk) Elzevier

Prof. Dr. G.J. (Gerjo) Kok

Sexual health counselling in HIV-care

INTERDISCIPLINARY TEAM

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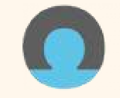
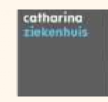

21-22 September 2019 • Rome, Italy

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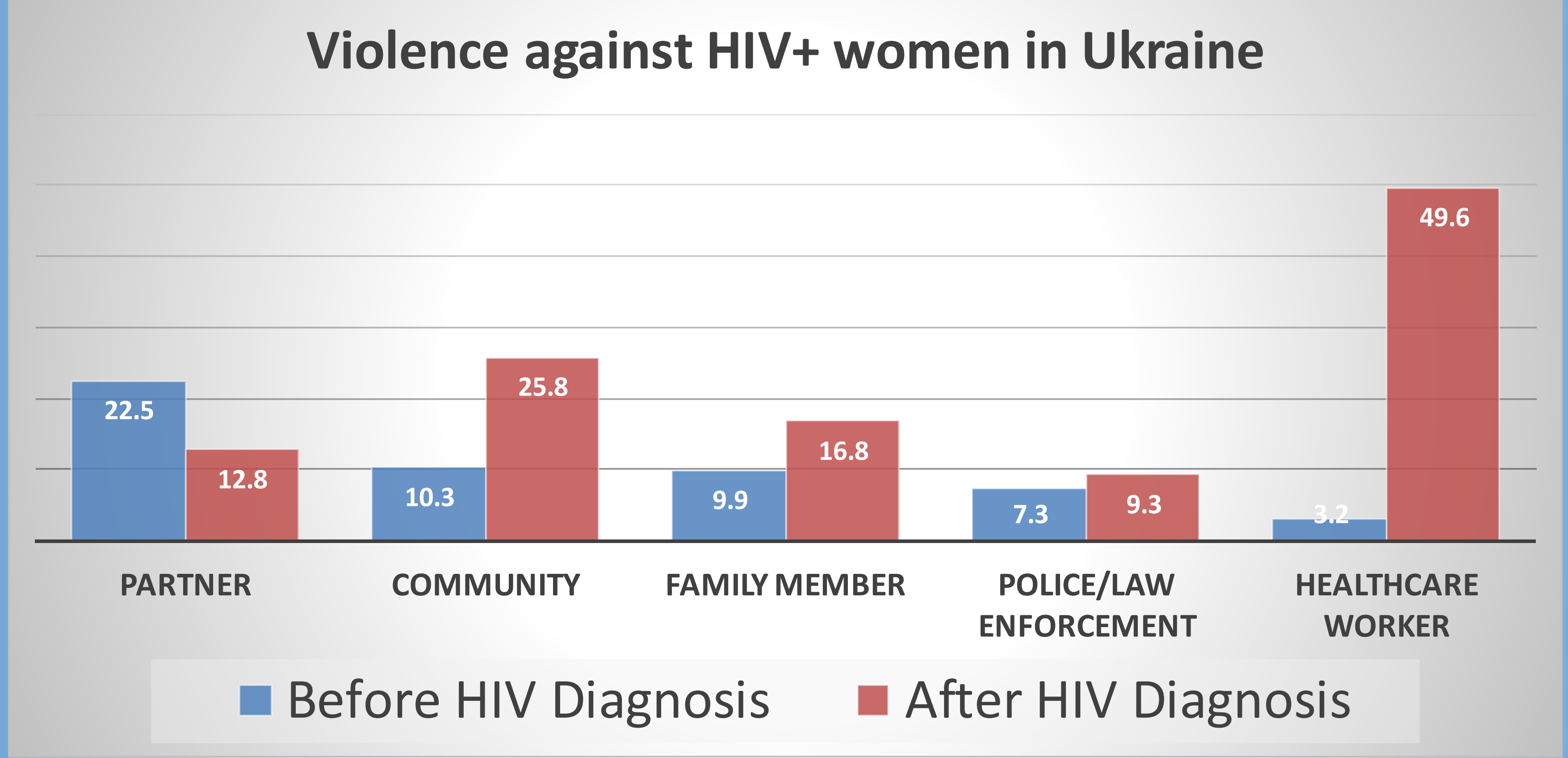
Addressing specific needs and rights of Women who Use Drugs Living near the Armed Conflict Zone in Ukraine

Svitlana Moroz
Svitanok Club, Ukraine

Women living with HIV in Ukraine

- The predominant majority of respondents (87.4%) are in the reproductive age.
- 32.3% have one or more sexual partners living with HIV, and 29.9% - without HIV.
- 42.3% learned about their HIV status during pregnancy.
- 54.7% gave birth to children after they learned about HIV, of them 15.9% have HIV positive children.
- 7.2% cannot get their partners to use a condom during the intercourse, and another 12.9% can do so only sometimes

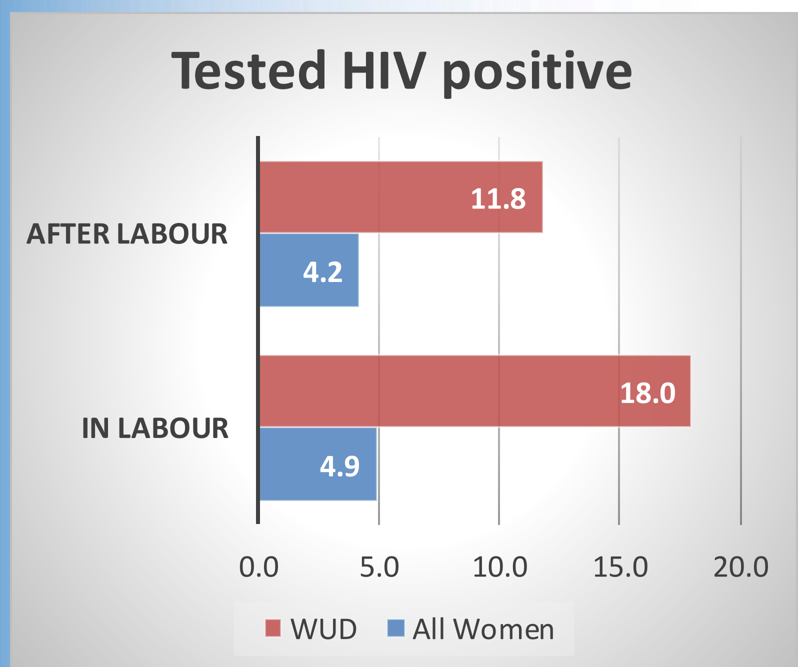
Women living with HIV in Ukraine

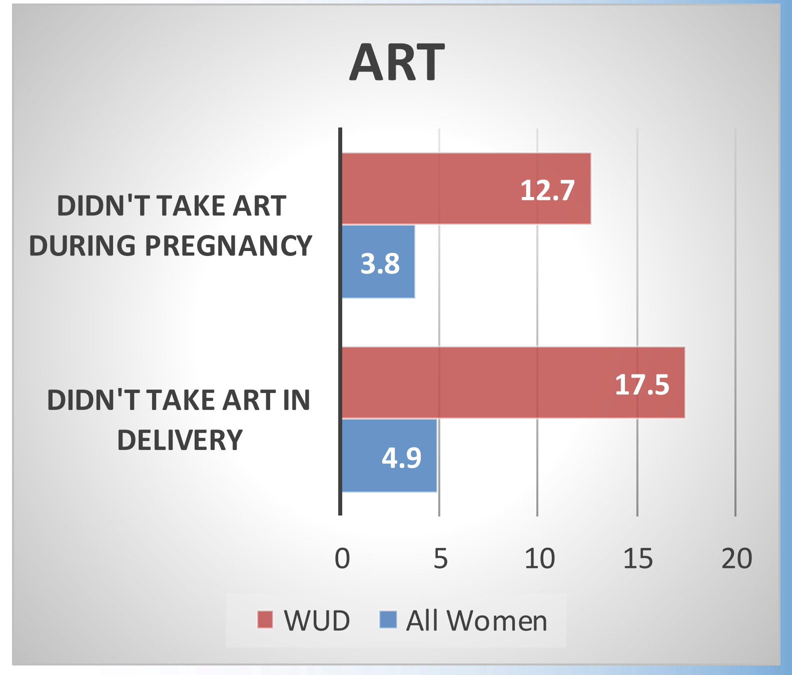


Violence against HIV+ women in Ukraine
22.5
12.8
10.3
25.8
9.9
16.8
7.3
9.3
3.2
49.6
PARTNER
COMMUNITY
FAMILY MEMBER
POLICE/LAW ENFORCEMENT
HEALTHCARE WORKER
Before HIV Diagnosis
After HIV Diagnosis

Vertical transmission and women who use drugs

Ukraine, 2013





Gender Lens: Women Who Use Drugs

Realities for Women who use drugs

Women

who used drugs

- police and IPV Violence
- societal and Self-Stigma
- under-represented in clinical trials and research
- tougher sentences and incarceration
- poor/no drug treatment and rehabilitation
- poor/no access to maternal healthcare
- removal of children from their custody
- OST is unavailable during pregnancy
- no voice and legal support

Armed conflict

- Impact on the degree of vulnerability of women from sexual, physical and economic violence
- Negative impact on the access of people who use drugs to essential health, including HIV treatment and prevention, opioid substitution therapy
- Many women who use drugs displaced and migrated to other parts of Ukraine to avoid the conflict

Community-based Research

Goal of the study:

- to examine the social, cultural and legal barriers to obtaining sexual and reproductive health services for women who use drugs living near the conflict zone in Ukraine.

Study population: women who have experience of drug use, and living near the temporarily occupied territories of Donetsk and Lugansk region, Ukraine.

Community-based Research

Methods

- The study utilized three data collection methods:
- Structured interviews with WUD
- In-depth interviews with WUD
- Inquiries to public health authorities on healthcare provision.

Structured interviews

- Structured, questionnaire-based interviews were conducted with **150 WUD**, each interview of around 60 minutes of duration.
- The questionnaire included over 100 questions grouped in the following blocks:
  - **General socio-demographic information**
  - **History of drug use**
  - **Access to HIV prevention and treatment services and treatment of co-infections**
  - **Sexual and reproductive health**
  - **Sex work**
  - **Violence.**

Socio-demographic characteristics

- **Age**: average 38 years, min. age 18 years, max. age 58 years
- **Language**: For 84,67% Russian was the primary language, and with an exception of one person the others spoke mainly Ukrainian at home.
- **Place of residence**:
  - 91.33% lived in urban settings;
  - **14% of respondents changed their place of residence due to the conflict** and moved to another city, and 4% changed their residence within the same city;
  - 12,67% have status of displaced person, but one quarter of them have no documents to prove it;
  - More than two thirds of displaced persons have not received any support as displaced.

Socio-demographic characteristics (2)

Marital status

- 14.66% married
- 36.66% unofficial marriage
- 16% widows

Children

- 68,67% of respondents had children
- There were 1-2 children average, one woman had 4 children, and one woman had 6 children

Education level

- 18% not finished secondary school
- 21.33% secondary school
- 14.67% professional college
- 22% technical college
- 2% unfinished higher education
- 3.33% higher education.

Socio-demographic characteristics (3)

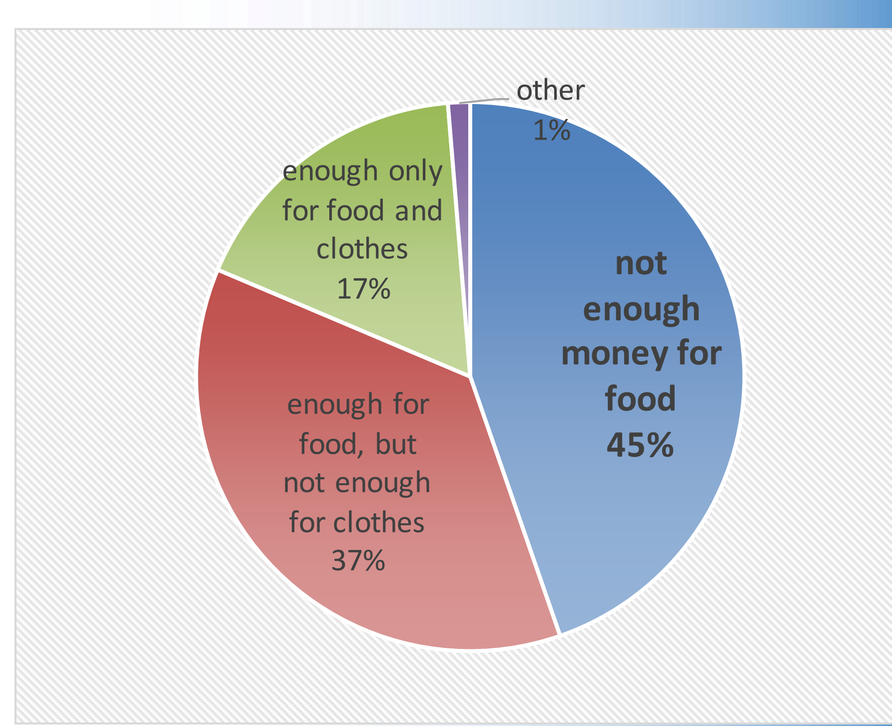
Work status at the moment of the interview:

- 56,7% unemployed
- 7,3% formally employed
- 16% informally employed
- other – 18%

(incl 14,7% who never worked).

Financial status:

- Monthly wage 43-541 USD
- 3867 UAH (142 USD) average



Drug use

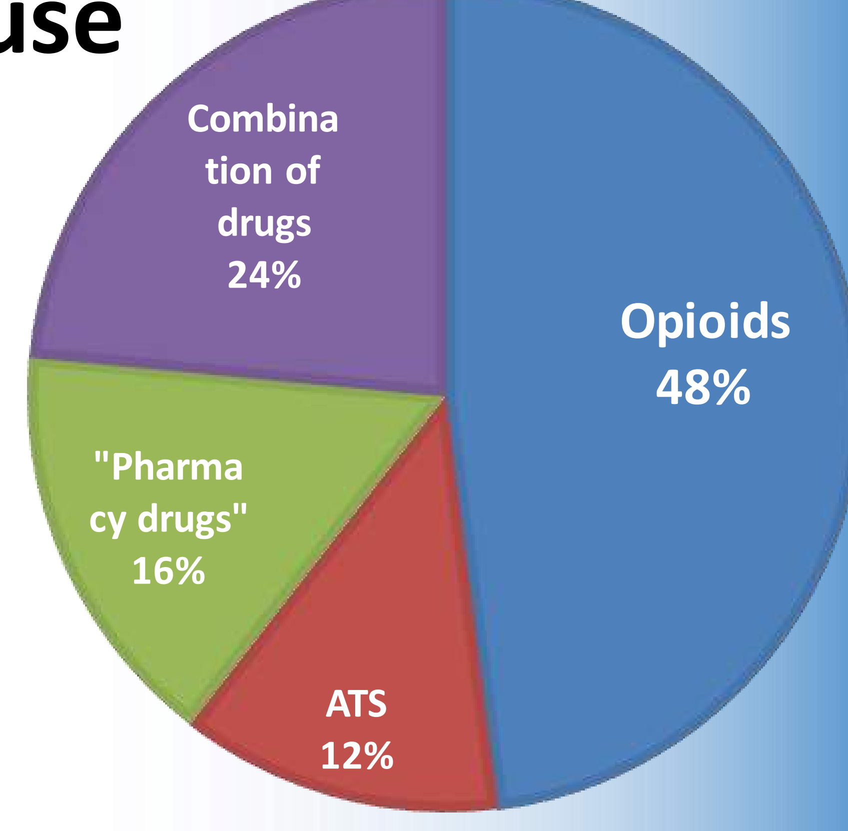
Minimal age of starting drug use 12 years, average age of drug use initiation - 20 years old.

Last drug used

- Opioids 48%;
- Amphetamine types stimulants (ATS) 12.5%;
- ‘Pharmacy drugs’ 16%;
- Others used a combination of drugs at the moment of the last drug use.

Overdose - 29.3% has experienced opioid overdose at least once

Only 6 persons (4%) received naloxone during the last 12 months



HIV testing

- Only 1 of 150 respondents never had HIV test
- Only 1 person had self-testing for HIV as the latest test
- Only 6 persons (4%) had their HIV testing by an outreach worker
- 4 persons do not know their HIV test
- Among 66 respondents who indicated that they were HIV negative, 84,85% got testing during the last 12 months
- 5 persons of 66 respondents who indicated that they were HIV negative haven't got an HIV test since April 2014
- 52,67% of respondents are **living with HIV**

ARV treatment (data on the respondents living with HIV)

- 3 persons have not ever been offered ARV treatment
- 12.66% of WLHIV (10 persons) have never received ARV treatment
- 38 persons (48.1% of WLHIV) have at least once stopped taking ARV treatment, 33 of them stopped taking treatment for some time after 2014
- 18 persons (22.78% of WLHIV) have never been tested for viral load
- 62 persons (78.48% of WLHIV) have never been tested for HIV drug resistance

Hepatitis C

- 56% of respondents indicated that they currently had hepatitis C
- 22% persons don’t know if they have HCV
- Only 1 person have got treatment free of charge
- 4 persons got treatment for out-of-pocket payments
- 91.86% of respondents who knew that they ever had had hepatitis C had never been treated

Harm reduction

- 11.33 % of respondents did not receive any harm reduction services during the last 12 months
- Only 6 persons (4%) received naloxone during the last 12 months
- Only 5 persons received food through harm reduction services during the last 12 months.

STI testing and treatment

- 39.33% have been never tested for STIs
- Only 10% of those who have been ever tested for STIs, have had their latest STI testing for free
- 79.33% of respondents have never received STI treatment
- None of those who received STI treatment received it free of charge
- 13 persons (8.6% of all respondents) reported that they had non-medically assisted self-treatment
- 33% haven’t used any contraception methods during the last 12 months.

Reproductive health

82% of women has pregnancy during their lifetime, and among those who were ever pregnant:

PREGNANCIES

5 and more
never pregnant
4 pregnancies
3 pregnancies
1 pregnancy
2 pregnancies

Reproductive health (2)

- 34.67% of respondents reported that they had **abortion**, among which:
  - 8 persons were recommended (by doctors) to have abortion because of drug use,
  - 1 - because she was receiving OST,
  - 1 - because of HIV positive status.
- 5.69% had to pay for the visits to maternity clinic and 4,08% didn't have access because they didn't have permanent registration.
- 3 women started **OST during pregnancy**,
- 10 persons continued OST during pregnancy (they started to receive treatment before it), and 1 person interrupted OST during pregnancy because of doctors advice.
- 16 women (13.01%) didn't accessed OST during pregnancy because they either didn't receive doctor's advice to do so or because OST was not available in the place of their residence.

Sex work

- 36 women (24% of participants) have sex worker experience
- 20% exchanged sex for money, drugs or food during the last 7 days
- Out of 36 persons who were ever involved in sex work, 8 persons have ever provided sex for the police and 6 – for military
- 24 out 36 who were ever involved in sex work were at least once forced to provide sexual services, and 4 persons indicated that it was done by the police
- 17 persons were physically abused while providing sexual services.

Violence

Intimate partner violence

- 35.33% experienced physical violence from their intimate partner
- 14% experienced sexual violence from their intimate partner
- 37 persons (67.27% of those who experienced any form of violence from intimate partner) have called police in case of violence.

Non-intimate partner violence

- 47 persons (31.33%) experienced physical violence (other than intimate partner) but only 7 persons turned to police in this case
- 30 persons (20%) experienced sexual violence (other than intimate partner) but only 3 persons called police in this case.

Crisis centres for women - None of women who experienced violence ever got support from a crisis centre for women or even asked such centre for help.

Deprivation or restriction of parental rights

"After the divorce, my husband, through the social welfare services, initiated the collection of documents about me being in OST program. ***When I used street drugs, he could not prove that I was a drug addict. Then, when I started taking OST, he managed to get a certificate from the drug registry. The Committee decided in father's favor. In fact, my OST treatment was the only reason they did it.*** *I had housing, I could provide everything necessary for the child's wellbeing. Before the commission meeting, I was asked one question: "How long have you been drug dependent?"*

Taniana, Lisichansk, Lugansk oblast

Non-protection from police violence

«... the doctors *registered that I was beaten and called the police, because this was the procedure. And when the police arrived, one of them was the same one who beat us. When he saw that it was me, he said:* ***Do you understand that we can take you out of the hospital now and just shoot you? And I will explain later that you are a separatist****".*

In the morning I called, I understood that someone from senior positions, and said: What do you want with your statement? What do you need to do to take it away? Maybe an apology is enough for you? I said no, that ***I want my complaint to go through the whole procedure, as it should be, for those who are guilty to carry the responsibility. ...*** *There was not even an answer. I was in Donetsk, and this is already uncontrolled territory,* ***no one ever called me about it, no answer came to me****»*

Svetlana, Kramatorsk

Torture and illegal detention due to drug use/OST

*".. packs on the head, beat strongly and on Mashokhedzh. It was in 2014, in October. There was beatings, and hammers ... **They used hammers to beat my fingers off**... Yes, **I was pregnant**. ... They didn't give me any food or drink ... My fingers don't move... I had the surgery then, and the joint was removed. Feet ... there was a wound.*

(They did it because you have drug dependence?)

*Yes, because I am on OST ... Well, **they beat so much** that ...*

*First, our hands were tied behind with the wire and you can't get rid of it ... We were kept in is the boiler room **on the floor, we had nothing at all, no mattresses, nothing**, nothing. We spent 10 days there such that ...*

(What about your pregnancy?)

*Well, **miscarriage** ... **I didn't have any undamaged piece of me**. Not on the face, nowhere, my whole body was so blue... And then there was the second basement, for 13 days ...*

Elena, Severodonetsk, Lugansk oblast

22 months in prison for OST

Natalia Zelenina, social worker of Svitanok Club, was stopped by ”DPR” police on November 5, 2017 when she passed through check point on her way home from an OST clinic in Vinnitsa (Central Ukraine).

She spent several days in police station and then was transferred to a pre-detention center where. She is jailed there until now being accused in the contraband of drugs because she carried 100 of buprenorphine pills for herself and her friend (also a client of OST program)

Methodological Considerations

- Non-randomised sampling (snowball sampling)
- Non-representative sampling for all the population of WUD in East Ukraine
  - but rather draws a portrait of the most vulnerable subgroup of WUD with HIV prevalence (over 50%), lowest social status and highest vulnerability for structural violence
- Results could be use to guide planning and implementation of SRH and other health services so that NO ONE IS LEFT BEHIND

Principles of project implementation and service provision:

- A woman-centred approach is underpinned by two guiding principles:
  promotion of human rights and gender equality
- GIPA principle and women's involvement
- Services should be voluntary, optional, informed, confidential and
  work for the benefit of each woman.
- Services see women as active participants in, as well as beneficiaries of.
- Care is provided in ways that respect women's autonomy in decision-making about their health
- Information and options to enable women to make informed choices.
- The needs and perspectives of women, their families and communities are central.
- The treatment of girls, unmarried women and those without children should be unbiased and to the same standard of attention and care as those who are married or have children.

Our Vision

- **harm reduction and HIV-related** services and programs are evidence-informed, low threshold (affordable, accessible and relevant) for all women, and in harmony with gender equality, human rights and public health frameworks;
- **sexual and reproductive health and rights services** are available, affordable, evidence-based, and free from coercion for marginalized women;
- **mobilization and empowerment of women** in order to address **gender-based violence and SRHR**;
- enhancing the practices of **human rights and health seeking behavior** of marginalized and inadequately served women in armed conflict affected area.

Chase the virus
not people
Eastern Europe
and Central Asia (EECA)
communities campaign
to stop stigma and discrimination
chasevirus.org

21-22 September 2019 • Rome, Italy

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Women & Girls: Optimizing Outreach, Care and Support

Carole Treston, RN MPH ACRN FAAN
Association of Nurses In AIDS Care

Equity: Girls & Young Women

PEPFAR

2003-2007: Emergency Response

- High impact countries
- Infrastructure established

2008-2012: Sustainability (4 mil Tx)

- Country driven
- Public Health
- Efficiencies (140K HCW)
- Policies >AIDS; stigma, IPV, gender

2013-2016: Transparency & accountability (7.7 mil Tx)

- Data driven
- Human Rights DREAMS

2018: 19 mil Tx

PEPFAR Results

PEPFAR LATEST GLOBAL RESULTS

2017

15.2 MILLION — Voluntary medical male circumcisions to prevent infections in men and boys

25-40 PERCENT — Decline in new HIV diagnoses among adolescent girls and young women through the DREAMS partnership

2.2 MILLION — Babies born HIV-free

85.5 MILLION — People received HIV testing services

14 MILLION* — Men, women, and children on lifesaving antiretroviral treatment

1 MILLION — Children on lifesaving antiretroviral treatment

6.4 MILLION — Orphans, vulnerable children, and their caregivers received support

250 THOUSAND — New health care workers trained

* As of March 30, 2018; all other numbers are as of Sept. 30, 2017.

PEPFAR is the largest commitment by any nation to address a single disease in history. Through the compassion and generosity of the American people, PEPFAR has saved and improved millions of lives, accelerating progress toward controlling and ultimately ending the AIDS epidemic as a public health threat.

DREAMS

Determined Resilient Empowered AIDS-free Mentored Safe

Kenya
Swaziland
Tanzania
South Africa
Uganda
Mozambique
Zambia
Malawi
Zimbabwe
Lesotho

GOAL: REDUCE NEW HIV INFECTIONS IN 15-24yo

Fig 1. The core package.

DREAMS
WORKING TOGETHER FOR AN AIDS-FREE FUTURE FOR GIRLS & WOMEN

The Core Package

Mobilize Communities for change

Community Mobilization & Norms Change

School-Based Interventions

VMMC (Other PEPFAR Programming)

Reduce Risk of Sex Partners

HTS and Tx for Men (Other PEPFAR Programming)

Characterization of Male Partners to Target Highly Effective Interventions (ART, VMMC)

Empower Girls & Young Women and reduce risk

Strengthen Families

Parenting/ Caregiver Programs

Social Protection (Education Subsidies, Combination Socio-Economic Approaches)

Youth-friendly Sexual and Reproductive Health Care (Condoms, HTC, PrEP, Contraceptive Mix, Post-Violence Care)

Social Asset Building

Determined | Resilient | Empowered | AIDS-Free | Mentored | Safe

Saul J, Bachman G, Allen S, Toiv NF, Cooney C, et al. (2018) The DREAMS core package of interventions: A comprehensive approach to preventing HIV among adolescent girls and young women. PLOS ONE 13(12): e0208167.
https://doi.org/10.1371/journal.pone.0208167
https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0208167

21-22 September 2019 • Rome, Italy

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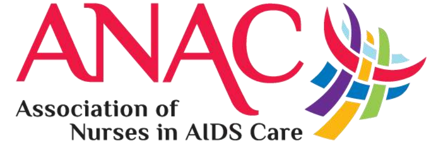
The Role of Nurses in Human Rights

Carole Treston, RN MPH ACRN FAAN
Association of Nurses In AIDS Care

Association of Nurses in AIDS Care

Mission: ANAC fosters the professional development of nurses and others involved in the delivery of health care for persons at risk for, living with, and/or affected by HIV and its comorbidities. ANAC promotes the health, welfare, and rights of people living with HIV around the world.



Association of Nurses in AIDS Care

Core Ideology: Public policy must be grounded in patient advocacy, human rights, compassion, and social justice. We promote the inclusion of the nursing perspective in promoting the health, welfare, and rights of all individuals affected by HIV and its comorbidities.

Two Fundamental Beliefs:

- Nurses can have an influential and powerful voice as public policy advocates.
- Nurses have expertise related to health care and human rights.

ANAC
Association of
Nurses in AIDS Care

Nurses and Advocacy

Advocacy: Seeing a need and finding a way to address it

Advocate: One that pleads, defends, or supports a cause or interest of another

Nurses: Provide 24-hour continuity of care and close surveillance

Are advicates for patients

Lead health promotion

Educate patients and the public on the prevention of illness and injury

ANAC
Association of
Nurses in AIDS Care

Nursing is Founded in Public Health Policy & Social Justice Advocacy

Health and Hospital Reform
Health and Hunger Reform in India
Women's rights and workforce equality
Sex workers rights
Big Data

ANA Code of Ethics
2015 Year of Ethics

Revised Code released Jan 2015

Establishes ethical standards for the profession

Serves as a guide for nurses to use in ethical decision making

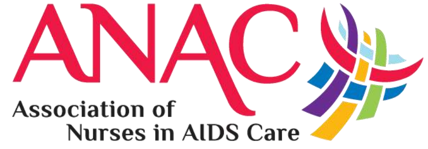
1. Respect for the inherent dignity, worth and uniqueness of every patient, unrestricted by social and economic status, personal attributes, or the nature of the health problem.
2. Commitment is to the patient, whether an individual, family, group or community.

ANAC
Association of Nurses in AIDS Care

ANA Code of Ethics

8. Collaborates with other health professionals and the public in promoting community, national, and international efforts to meet health needs.

9. The profession of Nursing as represented by associations is responsible for articulating nursing values, maintaining integrity of the profession and for shaping social policy.



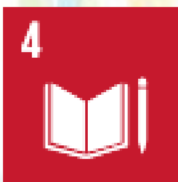
Global Human Rights Issues 2019

- HIV/AIDS – 35 million worldwide
  - Poverty
  - Racism
  - Gender Equality
  - Rights of Key Populations (MSM, PWID, Incarcerated, SW)
- TB- 1.8 million deaths/year: MDRTB (incarcerated)
- Growing VH epidemics – 320 million worldwide
- Maternal & reproductive health
- Refuge & migrant health & rights- 258 million worldwide
- Climate change

Poverty

Hunger

Healthcare



Education

Gender Equality

- Reduce global maternal mortality
- End preventable deaths of newborns and children under 5 years of age
- End the epidemics of AIDS, TB, malaria. Combat hepatitis, water-borne diseases and other communicable diseases
- Reduce premature mortality from non-communicable diseases through prevention and treatment and promote mental health and well-being
- Ensure universal access to sexual and reproductive health-care services

- Achieve universal health coverage, including financial risk protection, access to quality essential health-care services and medicines and vaccines for all

End all forms of discrimination against all women and girls everywhere

Eliminate all forms of violence against all women

Eliminate all harmful practices, such as child and forced marriage and female genital mutilation

Undertake reforms to give women equal rights to economic resources, ownership and inheritance

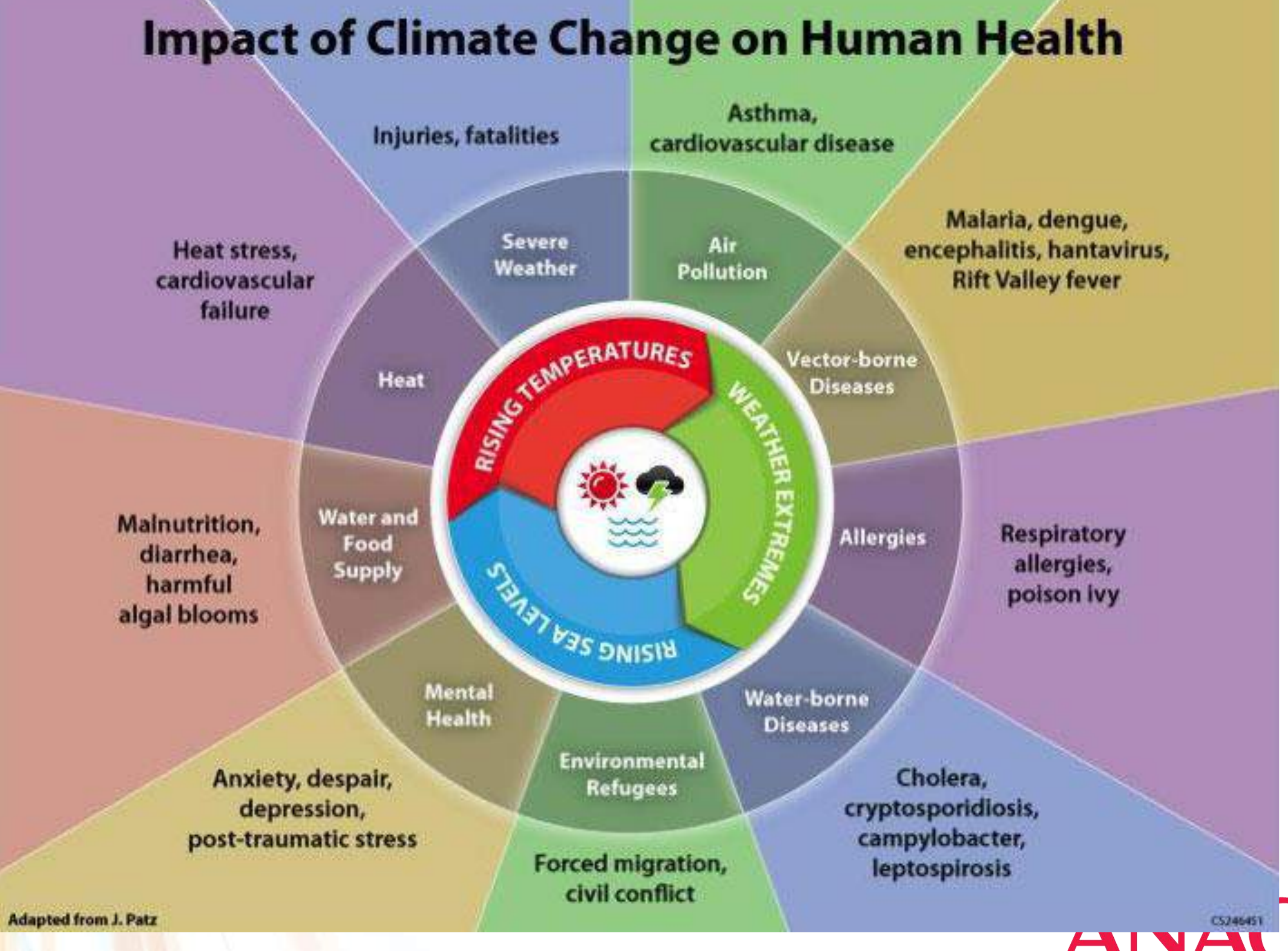
Ensure universal access to sexual and reproductive health and reproductive rights

Ensure women's full participation and equal opportunities for leadership at all levels of decision making in political, economic and public life

GOAL 13: Take urgent action to combat climate change and its impacts

13.1 Strengthen resilience and capacity to climate-related disasters in all countries
13.2 Integrate climate change measures into national policies and strategies
13.3 Improve education & capacity on climate change mitigation (ex-early warning)
13.A Implement and fully operationalize the Green Climate Fund.
13.B Raise capacity for effective climate change-planning and management in least developed countries and small island nations including focusing on women, youth and local and marginalized communities

Global Health Policy Issues 2019



ANAC
Association of Nurses in AIDS Care

Global Health Policy Issues 2019

ANAC
Association of
Nurses in AIDS Care

Global Health Policy Issues 2019

ANAC Association of Nurses in AIDS Care

Support a strong global nursing workforce

90-90-90*

Ambitious targets require greater investments in nursing

JULY 2016

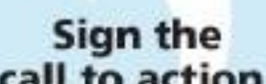
Join us and sign the call to action now!

nursesinaidscare.org/signthecall

* 90-90-90 refers to UNAIDS HIV treatment goals to end the AIDS epidemic globally, released in 2014: By 2020, 90% of all people living with HIV (PLWH) will know their HIV status; 90% of all people with diagnosed HIV will receive sustained antiretroviral therapy (ART); and 90% of all people on ART will have viral suppression.

Access. Equity. Rights.

Demand greater investments in **NURSING**



Sign the call to action

nursesinaidscare.org/signthecall

Access
Improving access to healthcare by removing political, legal and economic barriers to nurse-led care

Equity
Building sustainable solutions by requiring equitable representation of nurses on policy, guidelines and other decision making bodies

Rights
Demanding an end to HIV stigma, discrimination and unjust HIV criminalization

Nurses:

Ensure patients' rights to equitable, accessible health care

Represent 80% of the global healthcare workforce

Provide care for underserved and vulnerable populations

Provide evidence-based person-centered HIV care

Provide care along the full HIV care continuum

Are central to achievement of ambitious HIV prevention, care and treatment targets

We call for:

- Policy changes to support nurse-led care
- Greater investments in nursing
- Support for interprofessional collaboration
- Equity in decision making

Nurses:

Ensure patients' rights to equitable, accessible health care

Represent 80% of the global healthcare workforce

Provide care for underserved and vulnerable populations

Provide evidence-based person-centered HIV care

Provide care along the full HIV care continuum

Are central to achievement of ambitious HIV prevention, care and treatment targets

We recognize that

- Nurse-led care is effective and evidence based.
- Health policies and legislation have not kept pace with the vital role of nurses.
- Ambitious targets require investments in the nursing workforce, nursing education and research.
- Nurses are under represented on decision making bodies, global HIV task forces, policy and guidelines committees.

Therefore we call for

- Advancing nurse-led care through policies and legislation that support nurses' true role in HIV prevention, care and treatment.
- Resources, budget allocation and staffing structures that reflect the central role of nursing to HIV care and achievement of 90-90-90.
- Health systems that ensure strong interprofessional collaboration.
- Equitable representation of nurses on healthcare and HIV decision making bodies.

Global Gag Rule (Mexico City policy)

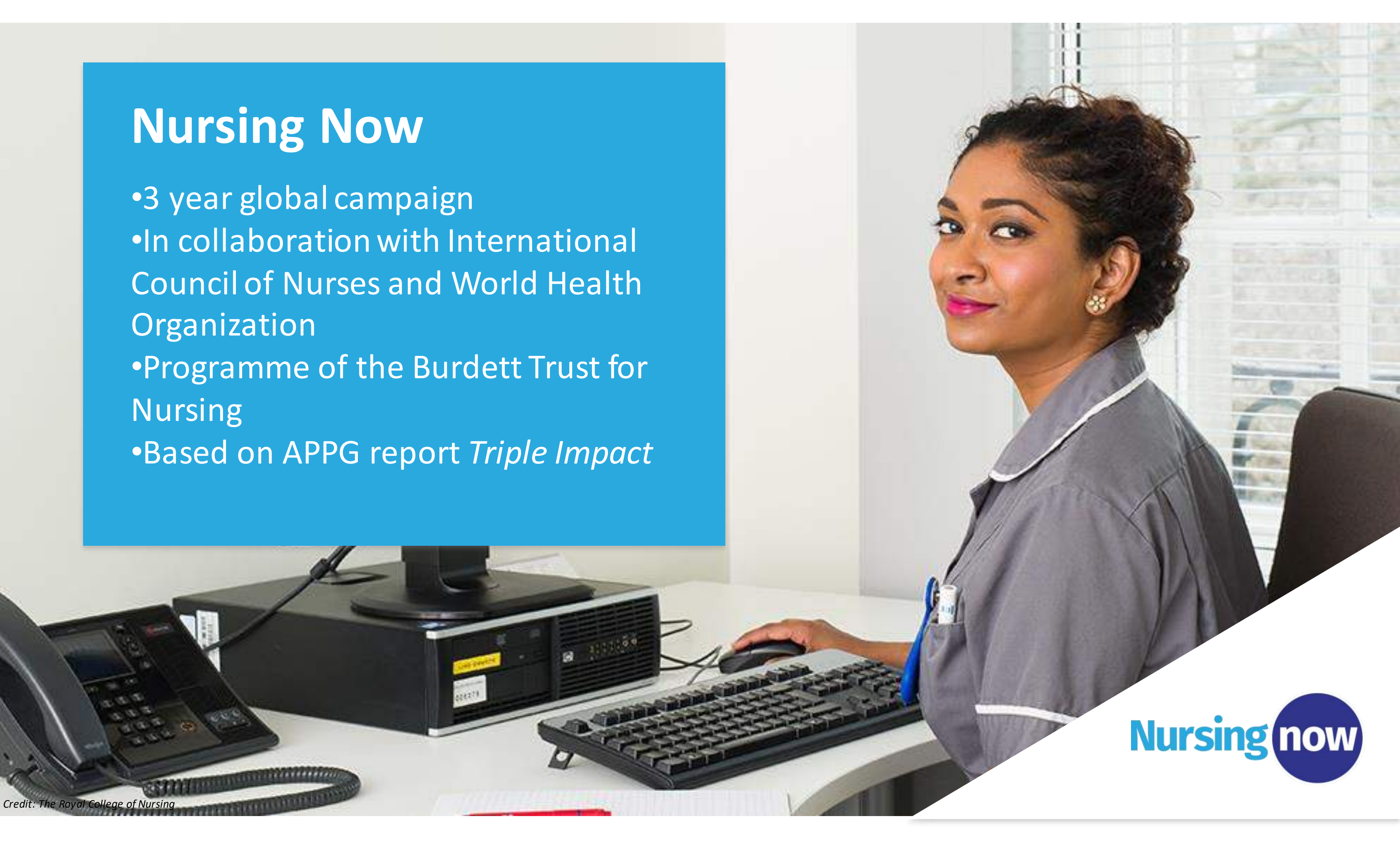
ANAC
Association of
Nurses in AIDS Care

Nurses Roles in Human Rights & Advocacy: Change Agents

- Educate yourself
- Join a nursing organization
- Participate in coalitions
- Represent the nursing perspective
- Advocate for your patients
- Partner with PLWHA (or other patient groups)
- VOTE

Nurses Roles in Human Rights & Advocacy: Actions

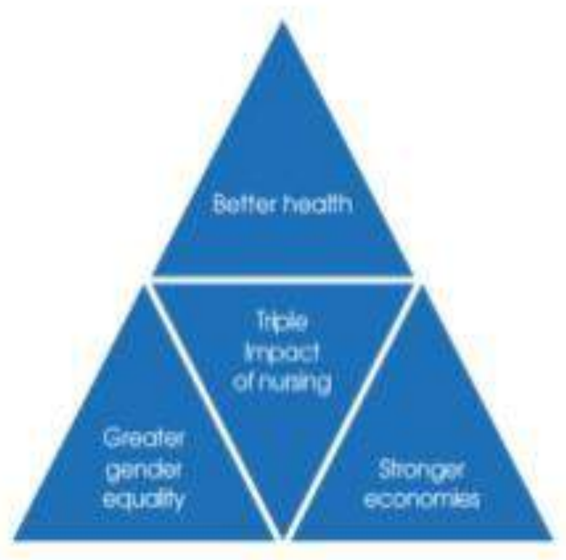
- Community and Family Discussions
- School & Church Activities
- Letters to Editors
- Expert Testimony
- Legislative Visits
- Court Actions
- Local and National Boards
- Social Media


Nursing Now
•3 year global campaign
•In collaboration with International Council of Nurses and World Health Organization
•Programme of the Burdett Trust for Nursing
•Based on APPG report *Triple Impact*
Nursing now
Credit: The Royal College of Nursing

Nursing Now: Triple Impact

Triple Impact

All-Party Parliamentary Group on Global Health



All-Party Parliamentary Group on Global Health

Campaign vision
To improve health globally by raising the profile and status of nurses worldwide.
Influencing policymakers and supporting nurses to lead, learn and build a global movement.
Nursing now
Credit: The Royal College of Nursing

Nursing Now 5 Tactics

- Ensure that nurses and midwives have a more prominent voice in health policy-making
- Encourage greater investment in the nursing workforce
- Recruit more nurses into leadership positions
- Conduct research that helps determine where nurses can have the greatest impact
- Sharing of best nursing practices

Nursing now

21-22 September 2019 • Rome, Italy

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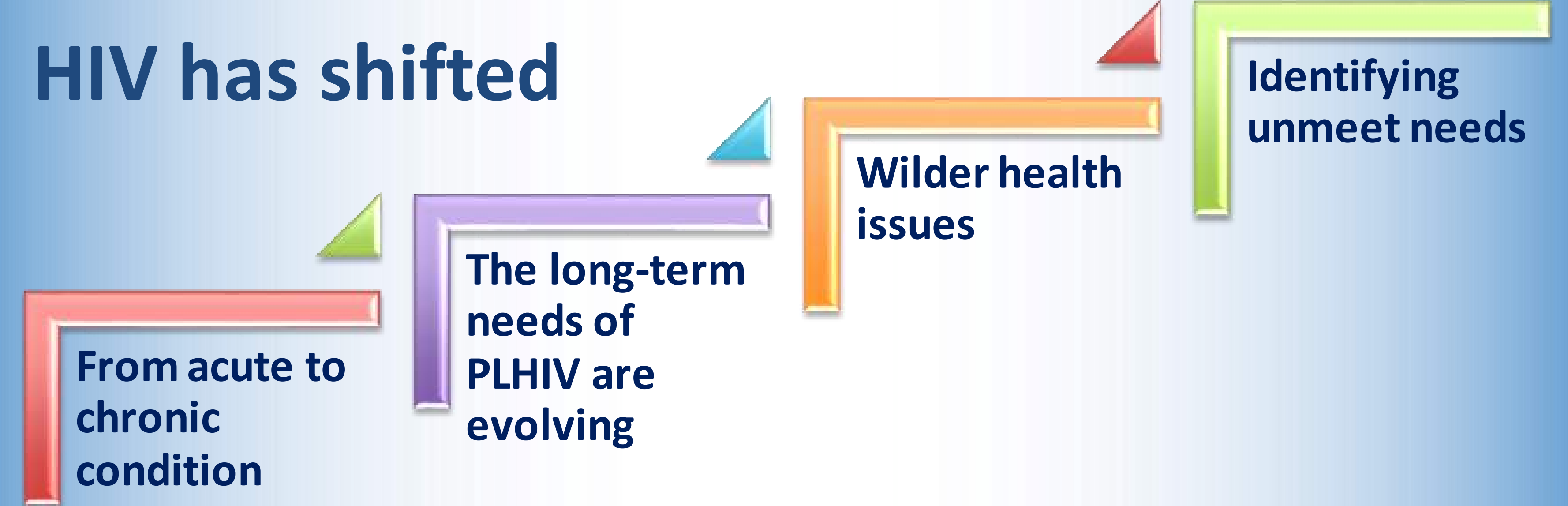
Evolution in Progress
Nurse leadership in developing innovative models of care

Catarina Esteves,
Cascais Hospital - Portugal

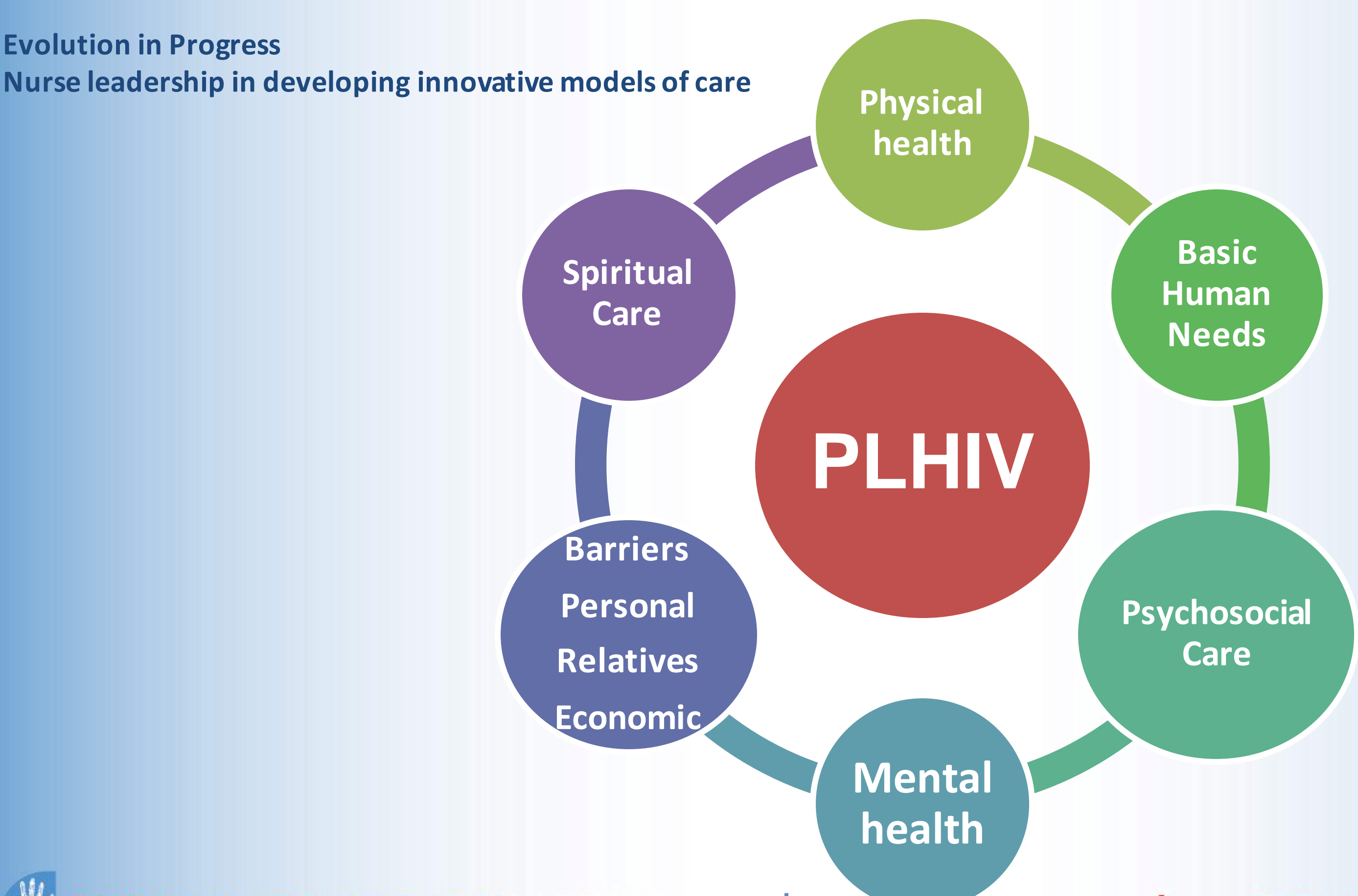
HIV has shifted



References: WHO, 2015. Draft global health sector strategy on HIV, 2016-2021

Beyond viral load

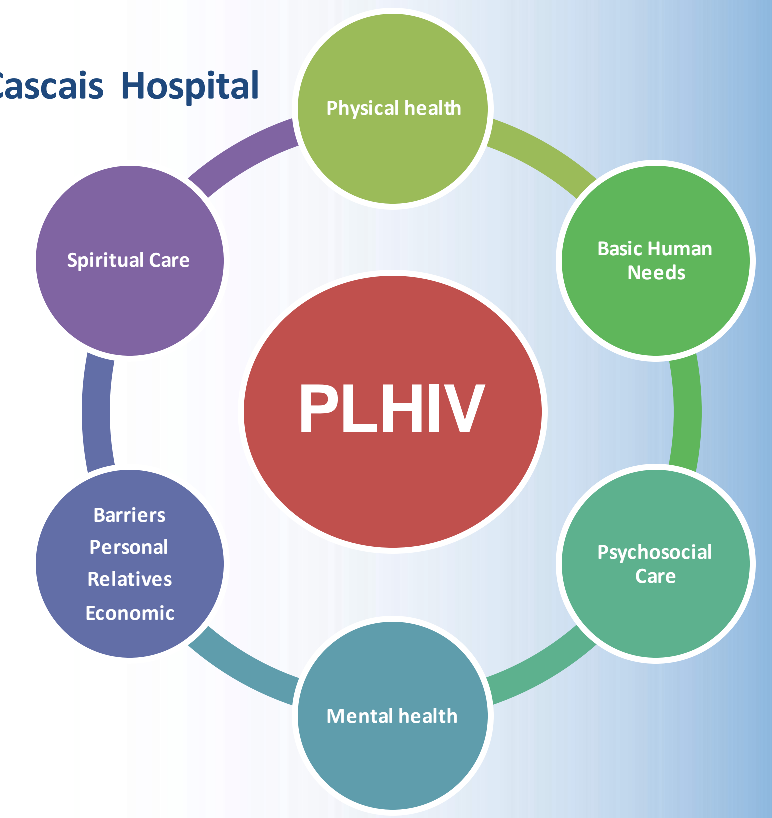
- Holistic Care


Evolution in Progress
Nurse leadership in developing innovative models of care
Physical health
Basic Human Needs
Psychosocial Care
Mental health
Barriers
Personal
Relatives
Economic
Spiritual Care
PLHIV

Evolution in Progress
Nurse leadership in developing innovative models of care

Nursing Consultations in Cascais Hospital

- 1st Nurse Appointment
- During hospitalization / pre-discharge
- Adherence
- Programmed output – prisons
- Silver: 50 +
- Shared care
- Therapeutic procedures
- Unscheduled
- Disclosure of the diagnosis
- Rapid Test
- Surveillance of missed appointments
- Post Exposure Prophylaxis



Prevention

Prioritize high-impact interventions targeting populations most vulnerable to HIV infection with:

- Promotion and access to condoms
- Pre-Exposure Prophylaxis (PrEP)
- Post-Exposure Prophylaxis (PPE)
- Harm reduction "Say No to a Second Hand Syringe”

REFERENCES:
- National Program for HIV and AIDS in Portugal, PROGRAMA NACIONAL PARA A INFEÇÃO VIH E SIDA. Ministério da Saúde. Direção-Geral da Saúde. **Infeção VIH e SIDA I Desafios e Estratégias 2018**. Lisboa, 2018. Available in: https://www.sns.gov.pt/wp-content/uploads/2018/07/RelatorioVIH_SIDA2018.pdf

Evolution in Progress
Nurse leadership in developing innovative models of care

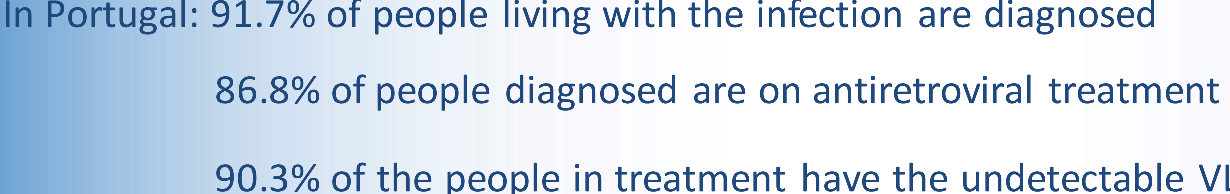
Screening, Diagnosis and Referral

- Early diagnosis of HIV infection - **availability of the rapid test** in Primary Health Care, Centers for HIV Counseling and Early Detection, Community Based Screening, Specialty Hospital Consultations, and Community Pharmacies.
- Model of treatment for the **prison population** living with HIV and HCV infection: movement of hospital health professionals to prisons, in order to provide hospital health care to the prison population.

REFERENCES:
- National Program for HIV and AIDS in Portugal, PROGRAMA NACIONAL PARA A INFEÇÃO VIH E SIDA. Ministério da Saúde. Direção-Geral da Saúde. **Infeção VIH e SIDA I Desafios e Estratégias 2018**. Lisboa, 2018. Available in: https://www.sns.gov.pt/wp-content/uploads/2018/07/RelatorioVIH_SIDA2018.pdf

Screening, Diagnosis and Referral

- Goals 90-90-90 (UNAIDS)



In Portugal: 91.7% of people living with the infection are diagnosed

86.8% of people diagnosed are on antiretroviral treatment

90.3% of the people in treatment have the undetectable VL

- **"Cities on the Fast Track to End the HIV Epidemic"**:

Cascais, Lisbon, Oporto and Amadora/Sintra are Fast Track Cities

REFERENCES:
- National Program for HIV and AIDS in Portugal, PROGRAMA NACIONAL PARA A INFEÇÃO VIH E SIDA. Ministério da Saúde. Direção-Geral da Saúde. **Infeção VIH e SIDA I Desafios e Estratégias 2018**. Lisboa, 2018. Available in: https://www.sns.gov.pt/wp-content/uploads/2018/07/RelatorioVIH_SIDA2018.pdf

Patient-centered care allows:

- Better understanding of broader health issues affecting PLHIV
- PLHIV to be co-responsible in the care process and active in health gains
- Facilitate resource allocation more effectively and justify spending
- Promotion of continuity of care, connection and retention of health care
- Promote behavioral values of the recovery process, reintegration, improve the results and the quality of health care.
- Focus of interventions in health promotion, disease prevention and health gains in the person as a whole, inserted in the family and community.

We are

Thank you

Catarina Esteves
catarina.esteves.santos@hospitaldecascais.pt

21-22 September 2019 • Rome, Italy

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The future of Nurses in HIV

Catarina Esteves
Cascais Hospital - Portugal

What role do nurses play in HIV care?

What are the benefits of nurses in HIV care?

The future of Nurses in HIV

For the healthcare system to know how best to use nurses in HIV care, it is important to understand the role played by nurses and its impact.

References:

1. Tunnidiff SA, Piercy H, Bowman CA, Hughes C, Goyder EC. The contribution of the HIV specialist nurse to HIV care: A scoping review. Journal of Clinical Nursing 2013;22(23-24):3349- 60.
2. Position statement: Advanced practice registered nurses full practice authority. Journal of the Association of Nurses in AIDS Care 2014;25(5):465-7.
3. Ding L, Landon BE, Wilson IB, Hirschhorn LR, Marsden PV, Cleary PD. The quality of care received by HIV patients without a primary provider. AIDS Care 2008;20(1):35-42.
4. World Health Organization. Task shifting: Rational redistribution of tasks among health workforce teams: Global recommendations and guidelines. Available at: http://www.who.int/healthsystems/TTR-TaskShifting.pdf. Geneva: World Health Organization; 2007.
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6. Mdege ND, Chindove S, Ali S. The effectiveness and cost implications of task-shifting in the delivery of antiretroviral therapy to HIV-infected patients: A systematic review. Health Policy and Planning 2013;28(3):223-36.
7. Kredo T, Adeniyi FB, Bateganya M, Pienaar ED. Task shifting from doctors to non-doctors for initiation and maintenance of antiretroviral therapy. Cochrane Database of Systematic Reviews 2014;7.
8. Wilson IB, Landon BE, Hirschhorn LR, McInnes K, Ding L, Marsden PV, et al. Quality of HIV care provided by nurse practitioners, physician assistants, and physicians. Annals of Internal Medicine 2005;143(10):729-36.
9. Jones-Parker H. Primary, secondary, and tertiary prevention of cardiovascular disease in patients with HIV disease: A guide for nurse practitioners. Journal of the Association of Nurses in AIDS Care 2012;23(2):124-33.

Present – What is done:

- Nurses are already providing a significant amount of HIV care.
- High levels of experience, a focus on a single condition, and either participation in HIV care teams or other easy access to physicians with HIV expertise may be key factors in the high performance scores among nurse practitioners.
- As people with HIV live longer, all providers – including nurse practitioners - will be caring for patients with comorbidities and more complex clinical issues.

Present – What is done:

- Nurses are change agents, have the role of educator
- Nurses have valuable insights and unique abilities to contribute as partners with other health care professionals in improving the quality and safety of care
- Sensitize the contribution of quality nursing care and scientific value and delivered to a high standard of care provided by nurses

Future -> What can be done:

- Tackling stigma and discrimination is undoubtedly a complex and ongoing work. We, as nurses, as health educators, can and should take advantage of this challenge
- Training all health professionals: standardize language and practice care for better and universal care

Future -> What can be done:

- Nurses should be fully engaged with other health professionals and assume leadership roles in redesigning care and national/ international guidelines in HIV care
- Uniting Nurses working in caring for people infected and affected by HIV (prison, addiction teams, primary health care, palliative care, home care…)

We are

Thank you

Catarina Esteves
catarina.esteves.santos@hospitaldecascais.pt

21-22 September 2019 • Rome, Italy

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Pick and Mix:
Sympathy, Empathy, Compassion
Communication between HCP and Patients
Christina Antoniadi, RN, Chelsea and Westminster Hospital NHS Foundation Trust
Damian Kelly, Patient Advocacy Alliance
HIV NURSING CONFERENCE | 21-22 September 2019 • Rome, Italy

Disclosures

- All views are our own

Welcome
HIV NURSING CONFERENCE | 21-22 September 2019 • Rome, Italy

Step 1: Define

- Please split into 3 groups
- A word will be given to you
- Work as a group to come up with a definition
- You have 5 minutes!!!!
- Present your work to the whole group

Step 2: Analyse

- Please work within your group while you read through the case study
- Complete the paper in front of you as you go along
- Select one representative per table
- You have 15 minutes

Step 3: Family meeting

- What is the role of the nurse?
- Who is acting as the patients' advocate?
- Patient outcomes in person-centred care

What would you need to change in your own practice?
HIV NURSING CONFERENCE | 21-22 September 2019 • Rome, Italy

THANK YOU

- Christina Antoniadi, Chelsea and Westminster Hospital NHS Foundation Trust
Christina.Antoniadi@nhs.net
- Damian Kelly, Patients Advocacy Alliance
damian@patientadvocacyalliance.com

Photo credits: Viktor Talashuk and Analia Baggiano

References

- **Sympathy**: implies a desire, almost an urge, to help or aid an individual in order to relieve his distress. Travelbee, 1964
- **Empathy:** is to perceive the internal frame of reference of another with accuracy and with the emotional components and meanings which pertain thereto as if one were the person, but without ever losing the "as if" condition. Carl Rogers, 1957
- **Compassion:** A deep awareness of the suffering of another coupled with a wish to relieve it. Chochinov, 2007

21-22 September 2019 • Rome, Italy

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IN PARTNERSHIP WITH:

Women living with HIV in Clinical Research

Christina Antoniadi, RN, Chelsea and Westminster Hospital
NHS Foundation Trust
Co-opted member of the NHIVNA Executive Committee

Disclosures

- All views are my own.
- This presentation is based on the research of others.

What we know

Every cell has a sex, and all bodies are influenced by gender. Integrating these factors into medical education, training and clinical practice will improve health care for all.

Sex and Gender Women's Health Collaborative http://sgwhc.org/

What we know

TED Ideas worth spreading WATCH DISCOVER

Alyson McGregor | TEDxProvidence

Why medicine often has dangerous side effects for women

Share

Add to list

Like

Recommend

ALYSONMCGREGOR

15:16

September 2014

Dr. Alyson McGregor

Sex and Gender Women's Health Collaborative

A couple of questions:

- Are there different signs of heart attack in men and women?

- Which are they?

What we know

Discomfort or tingling in arms, back, neck, shoulder or jaw

Most common IN MEN...

Chest pain

Shortness of breath

Watch for THE SIGNS

Sudden dizziness

Heartburn-like feeling

Additional symptoms, most common IN WOMEN...

Cold sweat

Nausea or vomiting

Unusual tiredness

The Heart foundation: https://theheartfoundation.org/2017/03/29/heart-attack-men-vs-women/

What we know

PubMed
US National Library of Medicine
National Institutes of Health

Advanced

Format: Abstract

Menopause. 2019 Sep 9. doi: 10.1097/GME.0000000000001412. [Epub ahead of print]

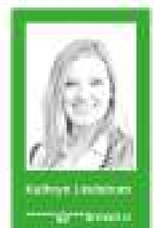
Statin therapy: does sex matter?

Faubion SS[1,2], Kapoor E[1,2,3], Moyer AM[4], Hodis HN[5], Miller VM[6]

CONCLUSIONS:
Many of the trials that have established the efficacy and safety of statins were conducted predominantly or entirely in men, with results extrapolated to women. **Additional research is needed** to guide clinical recommendations specific to women.

Key points

- When it comes to CVD, a typical presentation may not be accurate for half of the population
- In CVD, sex and gender differences contribute to a lower perceived risk of morbidity in women than in men
- A typical presentation of CVD must be further defined to include the sex that it describes
- We need to reclassify typical and atypical presentations of CVD as this terminology contributes to bias that may lead to incorrect diagnoses



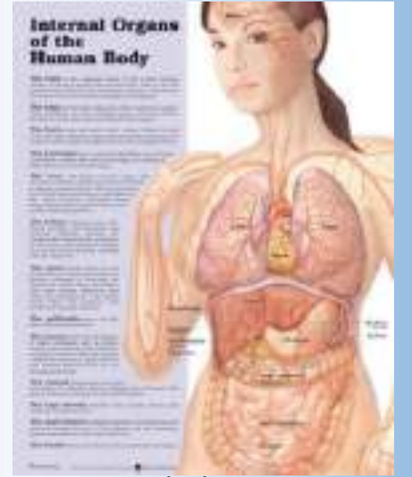
HealthManagement, Volume 19 - Issue 4, 2019

Sex & Gender Impacts in Cardiovascular Disease: A "Typical" Presentation of Cardiovascular Disease?

Share

Are there differences?

- **Biological Differences:**
- Hormonal profile: affects the absorption, binding and distribution of medication
- Smaller organs: affects the metabolism and elimination
- More % fat: affects distribution
- Varying plasma volume: affects distribution
- **Socio-economic differences:**
- Costs (time off work, child care, travel expenses)
- Knowledge + Referral
- Recruitment from appropriate sites
- Child bearing potential
- Carer duties



Anatomical Chart Company

Women living with HIV worldwide

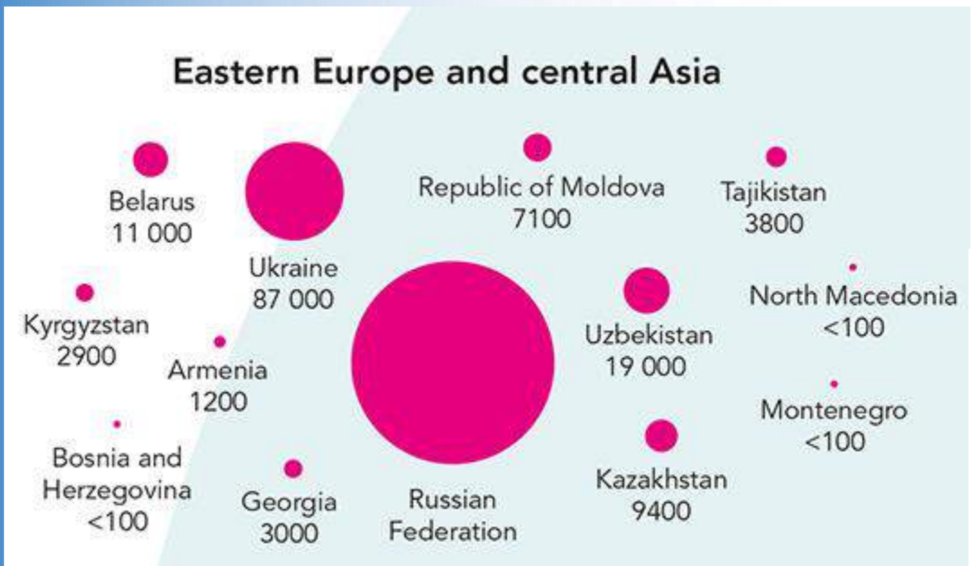
19.6 MILLION GIRLS AND WOMEN LIVING WITH HIV

Global 19 600 000

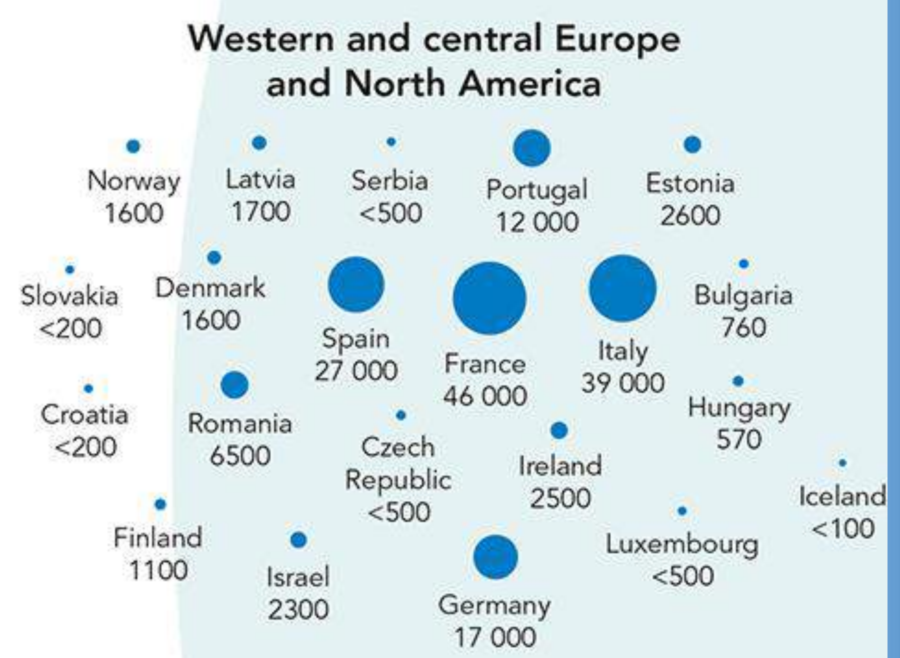
UNAIDS

UNAIDS: 37.9 million [32.7 million–44.0 million] people globally were living with HIV in 2018

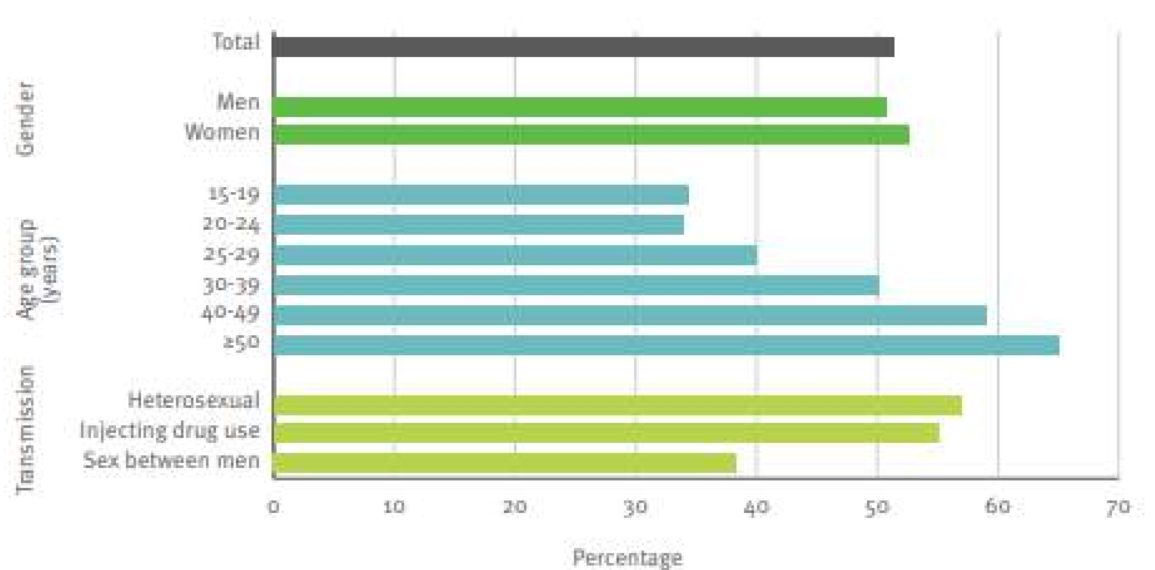
UNAIDS: Infographics, 09/2019



UNAIDS: Infographics, 09/2019



Late presenters



ECDC – WHO HIV/AIDS surveillance in Europe 2018 - 2017 data

HIV : leading cause of death in women

EASTERN EUROPE AND CENTRAL ASIA

New HIV infections (all ages)

New HIV infections among young people (15-24) - by sex

AIDS-related illnesses are the leading cause of death among 15–49-year-old females globally (hundred thousands)

Cause	Deaths (hundred thousands)
HIV	302.7
Maternal conditions	298.2
Ischaemic heart disease	182.3
Self-harm	164.1
Road injury	154.5
Tuberculosis	152.4
Stroke	143.4
Breast cancer	140.9
Cirrhosis of the liver	89.2
Diarrhoeal diseases	87.1

Source: Global health estimates 2016: deaths by cause, age, sex, by country and by region, 2000–
Geneva, World Health Organization; 2018.

Of every five new HIV infections among young people (15–24 years), three are among young women.

UNAIDS (2019) ‘Women and HIV — A spotlight on adolescent girls and young women

HIV Specific research

EATG

Representation of Women and Pregnant Women in HIV Research: A Limited Systematic Review

- 38% of study participants were women
- 81% of studies did not mention pregnancy
- 4% of participants were pregnant

2011

EATG

A Systematic Review of the Inclusion (or Exclusion) of Women in HIV Research: From Clinical Studies of Antiretrovirals and Vaccines to Cure Strategies

Women represented 23% of participants in 544 studies

2016

EATG

WOMEN'S PARTICIPATION BY TYPE OF HIV RESEARCH

Antiretroviral therapy
Vaccination
Cure
0% 20% 40% 60% 80% 100%
Female Male

Dr. Shema Tariq, 2018

Barriers and opportunities

Conclusions

- The number of women in trials is still disproportionate to that of men.
- Higher incidence of women participating in observational rather than interventional trials.
- Lack of information available
  - Recruited v Enrolled

Recommendations

- Women's needs can no longer be ignored.
- Hard Paternalism / Over protectionism is no longer a tenable position.
- Need for legislative changes which push for greater inclusion of women.
- Further research on additional barriers

M.J.Rapa et al., The participation of women living with HIV EATG 2018

Where are we now?

- **GRACE Study**: A Study to Compare the Effectiveness, Safety and Tolerability of PREZISTA (Darunavir)/Ritonavir by Gender and Race When Administered With Other Antiretroviral Medications in Human Immunodeficiency Virus (HIV) Positive Women and Men. (First results 2010) **67% women participants**

- **PRIME Study** - Positive transitions into the menopause : To explore the impact of the menopause on health and wellbeing of women living with HIV. (First results 2018)

- **ECHO Study**: Evidence for Contraceptive options and HIV Outcomes (first results 2019)

Is it a movement?

- **HIV activism**: research led by the needs of PLWHIV, Patient experts participating in research boards and as protocol reviewers
- **How many women among them?**
- **Is research relevant to women? Is it guided by their needs?**
- **Are protocols being developed to include women?**

- **Women's groups**: Sophia Forum, Women's Action Group (Gilead), SWIFT, WAVE, International Community of Women living with HIV, Salamander Trust

Next steps

Women's Involvement In Research

WiiR

Patients Advocacy Alliance

A training program open to activists who want to develop their knowledge about participation in clinical trials. Priority will be given to women (cis and trans) with an aim of 75% participation to the training.

References

- Faubion S'S et al, "Statin therapy: does sex matter?", Menopause, 2019 Sep 9. doi: 10.1097/GME.0000000000001412
- Kathryn Lindstrom and Theresa Rohr-Kirchgraber "Sex & Gender Impacts in Cardiovascular Disease: A "Typical" Presentation of Cardiovascular Disease?", HealthManagement, Volume 19 - Issue 4, 2019
- UNAIDS (2019) Infographics https://www.unaids.org/en/resources/infographics/girls-and-women-living-with-HIV
- **ECDC – WHO (2018) Regional Office in Europe "HIV/AIDS surveillance in Europe 2018 - 2017 data"**
- UNAIDS (2019) 'Women and HIV — A spotlight on adolescent girls and young women'
- **Westreich D et al, "**Representation of Women and Pregnant Women in HIV Research: A Limited Systematic Review", PLoS One. 2013; 8(8): e73398
- Curno MJ et al, "**A Systematic Review of the Inclusion (or Exclusion) of Women in HIV Research: From Clinical Studies of Antiretrovirals and Vaccines to Cure Strategies",** J Acquir Immune Defic Syndr. 2016 Feb 1;71(2):181-8. doi: 10.1097/QAI.0000000000000842
- **Solomon D et al, "Cardiovascular disease in women living with HIV: A narrative review",** Maturitas. 2018 Feb;108:58-70. doi: 10.1016/j.maturitas.2017.11.012. Epub 2017 Nov 14
- **M.J.Rapa et al., The participation of women living with HIV EATG 2018**
- **Currier J et al, "Sex-based outcomes of darunavir-ritonavir therapy: a single-group trial",** Ann Intern Med. 2010 Sep 21;153(6):349-57. doi: 10.7326/0003-4819-153-6-201009210-00002
- **Tariq S et al, "**The menopause transition in women living with HIV: current evidence and future avenues of research.", J Virus Erad. 2016 Apr; 2(2): 114–116
- Evidence for Contraceptive Options and HIV Outcomes (ECHO) Trial Consortium, "HIV incidence among women using intramuscular depot medroxyprogesterone acetate, a copper intrauterine device, or a levonorgestrel implant for contraception: a randomised, multicentre, open-label trial", The Lancet June 13, 2019DOI:https://doi.org/10.1016/S0140-6736(19)31288-7

Acknowledgements

- **Dr. Alyson McGregor**, MD, MA, FACEP, Associate Professor of Emergency Medicine Brown University, Co-Founder and Director for the Division of Sex and Gender in Emergency Medicine (SGEM), Co-Founder and Past Vice Chair of the organization Sex and Gender Women's Health Collaborative
- **UNAIDS**, infographics and data analysis
- **Dr. Shema Tariq**, postdoctoral clinical research fellow and honorary consultant HIV physician, Institute for Global Health, University College London
- **Mark Josef Rapa**, LL. D LL.M Healthcare Ethics and Law, University of Manchester
- **Damian Kelly**, Patients Advocacy Alliance

Thank you

Christina Antoniadi, RN

Chelsea and Westminster Hospital NHS Foundation Trust

Co-opted member of the NHIVNA Executive Committee

Contacts Details: Christina.Antoniadi@nhs.net

https://youtu.be/ahONORctR8k

Multidisciplinary HIV Family-Carousel

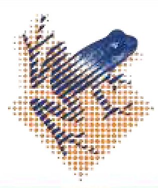
a Best Practice in HIV-Family Care at UMCG Groningen, the Netherlands

Dorien de Weerd
MANP – Nurse Practitioner
Infectious Diseases/HIV

University Medical Center Groningen

Content

- Introduction
- Some facts
- HIV in the Netherlands
- Pregnancy in HIV-infected women
- HIV care for asylumseekers
- Carousel consultation
- Strengths and challenges
- Take Home message



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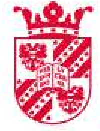
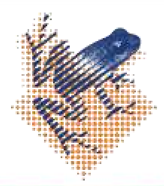
Paraguay
Botswana
Mozambique
New Caledonia
Australia
Chile
eSwatini
Lesotho
Uruguay
South Africa
New Zealand

The Netherlands

20.000 new asylumseekers in 2018
≈ 20% women *(CBS, IND 2019)*
60% pregnant of all women arriving in asylumcenters; mostly sub-Saharan African women, aged 20-24 yrs.
(GGD/Rutgers 2018)





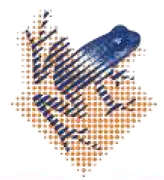
University Medical Center Groningen

HIV facts of the Netherlands

2018:
25.291 individuals diagnosed with HIV-1 (as adults):
70% men who have sex with men (MSM)
14% other men
16% women (heterosexually acquired)

Pregnant HIV+ women:

- Decline over time
- Universal first trimester screening (opt-out) since 2004
- 18% Dutch, 82% non Dutch



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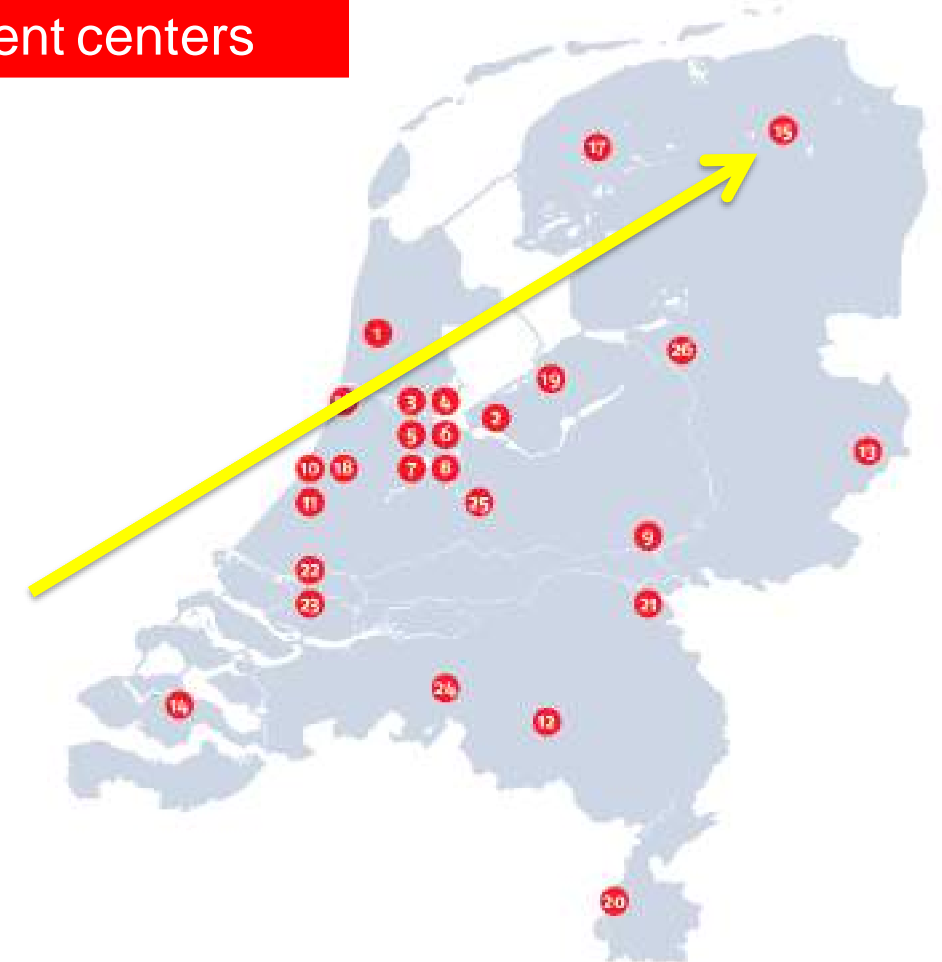
26 HIV treatment centers

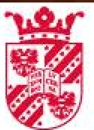


1) Noordwest Ziekenhuisgroep, 2) Flevoziekenhuis, 3) Academisch Medisch Centrum-Universiteit van Amsterdam (per juni 2018, Amsterdam UMC, locatie AMC), 4) DC Klinieken Lairesse - Hiv Focus Centrum, 5) OLVG, 6) MC Slotervaart, 7) Medisch Centrum Jan van Goyen, 8) VUmc (per juni 2018, Amsterdam UMC, locatie VUmc), 9) Rijnstate, 10) HagaZiekenhuis (locatie Leyweg), 11) HMC, 12) Catharina Ziekenhuis, 13) Medisch Spectrum Twente, 14) Admiraal De Ruyter Ziekenhuis, 15) Universitair Medisch Centrum Groningen, 16) Spaarne Gasthuis, 17) Medisch Centrum Leeuwarden, 18) Leids Universitair Medisch Centrum, 19) MC Zuiderzee, 20) Maastricht UMC+, 21) Radboudumc, 22) Erasmus MC, 23) Maasstad Ziekenhuis, 24) ETZ, 25) Universitair Medisch Centrum Utrecht, 26) Isala

HIV Monitoring

Groningen

UNIVERSITAIR MEDISCH CENTRUM GRONINGEN



university of groningen

University Medical Center Groningen

Facts

Ter Apel

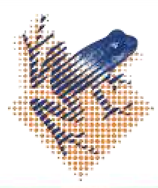
Groningen

Headquarter of the Immigration-Naturalization Service (IND)

Challenges in immigrant(pregnant) women

- Pregnant women with HIV are prone to many problems

Transmission
Fear
Crisis
No social network



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HIV-care for pregnant women & their families

- Referral by midwife
- Coordination by HIV Nurse Practitioner
- Carousel consultation

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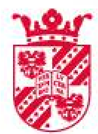
The Carousel

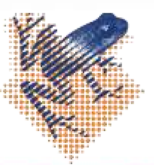
Pediatrician/pediatric hiv-nurse

NP HIV / ID-specialist

Gynaecologist

Social worker obstetric care





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The schedule

Time	NP/ ID specialist	gynaecologist	Pediatric ID-specialist hiv pediatric nurse	Social Worker obstetric care
10:00am	**Rose** *pregnant*	**Grace** *pregnant*		**Joy** *post partum*
10:30am	**Grace** *pregnant*	**Rose** *pregnant*	**baby Joy**	
11:00am	**Joy** *post partum*		**Rose** *pregnant*	**Grace** *pregnant*
11:30am		**Joy** *post partum*		**Rose** *pregnant*

Carousel meeting afterwards; registration of medical/psychosocial needs

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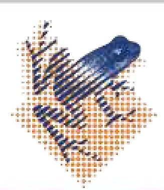
Strengths

- Short lined structure
- Dedicated team, frequent interaction with patient

Challenges

- Transfer of Care
- Medical Services Asylum seekers



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Take Home message

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Advanced Nursing Practice

Evolution in Progress: Nurse Leadership in Developing Innovative Models of Care

Gerjanne ter Beest,
RN, MSc, MANP

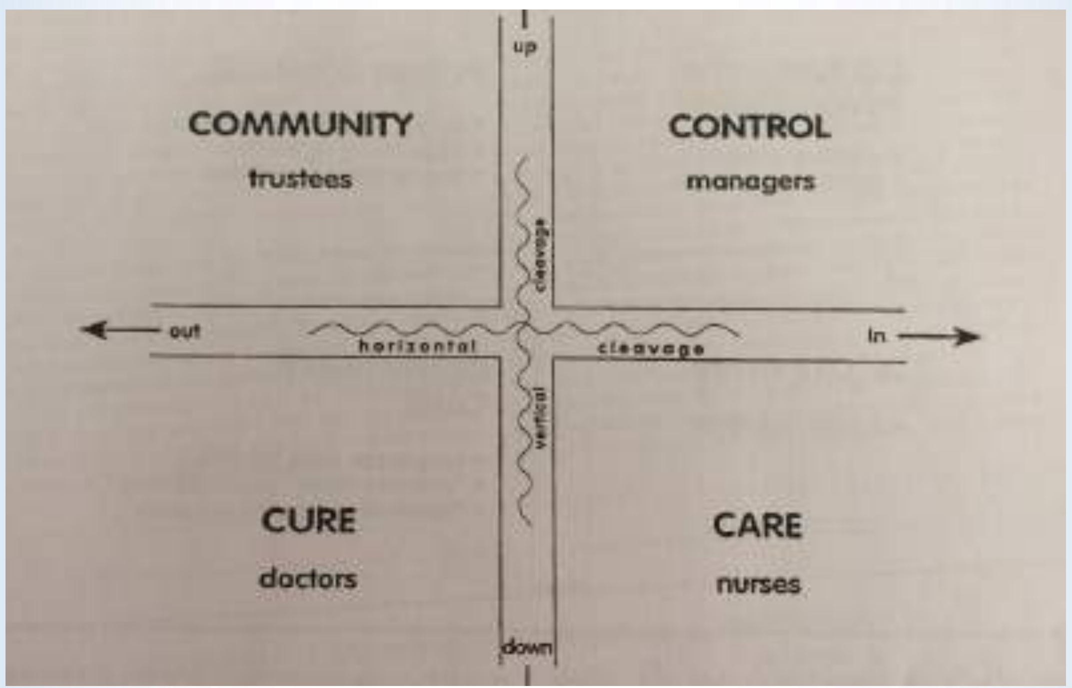
Florence Nightingale (1820 – 1910)

Nursing is a profession based on knowledge, obtained after thorough training. The relationship between a doctor and nurse is not a subordinate one but an equal one

Domain battle between doctor – nurse (±1850)

Doctors needed the nurses, but were not used to deliberating on an equal footing. Doctors linked nurses to the domain of medicine, instead of the profession of nursing. In the domain of medicine, nurses were forced into a position of a servitude and dependency

Nursing en managers



Invisible work (Allen)

Nursing Practice
Research
Professional identity

Much of the work nurses do is unseen. Recognition of this work would help shape education and practice, and ensure society has an accurate view of the profession

Making visible the unseen elements of nursing

In this article...
- Views about nurses and nursing
- The key elements of organising work
- How organising work impacts on healthcare

5 key points

1. The societal image of nurse as caregiver needs to be revised
2. Nurses carry out organising work, which is vital to good-quality healthcare
3. Little is known about organising work and nurses can

Hiv and nursing

HIV care in the Netherlands

HIV nursing care in the Netherlands

- HIV nurses (RN, BN)
- Nurse Practitioners (RN, BN, MANP), since 2018 independant practitioner (by law)

HIV nursing care in the Netherlands

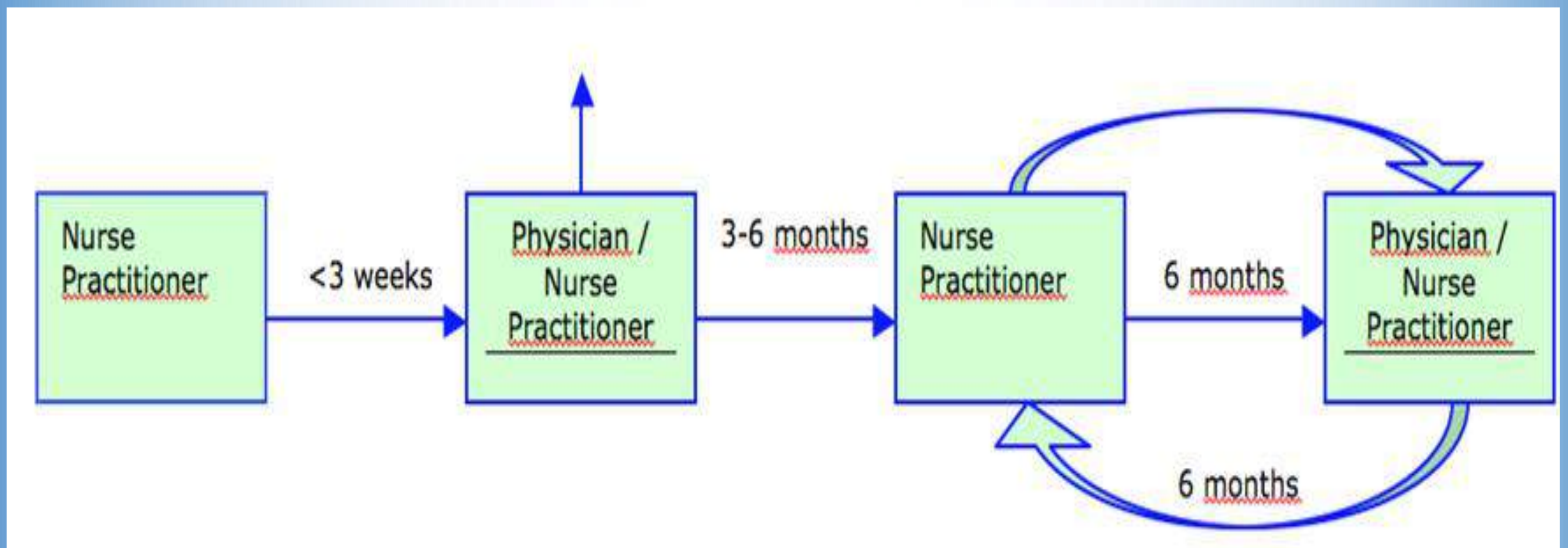
2018 Research on task distribution between

Nurse – NP – Physician in HIV treatment centers

- Nurse - NP: overlap in daily work / invisible work
- Physician - NP: diagnose / prescribing medication / physical examination

HIV nursing care in Arnhem

HIV nursing care in Arnhem



Lesson learned

We have to work on:

- Nursing Leadership
- Visibility

Thank you

Gerjanne ter Beest, RN, MSc
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Dutch society of HIV nursing
gterbeest@rijnstate.nl

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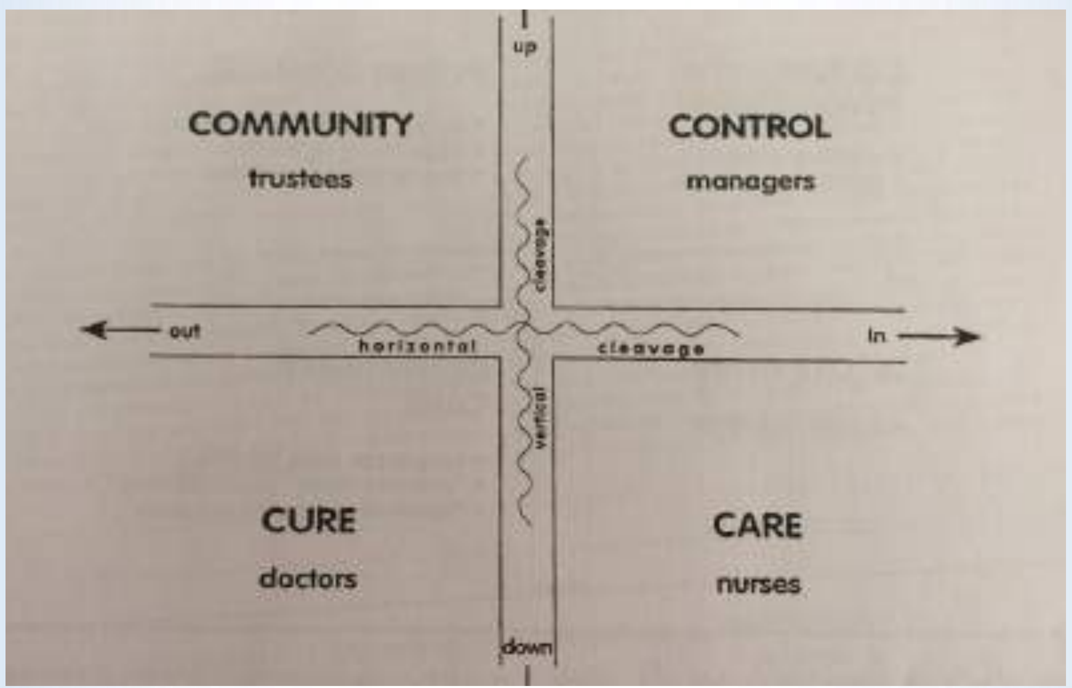

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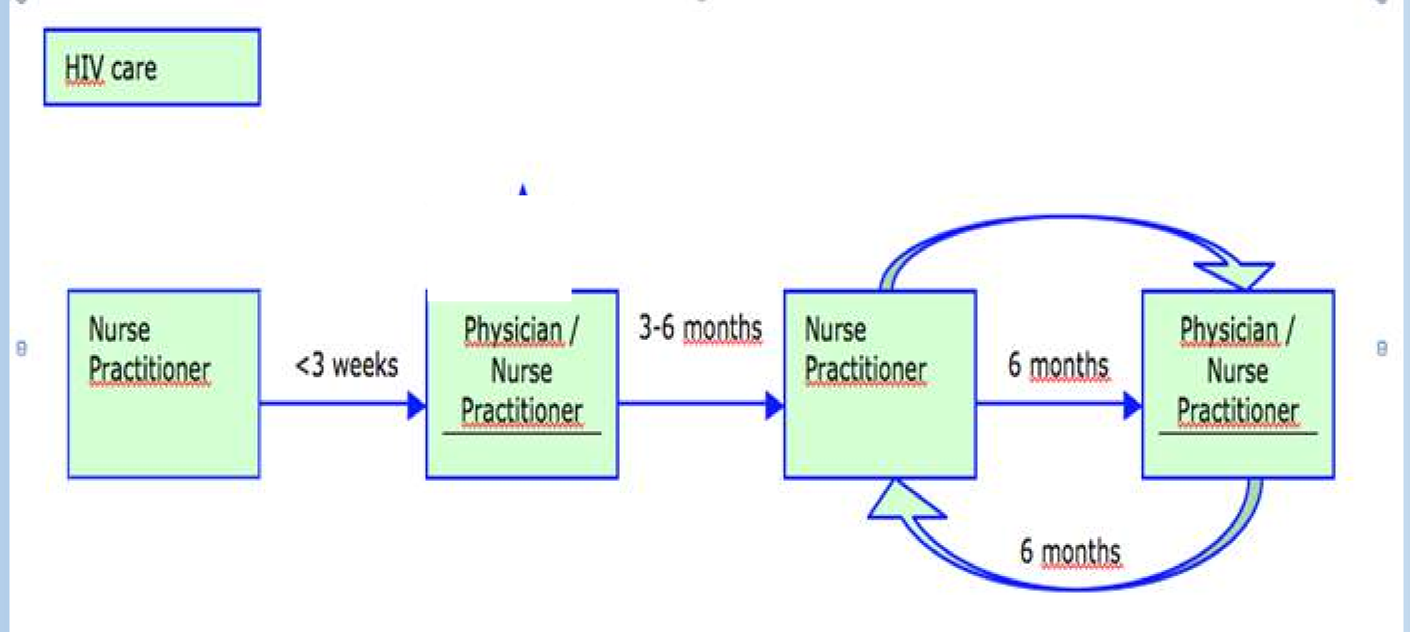

What about you in your daily practice?

1. Can you describe/quantify your value as an hiv nurse?
2. Do you have influence in the areas of treatment, care, policy? What are your limitations?
3. What are the challenges for you?
4. What do you want to develop; in skills, knowledge, care, policy…..

Summary

Munition, strength, power

- Nursing leadership
- Measuring, monitoring, researching
- Networking
- Sharing knowledge, experiences
- Joint ventures?

No nurse……….no future

Would you like to speak to the doctor in charge or the nurse who knows what's going on?

your ecards
someecards.com

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Scaling Up Nurse-Led/-Facilitated Interventions - Practical Examples

Gerjanne ter Beest,
RN, Msc, MANP

Continuum of HIV care at the end of 2017*

Number of individuals

HIV-positive	Diagnosed and linked to care	Retained in care	On cART	Viral suppression
23,100	20,844	19,675	19,289	18,270

90% (HIV-positive → Diagnosed and linked to care)

93% (Diagnosed and linked to care → On cART)

95% (On cART → Viral suppression)

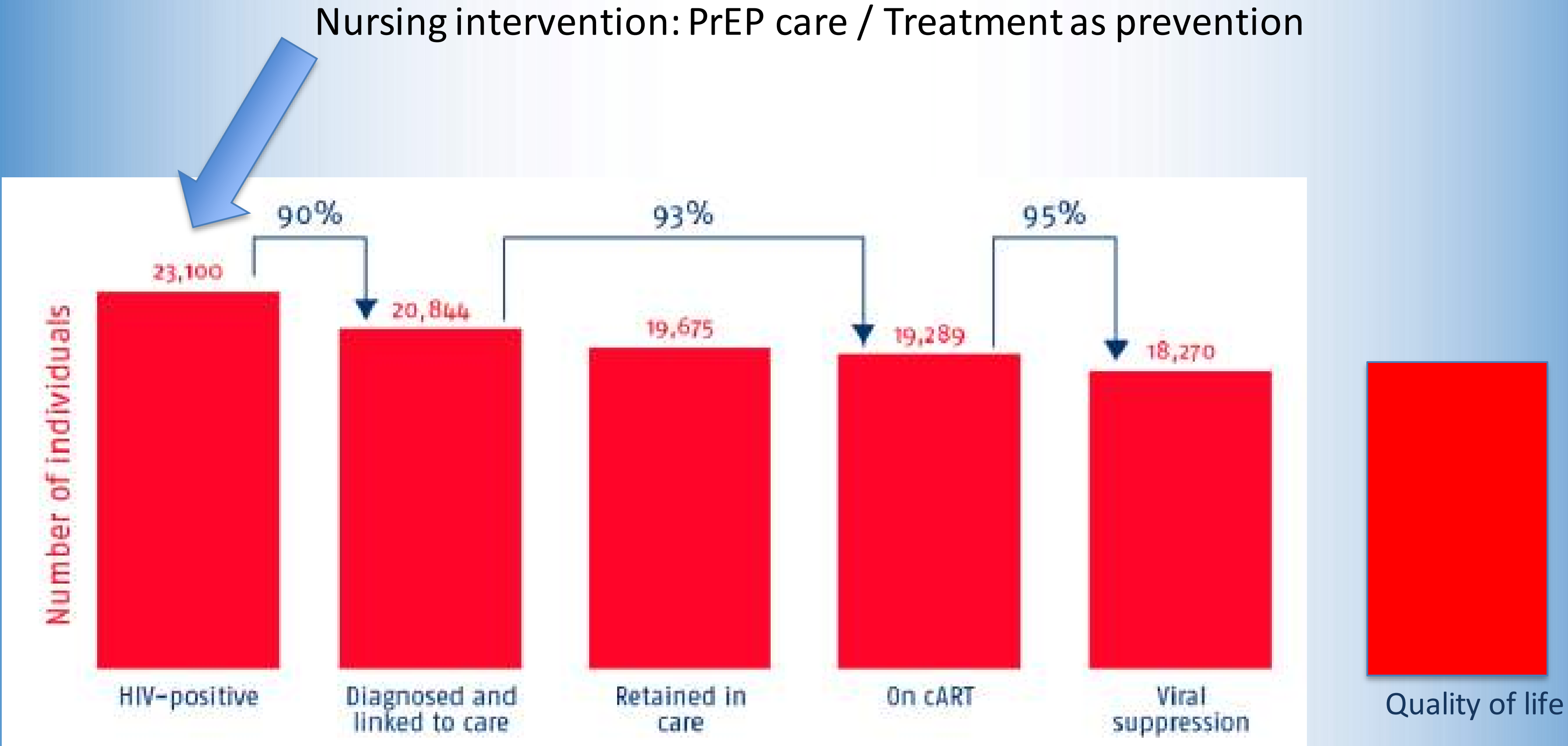
Quality of life

Steps forward in HIV prevention and HIV care

Steps forward in HIV prevention and HIV care

Ambitions

- No HIV transmission
- No deaths by AIDS
- No HIV stigma
- Optimal quality of life for people with HIV



Nursing intervention: PrEP care / Treatment as prevention
Number of individuals
90%
93%
95%
23,100
20,844
19,675
19,289
18,270
HIV-positive
Diagnosed and linked to care
Retained in care
On cART
Viral suppression
Quality of life

Nursing interventions on PrEP care / Treatment as prevention

Nursing interventions on informing about indicator diseases

Number of individuals

90%

93%

95%

23,100

20,844

19,675

19,289

18,270

HIV-positive

Diagnosed and linked to care

Retained in care

On cART

Viral suppression

Quality of life

Nursing interventions on accessible care

90%

93%

95%

23,100

20,844

19,675

19,289

18,270

Number of individuals

HIV-positive

Diagnosed and linked to care

Retained in care

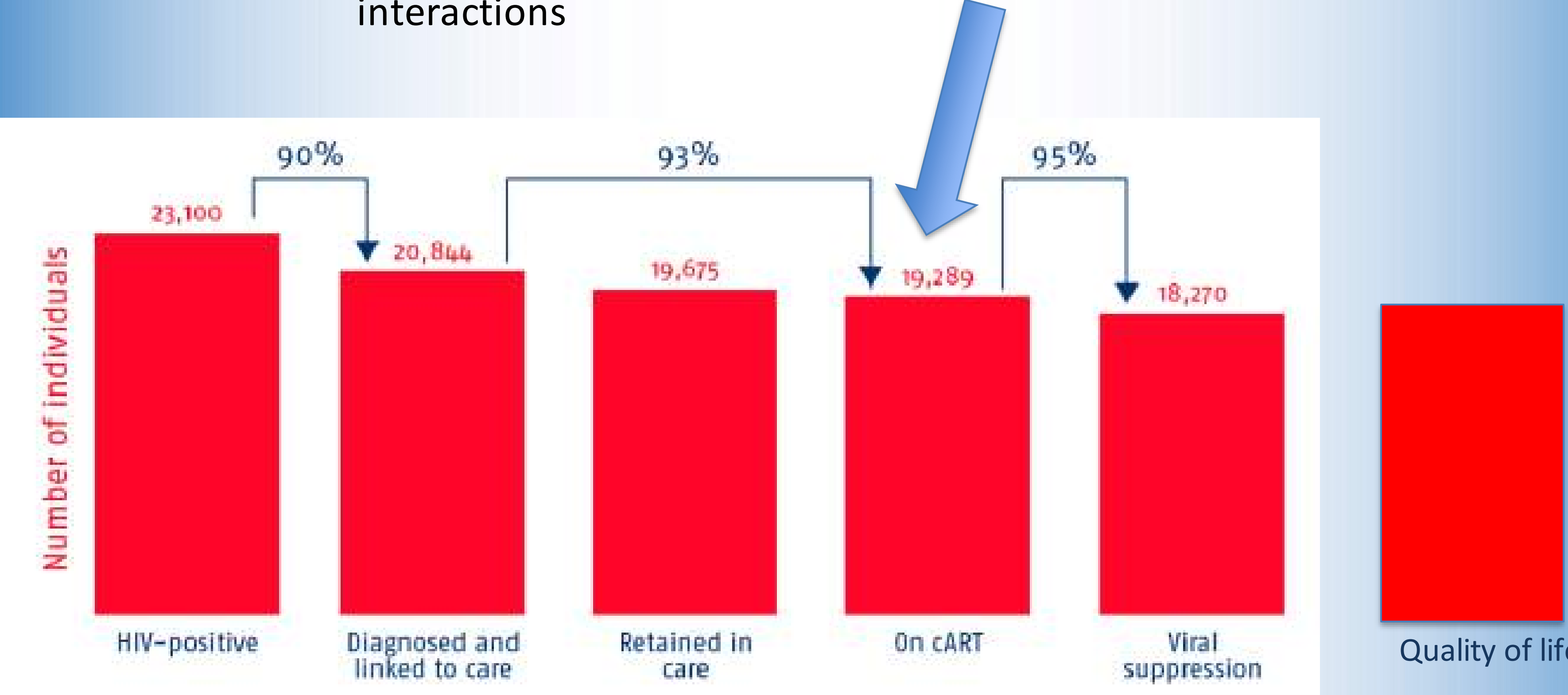
On cART

Viral suppression

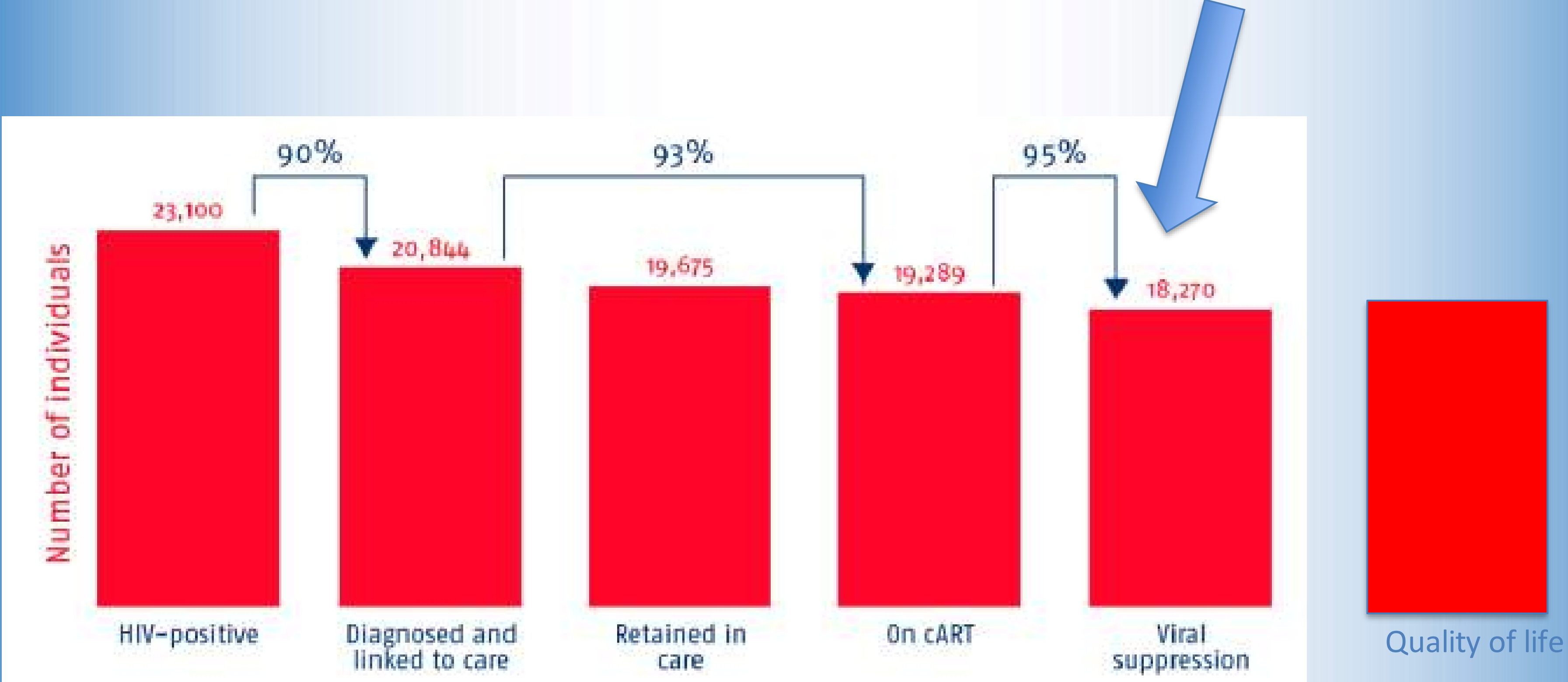
Quality of life

Nursing intervention: accessible care

Nursing interventions on starting ART, monitoring side effects , interactions



Nursing interventions on: adherence



Nursing interventions on peer contact, fighting stigma, promoting healthy lifestyle, sexual health

Nursing intervention on: sexual health

Conclusions

- We do many nursing interventions
- These interventions are not always visible for other stakeholders

We need to work on visibility

- by doing scientific research
- by showing nursing leadership
- what else can we do??

Thank you

Gerjanne ter Beest, RN, MSc
Rijnstate Hospital Arnhem, the Netherlands
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Evolution in Progress: Nurse Leadership in Developing Innovative Models of Care

RN Helena Mäkinen
Helsinki University Hospital

Unfortunately I heard

- ”nurses are good to keep a patient’s hand”
- I agree but then…
- ”nurses don’t discuss about medication, adherence, sexuality, peer support- it’s doctor’s work”
- ???

AIDS2018 Breaking barriers & Building bridges

What evyrybody need

- cooperation with multidisciplinary team
- encouragement and feedback from a multidisciplinary team
- natural support
- natural respect
- support each other’s good sides
- sharing

We Nurses

- we can
- we will
- we are ready
- we are brave
- we have knowledge
- we have skills

How

- we are near patient – trust
- studies, education, conferences
- sharing info
- networking
- multidisciplinary team for cooperation& sharing
- consultation

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Scaling up Nurse-Led/-Facilitated Interventions-Practical Example

RN Helena Mäkinen
Helsinki University Hospital

Networking with paperless population

- takes a lot of time
- cultural differences
- different perceptions of time
- some surprise every time
- patients learn step by step

Networking with paperless population

- 2011 pregnant woman came to infectious clinic, tested HIV positive here
- 2 years old daughter and father tested HIV positive also
- came from an other country from Europe
- lived in the car

Treat and travel

- baby was born in Finland, HIV negative
- from mother was found pulmonary tuberculosis after she travelled back to home country. She got TB treatment there.
- family travelled many times between home country and Finland

…continue

- 2016 the family came back
- mother was pregnant and borned a healthy baby, after it they travelled back to home country
- back to Finland 2018 with 6 months old baby
- father has got tuberculosis menigitis

Treat, counsel, support

- father takes DOT (Directly Observed Treatment) for TB in Health Center
- maybe this will be finished very soon
- I have seen father about 50 times, mother about 30 times and daughter once

100 tabl
Prednison 5 mg
MA TI KE TO PE LA SU

”Oil the wheels”

- daughter, mother and father have HIV treatment
- daughter’s and father’s virus load is undetectable, mother’s almost
- older kids wre in the school
- mother works
- father is on the sick leave

Home
Permanent residence permit

Social worker of child protection
Hospital’s social worker
Social worker who is also interpreter
Network Nurse
Mother's employer
MOTHER
DAUHGHTER
FATHER
Three other children
Nurse at the health station
Infectious deseases doctor
Pediatric Clinic
Pediatric
Women's clinic
Global Clinic

Thank you!

Kiitos!

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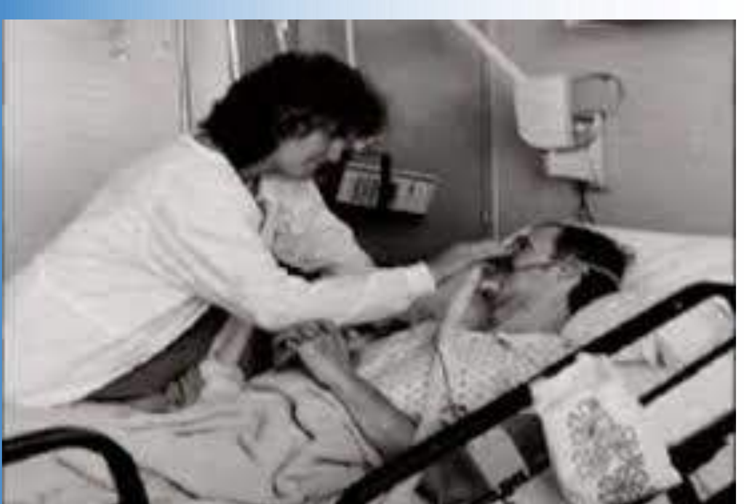
Nursing Leadership in the Fight Against HIV

Jackie Morton

NURSE LEADERSHIP in HIV

Who, what, where, when and why?



WHO IS A LEADER?

Florence Nightingale

Malala Yousafzai

Rowena Kincaid

What makes a leader

"A good nurse leader is someone who can inspire others to work together in pursuit of a common goal" *Catherine Meliniotis BA, BSN, RN, BC. March 30, 2015, AACN.*

"Leadership and learning are indispensable to each other."

– *U.S. President John F. Kennedy 1963*

Leadership

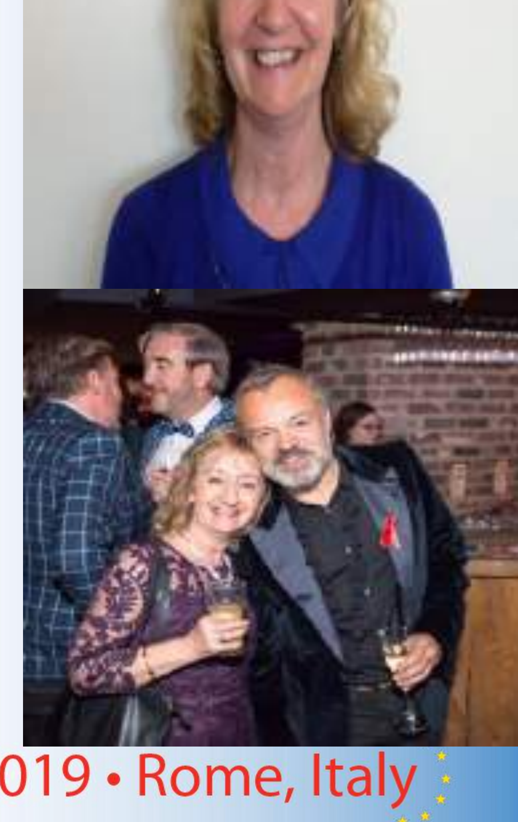
Personal

- Self awareness
- Accountability
- Resilience

Team work

- Leading change
- Challenging boundaries
- Learning from experience

Personal Achievement



Terrence Higgins Trust appoints trustee Jackie Morton as interim chief executive

Morton had a 40-year career in the NHS until her retirement in 2011. She was also chair of HIV Scotland, a charity that focuses on HIV education, policy and care, until earlier this year.

She remains actively involved in a number of related programmes, including the British HIV Association primary care project.

20 July 2015 by Daniel Farey-Jones, Charity News.

Journey beyond

What have I learnt

- Networks and peers.
- Understanding and knowledge
- Comfort zones
- Humility
- Challenge ‘the way it is’

What did I do with my new knowledge

WOMEN

AGEING

TARGETS

COMMISSIONING

POLICY

POLITICAL

Importance of nursing in HIV care

- Crucial role
- Achievement of national and local targets
- Prevention and treatment
- Continuum of care
- Educators and leaders of change

Making HIV care more effective

Affects a diverse range of people with very different needs

Chronic disease management

Complexity of care pathway

Sharing best practice

ASPECTS OF NURSING CARE IN HIV

- Building a network of care and support for newly diagnosed patients
- Monitoring, supporting and promoting self - management and retention in care
- Proactive support to enable re-engagement in care
- Co-ordinating packages of care for patients with complex needs.
- Health promotion including prophylaxsis risk reduction and partner notification

An examination of the contribution of specialist nursing to HIV service delivery
PIERCY, Hilary, BELL, Gill, HUGHES, Charlotte, NAYLOR, Simone and BOWMAN, Christine, December 2015.
Available from Sheffield Hallam University Research Archive (SHURA) at: http://shura.shu.ac.uk/18754/

WHAT MAKES A GOOD HIV NURSE

- Team work
- Knowledge and information
- Best practice
- Networks
- Language

RECOMMENDATIONS

- **Partnerships**
- **Education**
- **Influencers**
- **Share best practice**
- **Internal support networks.**
- **Research**

THANK YOU

- Rowena Kincaid 2 Sept 2016 RIP:

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HIV & Aging:
healthcare complexities and challenges

Jeffrey Kwong, DNP, MPH, ANP-BC, ACRN, AAHIVS, FAANP

Professor, Division of Advanced Nursing Practice

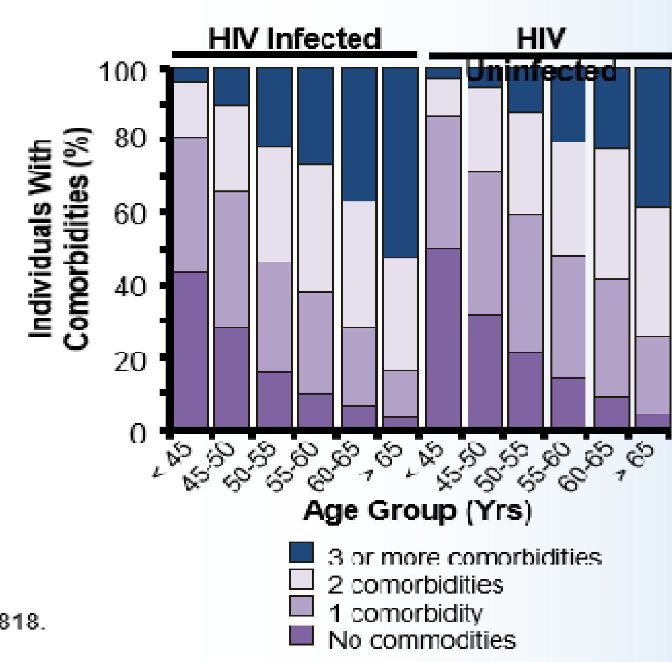
Rutgers School of Nursing

President, ANAC Board of Directors

ATHENA: Comorbidities Increase With Age and With HIV Infection

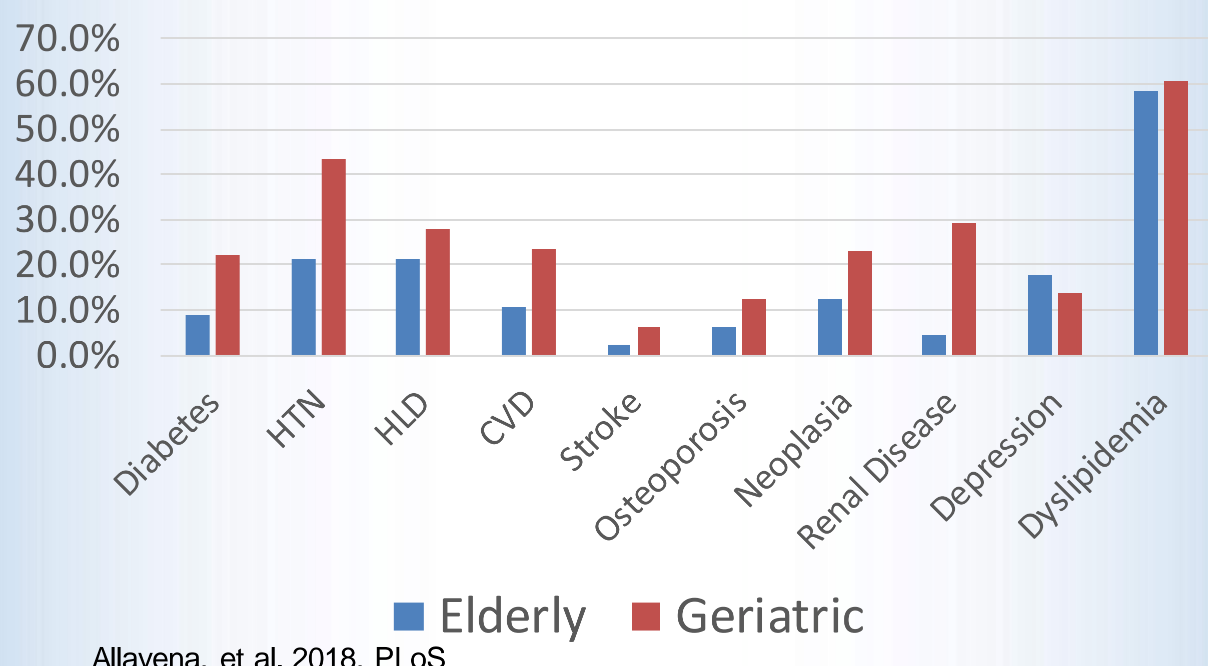
By 2030

- 84% of HIV+ pts will have ≥ 1 comorbidity
- 28% of HIV+ pts will have ≥ 3 NCDs
- 54% of HIV+ pts will be prescribed meds other than ART
  - Increased from 13% in 2010
- 20% will take ≥ 3 meds besides ART
  - Mostly driven by increase in CVD

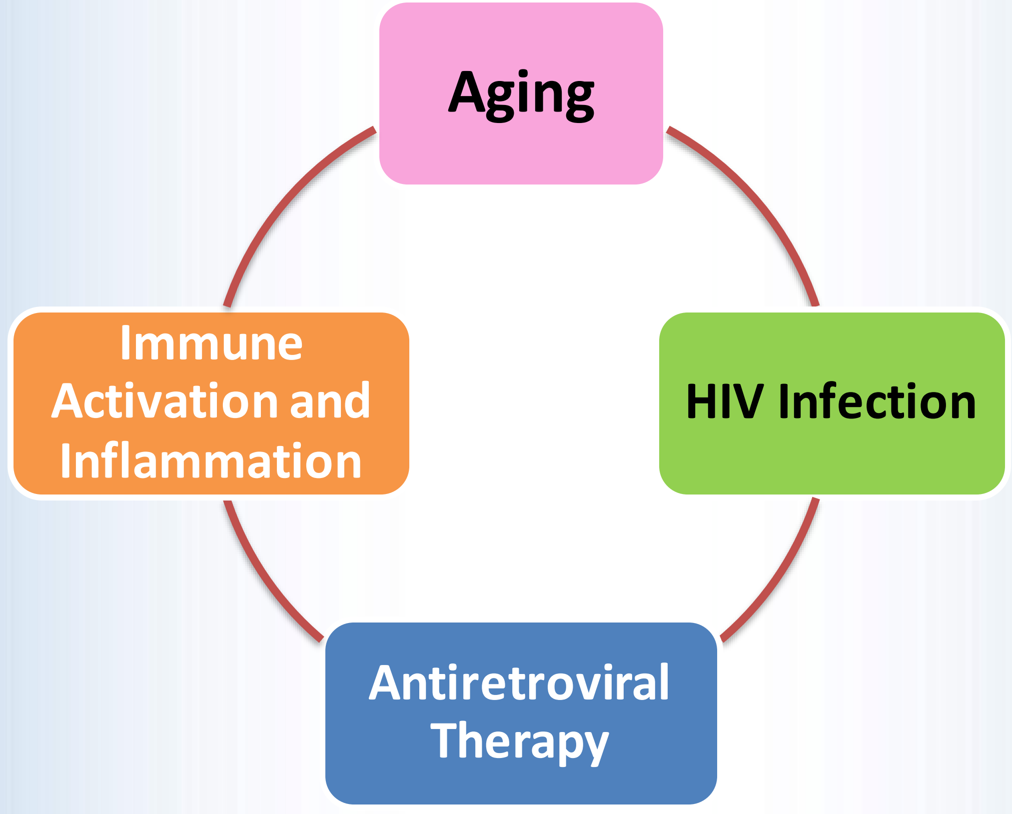


Smit M, et al. Lancet Infect Dis. 2015;15:810-818.

Co-Morbidities:

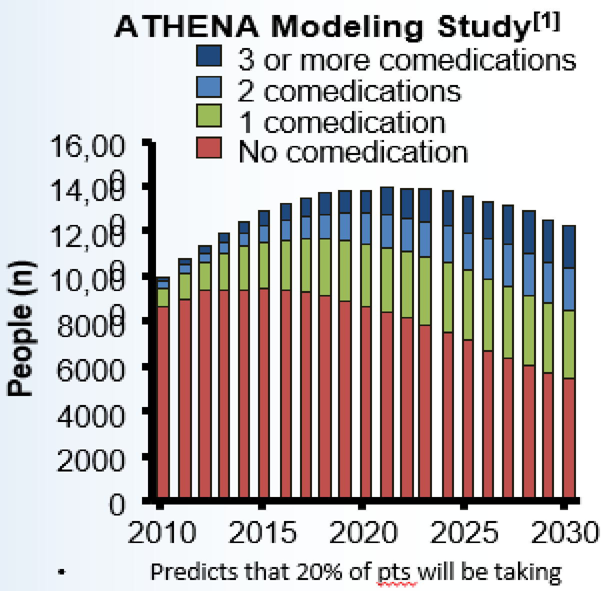


Allavena, et al. 2018, PLoS

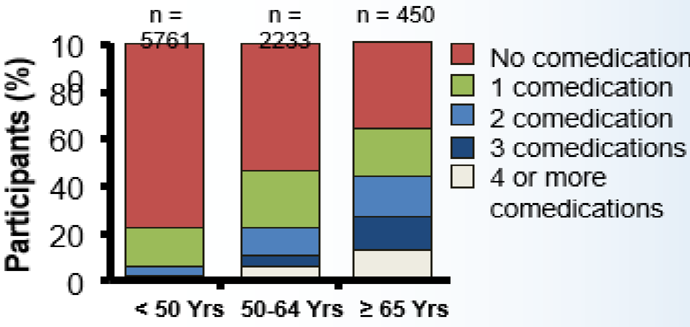

Aging
HIV Infection
Antiretroviral Therapy
Immune Activation and Inflammation

"Just one pill a day….."

ATHENA and Swiss HIV Cohort Studies: Polypharmacy Among HIV+ Pts on ART



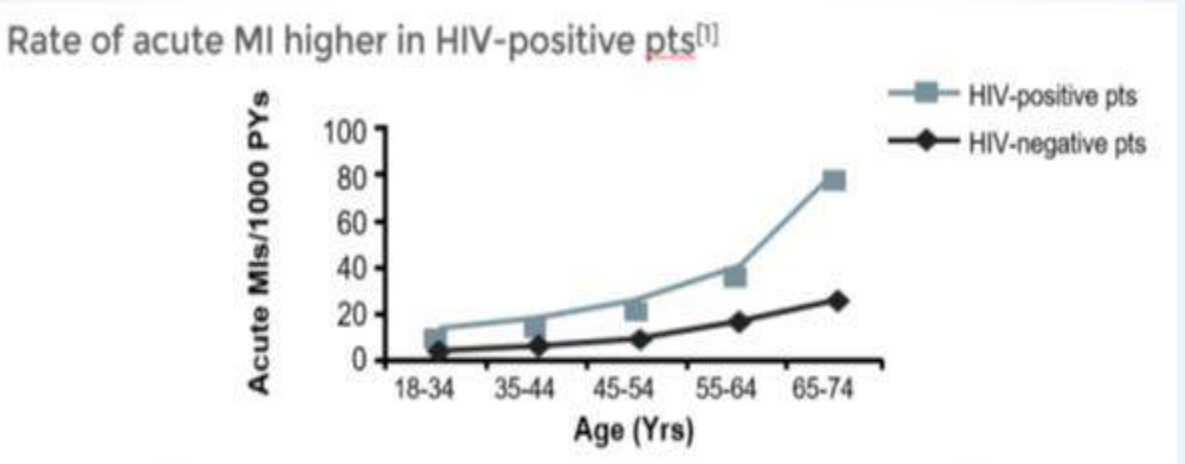
- Predicts that 20% of pts will be taking ≥ 3 meds other than ART in 2030



- 115 (5.2%) of 2233 participants 50-64 yrs of age and 64 (14.2%) of 450 participants ≥ 65 yrs of age received ≥ 4 meds other than ART

1. Smit M, et al. Lancet Infect Dis. 2015;15:810-818. 2. Hasse B, et al. Clin Inf Dis. 2011:1130-1139.

The Link Between HIV and Cardiovascular Disease and Age



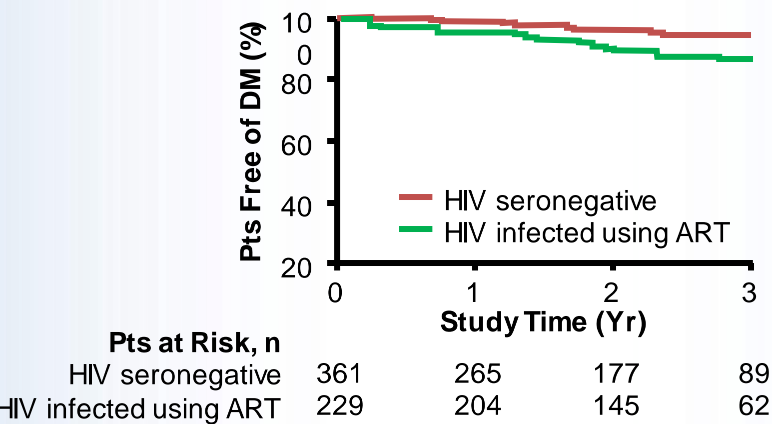
HIV infection is a risk factor for ischemic stroke[2]

HIV-infected men have a greater prevalence of coronary artery plaques[1,3]

1. Triant VA, et al. J Clin Endocrinol Metab. 2007;92:2506-2512. 2. Chow FC, et al. J Acquir Immune Defic Syndr. 2012;60:351-358. 3. Post WS, et al. Ann Intern Med. 2014;160:458-467.

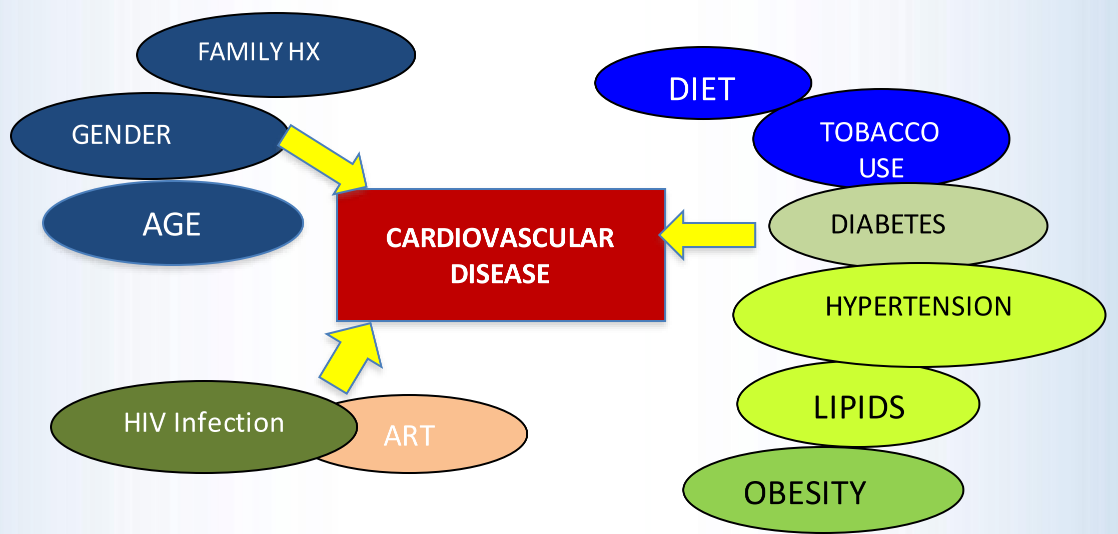
MACS: Rates of DM Increased in HIV-Positive Pts on ART

- Rate of incident **DM was 4.7 cases**/100 PYs in HIV-positive men vs **1.4 cases**/100 PYs in seronegative men



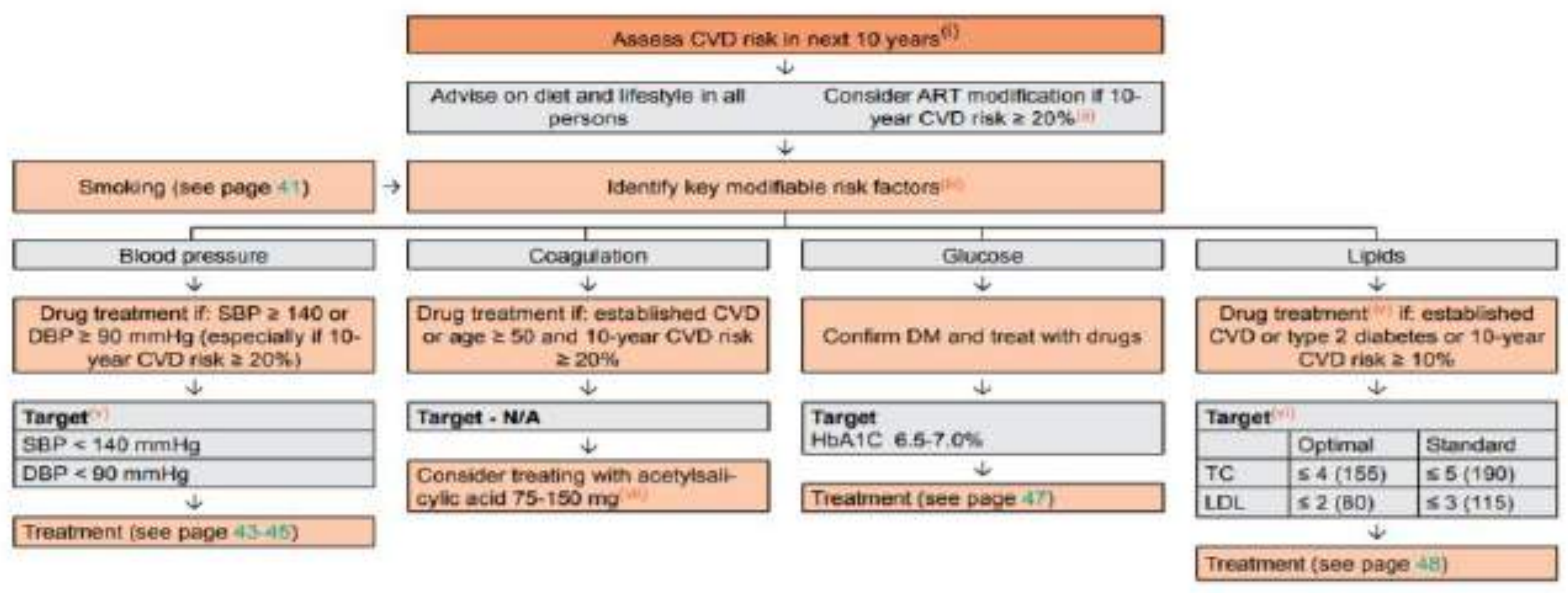
Brown TT, et al. Arch Intern Med. 2005;165:1179-1184.

Traditional Factors Are the Biggest Contributor to CVD in HIV Population



Prevention of CVD

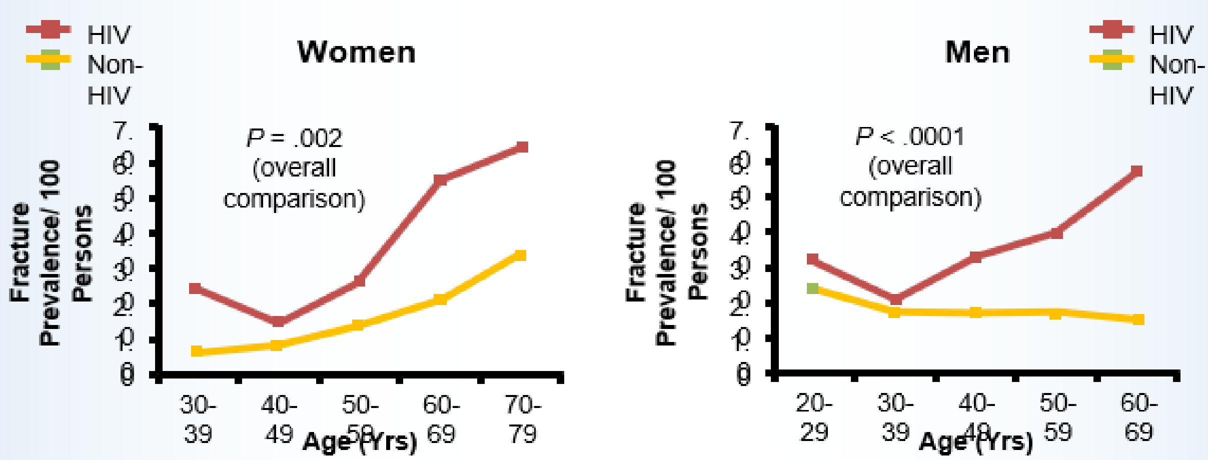
Principles: The intensity of efforts to prevent CVD depends on the underlying risk of CVD, which can be estimated[i]. The preventive efforts are diverse in nature and require involvement of a relevant specialist, in particular if the risk of CVD is high and always in persons with a history of CVD.



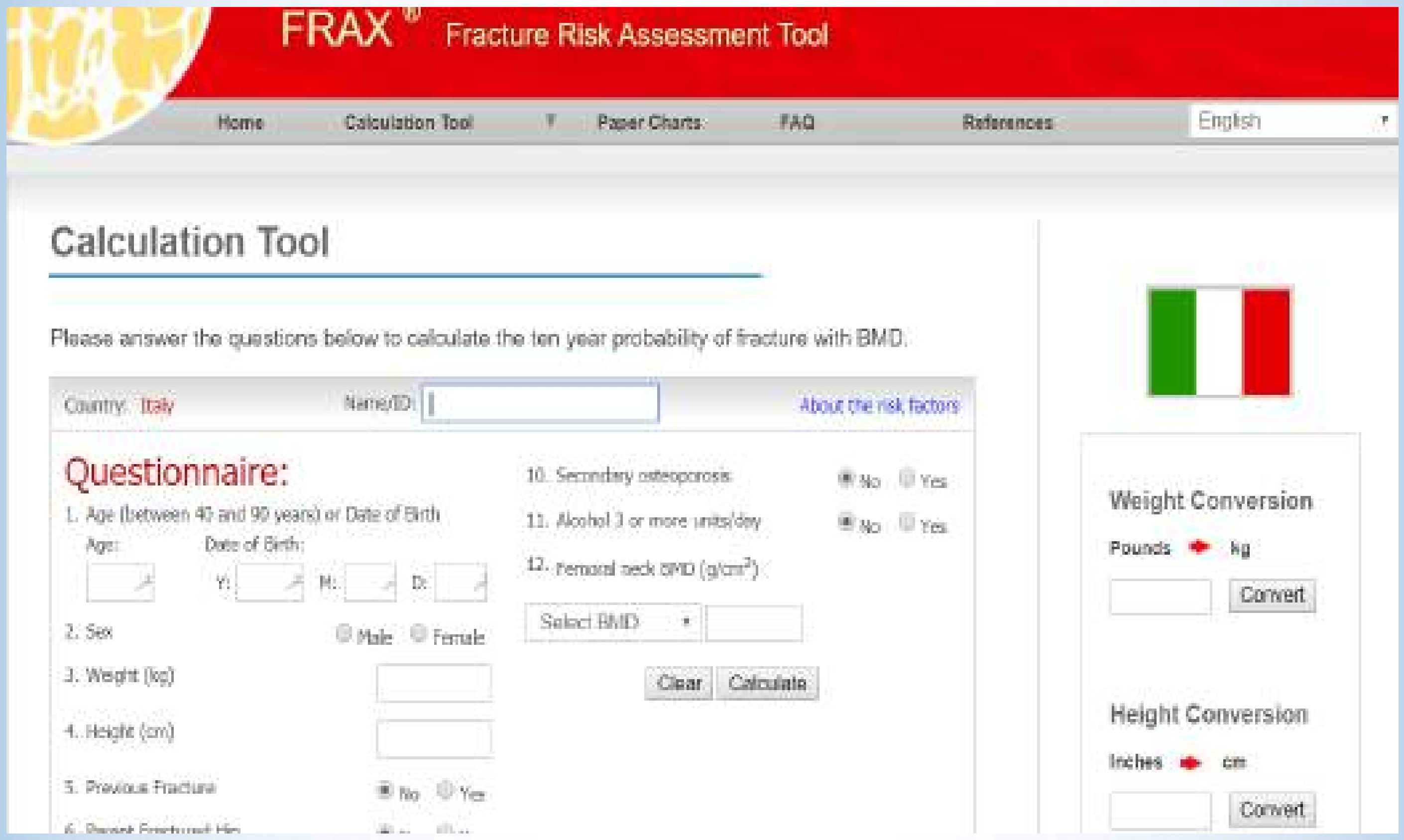
Source: EACS, 2018

Fracture Prevalence Is Increased in Older HIV-Positive Pts

- 8525 HIV-infected pts compared with 2,208,792 uninfected pts in Partners HealthCare System



Triant V, et al. J Clin Endocrinol Metab. 2008;93:3499-3504.


FRAX®
Fracture Risk Assessment Tool
Home
Calculation Tool
Paper Charts
FAQ
References
English
Calculation Tool
Please answer the questions below to calculate the ten year probability of fracture with BMD.
Country: Italy
Name/ID:
About the risk factors
Questionnaire:
1. Age (between 40 and 90 years) or Date of Birth
Age:
Date of Birth:
Y:
M:
D:
2. Sex
Male
Female
3. Weight (kg)
4. Height (cm)
5. Previous Fracture
No
Yes
10. Secondary osteoporosis
No
Yes
11. Alcohol 3 or more units/day
No
Yes
12. Femoral neck BMD (g/cm²)
Select BMD
Clear
Calculate
Weight Conversion
Pounds
kg
Convert
Height Conversion
Inches
cm
Convert

Strategies to reduce or prevent bone loss with ART initiation

- Avoid Tenofovir Disoproxil Fumarate (TDF)
- Avoid Protease Inhibitors
- Calcium and Vitamin D
- Biphosphonate Therapy
- Resistance training

Cancer

- Cancer risk elevated in older persons living with HIV vs non-HIV-infected.
- Lung, prostate, colorectal, breast cancer most common.
- Tobacco cessation and early detection are critical.

Yanik et al. 2016. AIDS, 30(10).

Cancer: Screening Methods[i]

Problem	Persons	Procedure	Evidence of benefit	Screening interval	Additional comments
Anal cancer	MSM and persons with HPV-associated dysplasia[ii]	Digital rectal exam ± anal cytology	Unknown; advocated by some experts	1-3 years	If anal cytology abnormal, anoscopy
Breast cancer	Women 50-70 years	Mammography	↓ Breast cancer mortality	1-3 years	
Cervical cancer	HIV-positive women > 21 years or within 1 year after sexual debut	Liquid based cervical cytology test	↓ Cervical cancer mortality	1-3 years	HPV testing may aid screening
Colorectal cancer	Persons 50-80 years with a life expectancy > 10 years	Faecal occult blood test annually or sigmoidoscopy every 5 years or colonoscopy every 10 years	↓ Colorectal cancer mortality	1-3 years	
HepatoCellular Carcinoma (HCC)	Persons with cirrhosis, persons with HBV co-infection at high risk of HCC or those who ever had chronic hepatitis[iii]	Ultrasound (and alpha-foetoprotein)	Earlier diagnosis allowing for improved ability for surgical eradication	Every 6 months	See pages 58 and 81
Prostate cancer	Men > 50 years with a life expectancy >10 years	PSA[iv]	Use of PSA is controversial	2-4 years	Pros: ↑ early diagnosis and modest ↓ prostate cancer specific mortality. Cons: overtreatment, adverse effects of treatment on quality of life

Source: EACS, 2018

Algorithm for Diagnosis and Management of HIV-Associated Neurocognitive Impairment (NCI) in Persons without Obvious Confounding Conditions

Abbreviations

CSF	cerebrospinal fluid
GDR	genotypic drug resistance test
HAD	HIV-associated dementia
MND	mild neurocognitive disorder
MRI	brain magnetic resonance imaging
NP	neuropsychological
OIs	opportunistic infections

HIV-positive person-self or their relatives complaining of, or care giver noting cognitive problems - without obvious confounding conditions[i] → Initial assessments[ii]

↓ Problems suspected

↓ Evaluation for depression and possible treatment[iii]

↓ Problems persisting but depression excluded or optimally managed

↓ NP examination[iv]

↓ NCI[v]

↓ Neurological examination, Brain MRI, CSF examination[vi]

↓ Additional causes of NCI other than HIV excluded

↓ Diagnosis: **HIV-associated NCI**

i **Obvious confounding conditions:**

1. Severe psychiatric conditions
2. Abuse of psychotropic drugs
3. Alcohol abuse
4. Sequelae from previous CNS-OIs or other neurological diseases
5. Current CNS-OIs or other neurological diseases

ii **The following questions may be used to guide doctor assessment**

1. Do you experience frequent memory loss (e.g. do you forget the occurrence of special events even the more recent ones, appointments, etc.)?
2. Do you feel that you are slower when reasoning, planning activities, or solving problems?
3. Do you have difficulties paying attention (e.g. to a conversation, book or movie)?

Answering "yes" to one or more of these questions may suggest the presence of cognitive disorders, although not necessarily linked to HIV.

iii See Depression: Screening and Diagnosis

iv **NP examination** will have to include tests exploring the following cognitive domains: fluency, executive functions, speed of information processing, attention/working memory, verbal and visual learning, verbal and visual memory, motor skills plus assessment of daily functioning.

v **NCI** is defined by impairment in cognitive function on the above neuropsychological test where performance is compared to age- and education-matched appropriate controls and is considered clinically significant.

vi **Neurological examination, brain MRI and CSF examination** are required to exclude other pathologies and to further characterise HIV-associated NCI by including assessment of CSF HIV-VL level and, where appropriate, evidence for genotypic drug resistance (GDR) in a paired CSF and plasma sample.

vii **CSF escape definition:**
either CSF HIV-VL detectable and plasma HIV-VL undetectable; or both CSF HIV-VL and plasma HIV-VL detectable, with CSF HIV-VL higher than plasma HIV-VL

viii **Including all situations that do not fulfil the CSF escape definition**

ix **Triple ART regimen**

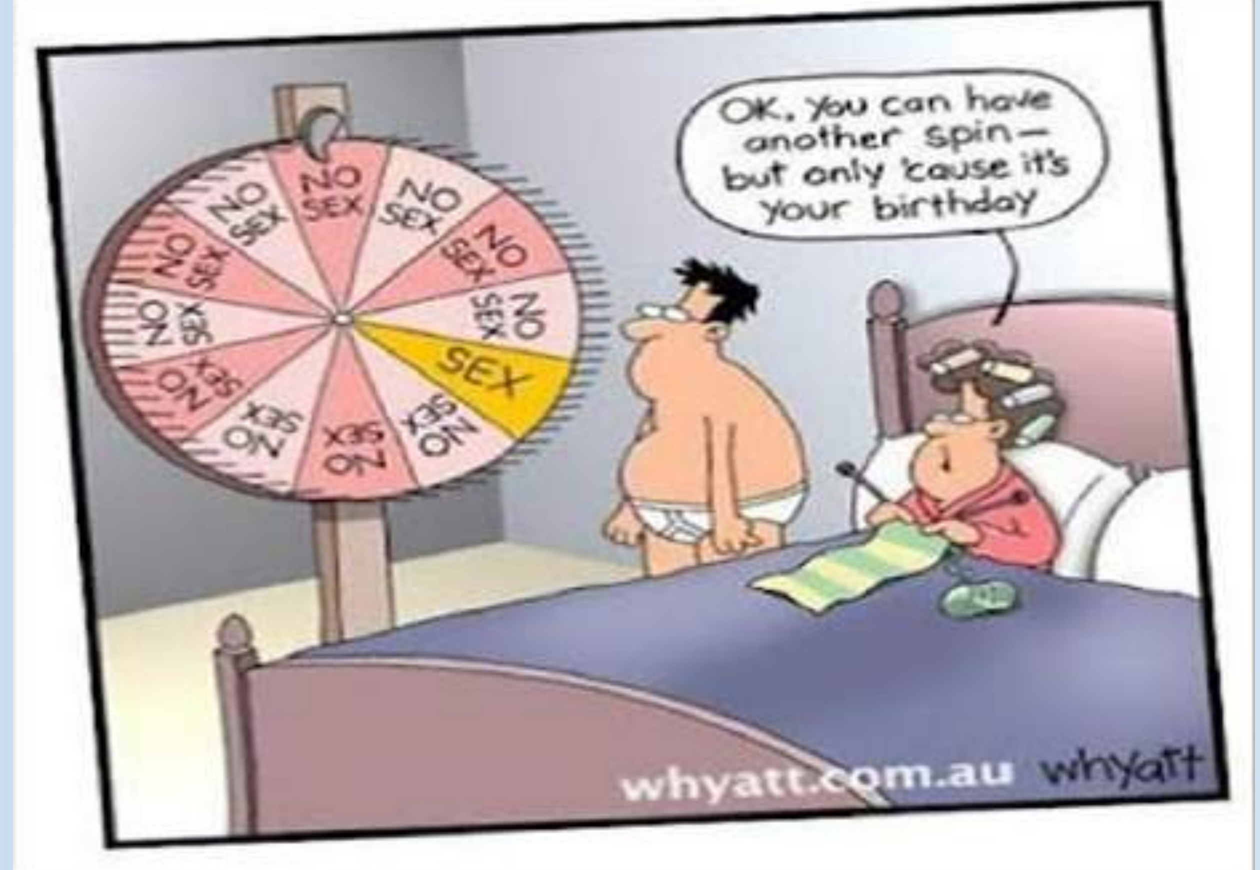
x **ART drugs with potential beneficial or detrimental effects on the CNS**

Definition of potentially CNS-active drug

ARV drugs with either:

1. demonstrated clear CSF penetration when studied in healthy

Depression & Isolation



OK, you can have another spin— but only 'cause it's your birthday
NO SEX
NO SEX
NO SEX
NO SEX
SEX
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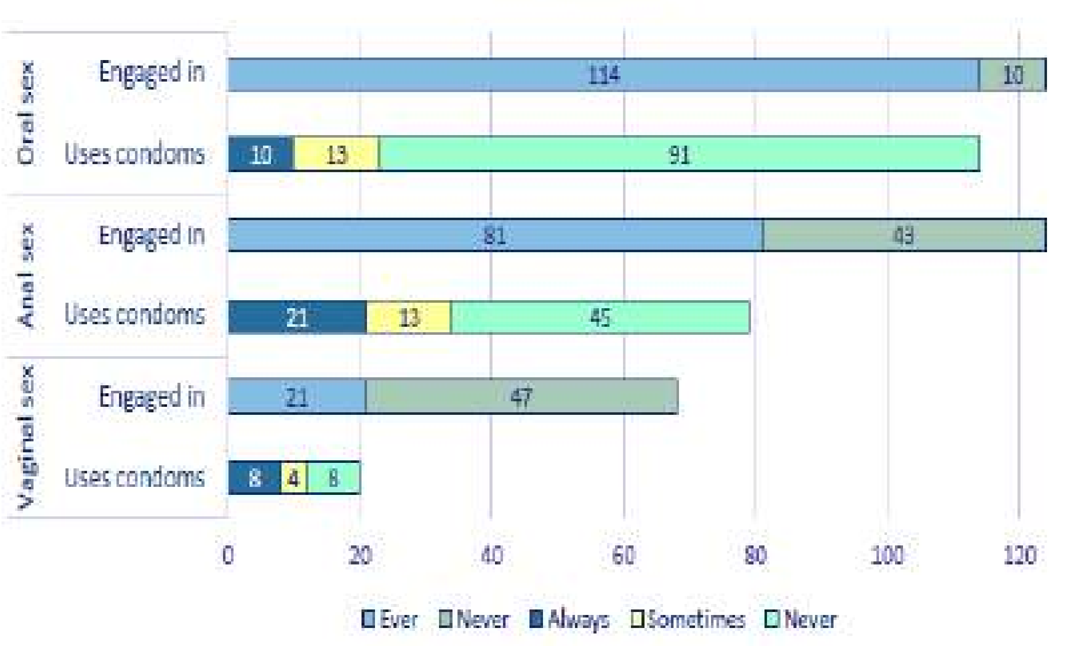
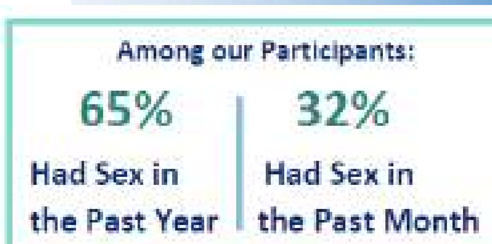
NO SEX
NO SEX
NO SEX
NO SEX
NO SEX
NO SEX
whyatt.com.au
whyatt





Acria, 2018

U=U
UNDETECTABLE = UNTRANSMITTABLE

Prevention

- 38% of men and 22% of women discussed sex with their provider

45%
INCREASE
in demand for geriatricians, 2013-2025*

Geriatrics Workforce Supply & Demand*

Supply
Demand

2013
2025

0 5000 10000 15000 20000 25000 30000 35000

Full-Time Geriatricians in Clinical Practice

Source: American Geriatrics Society

HARTFORD INSTITUTE FOR GERIATRIC NURSING
NYU RORY MEYERS COLLEGE OF NURSING

GAPNA

GERONTOLOGICAL
SOCIETY OF AMERICA

NICHE

ANAC
Association of
Nurses in AIDS Care

National Hartford Center of
Gerontological Nursing Excellence

AIDS
United

National Academy on an Aging Society

Take Home Points

- **Co-morbid chronic disease** plays a role in patients with long-standing disease and those who are aging.
- **Modification of risk factors** (smoking cessation, exercise, lipid management) may improve or reduce risk of CVD, CKD, osteopenia.
- **Early diagnosis and treatment** can improve outcomes in this population.
- Clinicians, policy makers, and educational institutions need to work collaborative to address **healthcare workforce issues**.

References & Resources

- HIV-Age.org

www.hiv-age.org

- Adults 50 and Over

http://www.cdc.gov/hiv/group/age/olderamericans/index.html

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MSM Case Study

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Professor, Rutgers University School of Nursing

President, Association of Nurses in AIDS Care

New York, NY, USA

Learning Objectives

- Discuss the impact of stigma on HIV screening and prevention among MSM
- Describe disparities of HIV-associated co-morbidities among MSM living with HIV
- List at least 2 clinical considerations in caring for MSM living with or at-risk of HIV

Case 1: RC

34 y.o. male who presents to for an initial exam. He tells you he is here to "***make sure everything is okay***."

- **Past Medical History:**
  - Depression.
- **Medications**:
  - sertraline 100mg daily
- **Allergies**: NKDA

- **Family history**:
  - Type II Diabetes Mellitus and Hypertension
- **Personal/Social History**:
  - former smoker (1 ppd x 10 years quit 5 years ago);
  - works in retail sales

Case 1: Continued

- What additional information would you like to know now?

Sexual History: Do Ask, Do Tell

- Various ways to approach sexual history taking
- The most important thing is to ask

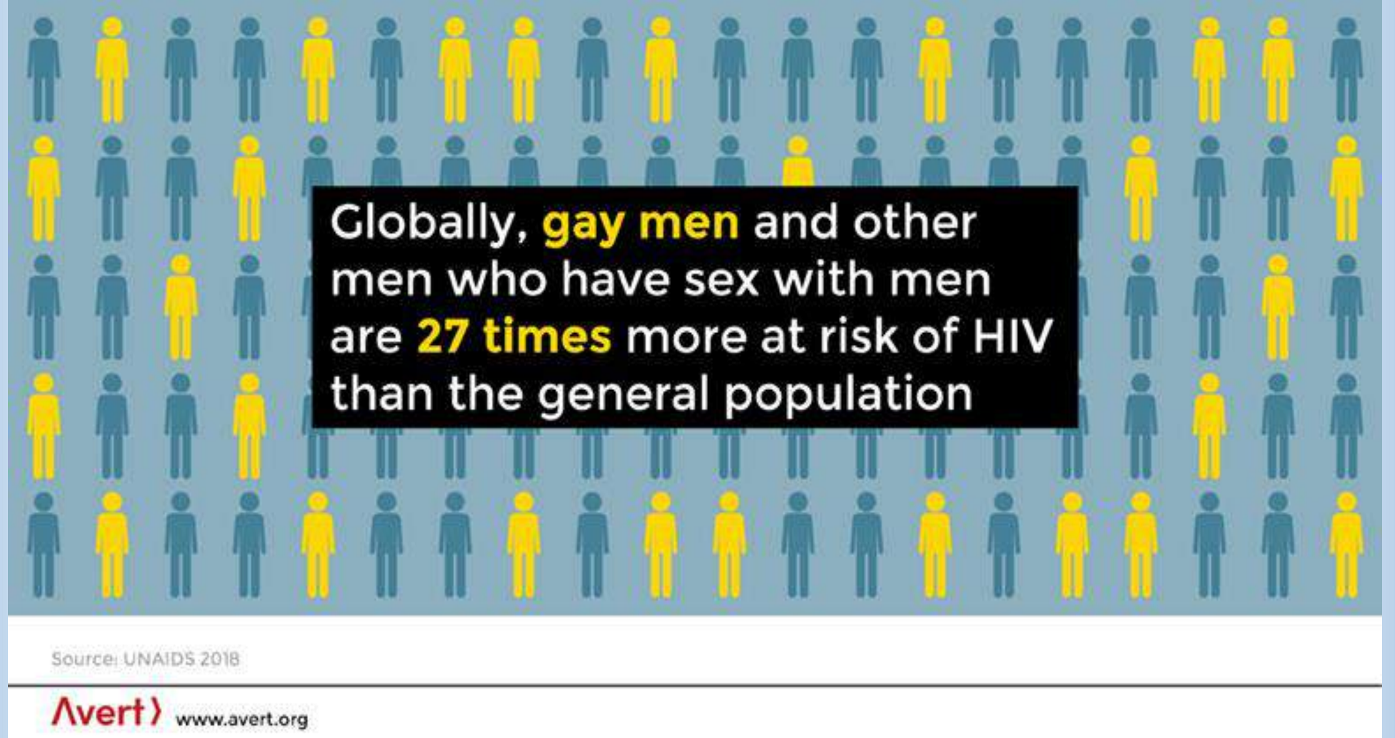
The 5 P's

- Partners
- Practices
- Prevention of STIs
- Past history of STIs
- Pregnancy

Case 1: Continued

- He informs you that he has sex with men only.
- His last HIV test was about 6 months ago.
- He has a past history of syphilis about 6 months ago.
- He uses condoms “most of the time”
- Denies any dysuria, discharge, sores, LAD, rash

What are your main concerns now?


Globally, gay men and other men who have sex with men are 27 times more at risk of HIV than the general population
Source: UNAIDS 2018
Avert
www.avert.org

Estimated HIV Incidence among Persons Aged ≥13 Years, by Transmission Category 2010–2016—United States

Male-to-male sexual contact

Heterosexual contact

Injection drug use (IDU)

Male-to-male sexual contact and IDU

Estimated HIV Incidence, No. (in thousands)

0 2 4 6 8 10 12 14 16 18 20 22 24 26 28

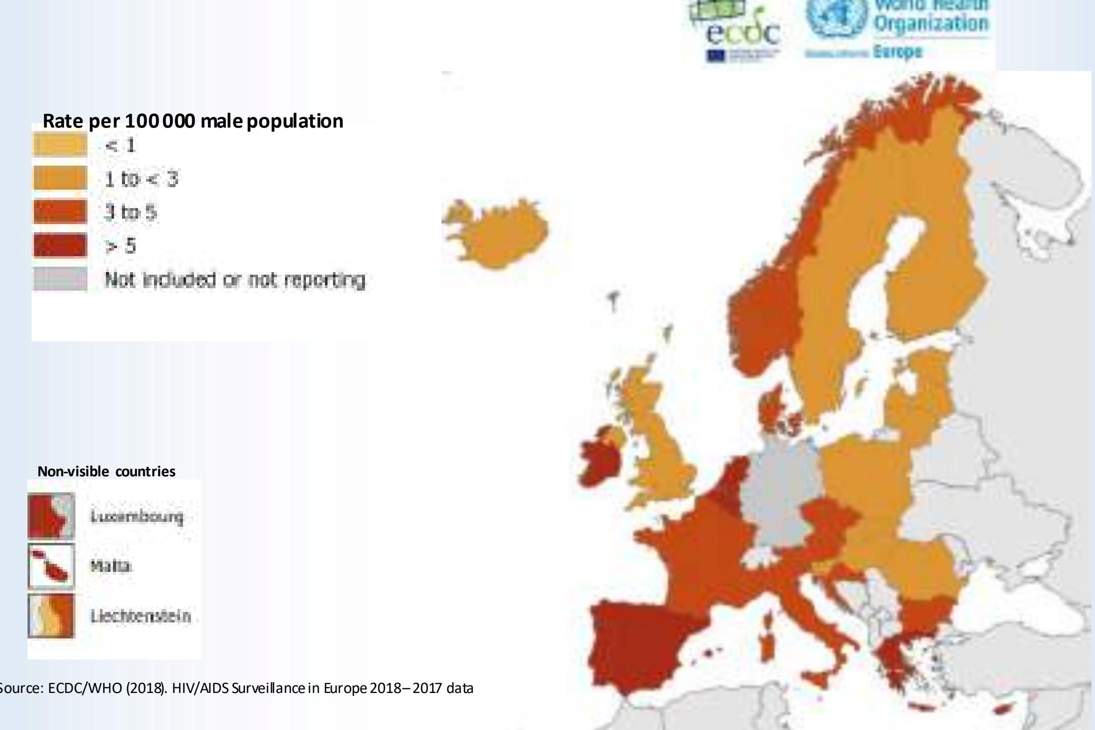
2010 2011 2012 2013 2014 2015 2016

Year of infection

Note. Estimates were derived from a CD4 depletion model using HIV surveillance data. Data have been statistically adjusted to account for missing transmission category. Heterosexual contact is with a person known to have, or to be at high risk for, HIV infection.

* Difference from the 2010 estimate was deemed statistically significant ($P < .05$).

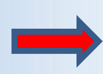
New HIV diagnoses attributed to sex between men, 2017, EU/EEA



Source: ECDC/WHO (2018). HIV/AIDS Surveillance in Europe 2018– 2017 data

New HIV diagnoses in the EU/EEA 2017

Reporting countries/number of countries*	30/31
Number of HIV diagnoses	25 353
Rate per 100 000 population (adjusted for reporting delay)	6.2
Male-to-female ratio	3.1
Percentage of new diagnoses CD4<350 cells/mm^3	49%
Transmission mode (%)	
Sex between men	38
Heterosexual transmission (men)	17
Heterosexual transmission (women)	16
Injecting drug use	4
Vertical transmission	<1
Unknown	24



* Due to technical issues no 2017 data were received from Germany

Source: ECDC/WHO (2018). HIV/AIDS Surveillance in Europe 2018 – 2017 data

Countries showing declines in the rates of new HIV diagnosis reported in MSM, 2008-2017

Rate of new diagnoses in MSM per 100 000 male population

14
12
10
8
6
4
2
0

2008 2009 2010 2011 2012 2013 2014 2015 2016 2017

Year of diagnosis

Belgium
Greece
Luxembourg
Netherlands
Spain
United Kingdom
Switzerland

Source: ECDC/WHO (2018). HIV/AIDS Surveillance in Europe 2018 – 2017 data

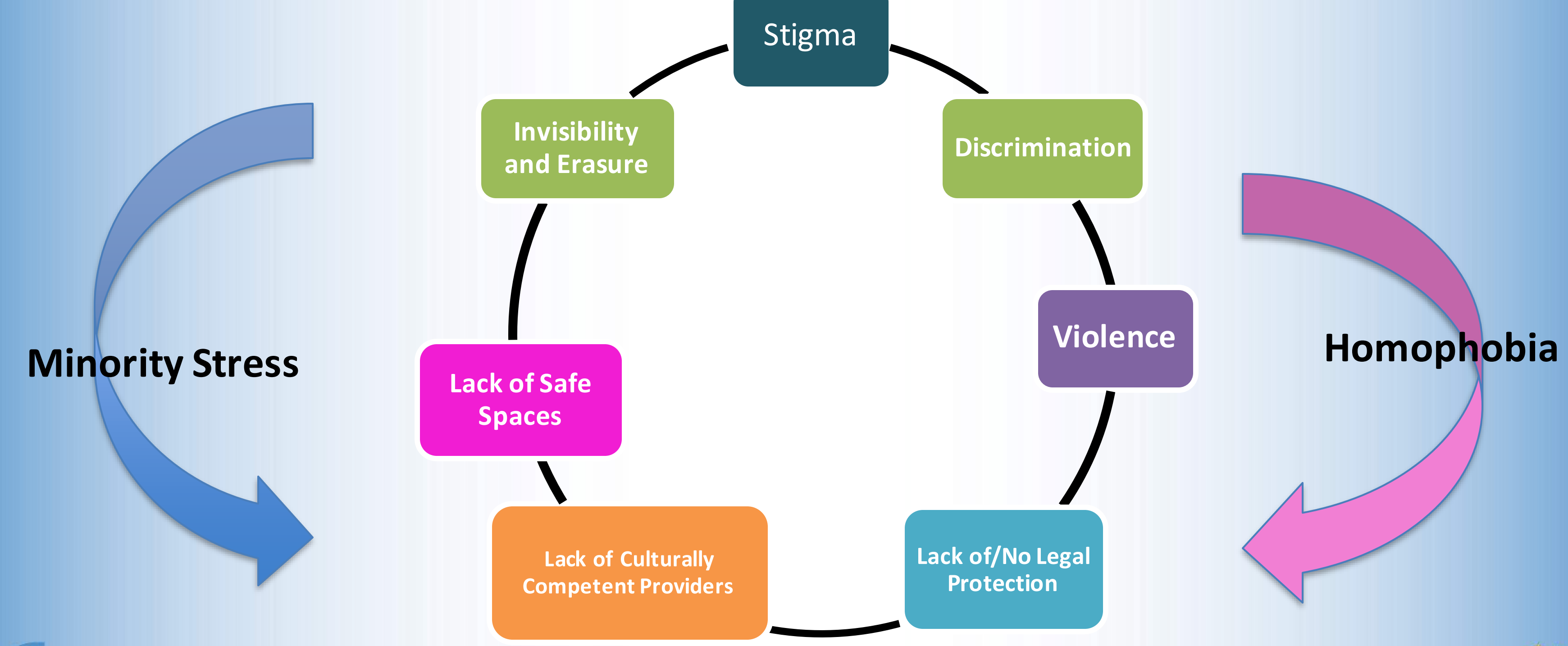
MSM are disproportionately at risk for and affected by HIV, STI and viral hepatitis

Proportion of new diagnoses attributed to sex between men, EU/EEA, 2016

Source: ECDC, Sexually transmitted infections in Europe, 2016; Hepatitis B and C in Europe, 2016; ECDC/WHO HIV Surveillance in Europe 2016 data, 2017

Why the difference?

Why do MSM experience more health disparities?



https://www.avert.org/professionals/hiv-social-issues/key-affected-populations/men-sex-men

67 countries criminalise same-sex activity

In at least 8 countries, the **death** penalty is implemented for same-sex sexual relations

Source: UNAIDS Data 2019

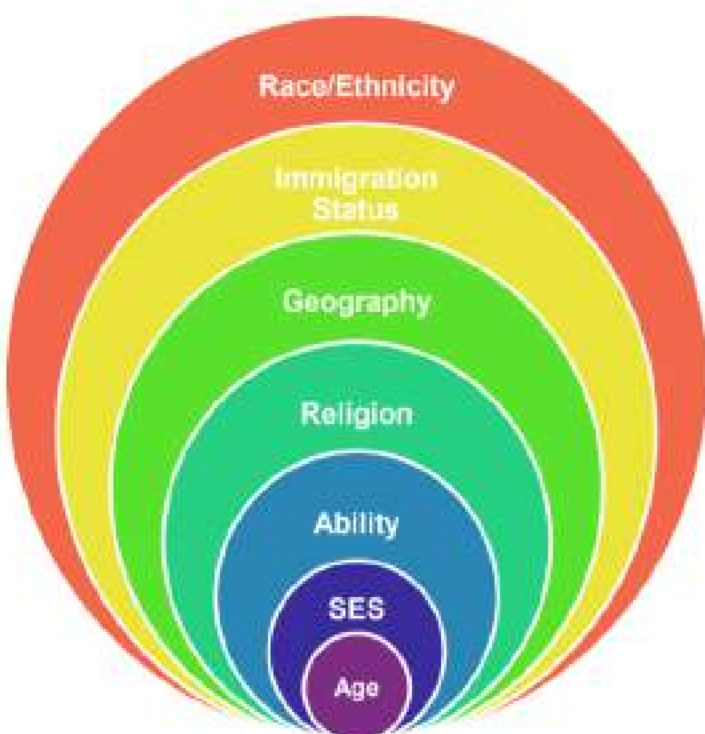
Avert www.avert.org

Homophobia impedes addressing HIV/STI

- Prejudice, threats, and violence against MSM
- Criminalization of same sex behavior
- Lack of training for health care workers
- **All lead to avoidance of care**

(Gonser, J Cult Divers, 2000; Meyer, AJPH, 2001; Mayer, AJPH, 2008; Bettancourt, Cultural Competence in Health Care, 2002)

Intersectionality and health disparities



A gay man has to deal with homophobia. A black man has to deal with racism. But a black gay man will have to deal with homophobia and racism (often at the same time). It is often the case that he will face racism inside the LGBT community and homophobia in the black community.

Having an intersectional identity often generates a feeling that someone does not completely belong in one group or another, and can lead to isolation.

Source: Fenway Institute

Biopsychosocial Drivers of the Syndemic in Gay, Bisexual and Other Men Who Have Sex With Men

Biological Influences
Prevalence of Infectious Disease
Infectiousness
Suceptibility
Efficacy of Treatment
Efficacy of Risk Reduction Strategies

Behavioral Influences
Partner Selection
Number of Partners
Sexual Behavior
Retention in Medical Care
Treatment Initiation and Adherence
Choice of Risk Reduction Strategy
Adherence to Risk Reduction Strategy

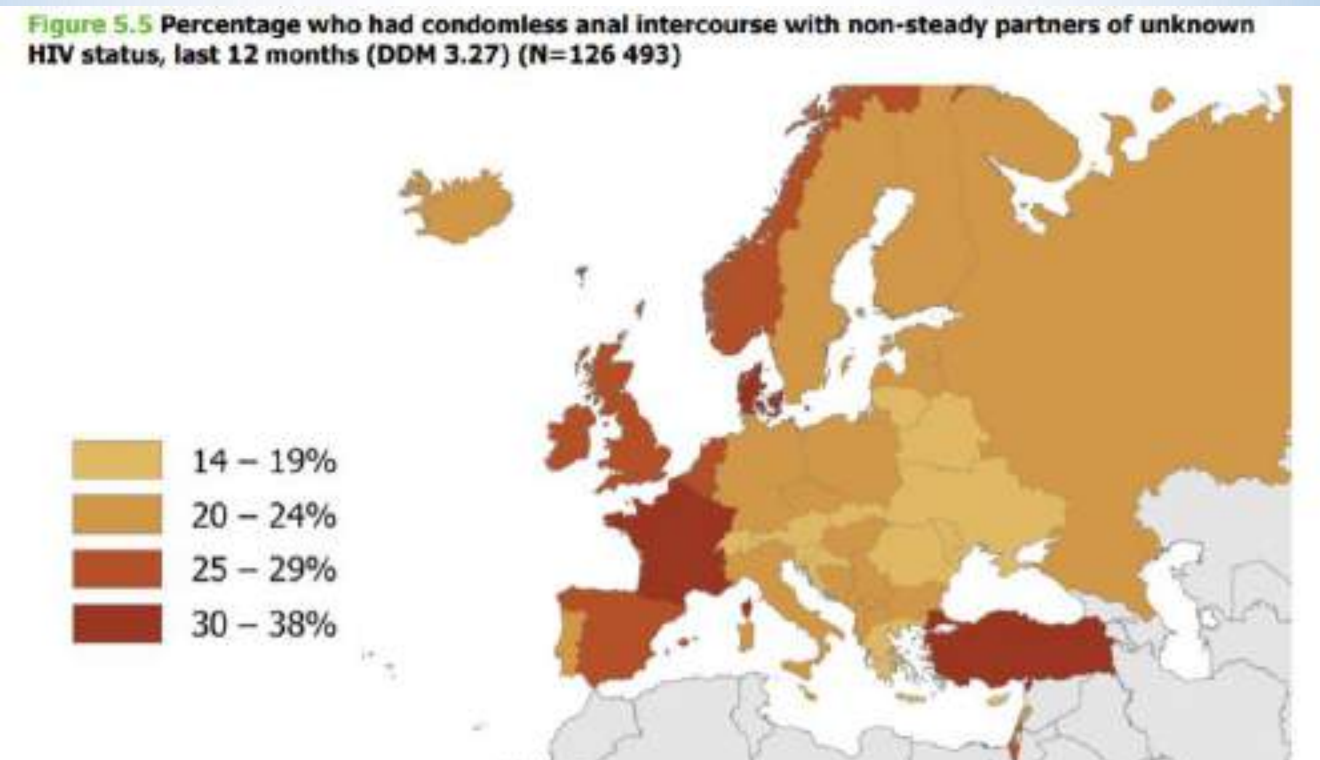
Psychosocial and Structural Influences
Knowledge, Attitudes and Beliefs
Minority Stress, Homophobia and Racism
Social Capital and Social Support
Safe Schools and Legal Protections
Allocation of Public Resources
Access to Information and Tools

Syndemic Health Problems

NOTE: STIs = Sexually Transmitted Infections

SOURCE: Halkitis PN, Wolitski RJ, Millett GA. A holistic approach to addressing HIV infection disparities in gay, bisexual, and other men who have sex with men. American Psychologist. 2013;68/4:261-73.

Condomless anal intercourse

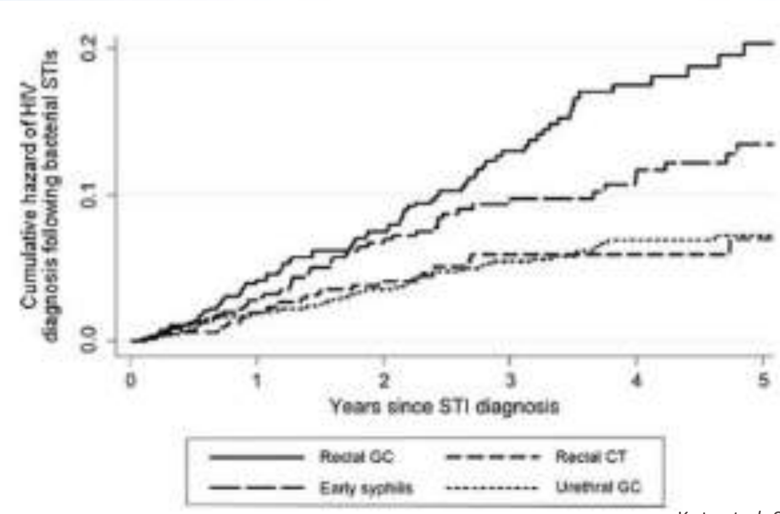


Condomless anal sex can lead to mucosal changes that increase HIV risk without STI

- 41 HIV- MSM who reported condomless receptive anal sex (CRAS) with an HIV- partner were compared to 21 who never engaged in CRAS
- Rectal CD8+ T cells in CRAS+ MSM showed greater proliferation status (i.e. ↑ Ki-67, CD38, CCR5, α4β7)
- Rectal CD4+T cells showed ↑ IL-17, and CD8+T cells showed ↑ pro-inflammatory cytokines
- Rectal microbiota of CRAS+MSM was enriched for prevotellaceae, associated with mucosal injury and repair.

Kelley, Mucosal Immunol, 2017

Rectal gonorrhea and syphilis are predictive of future HIV infection



Katz *et al. Sex Trans Dis.* 43(4):249-254, 2016.
Also Bernstein et al from SF and Pathela et al from NYC

Extragenital STI Screening is Important

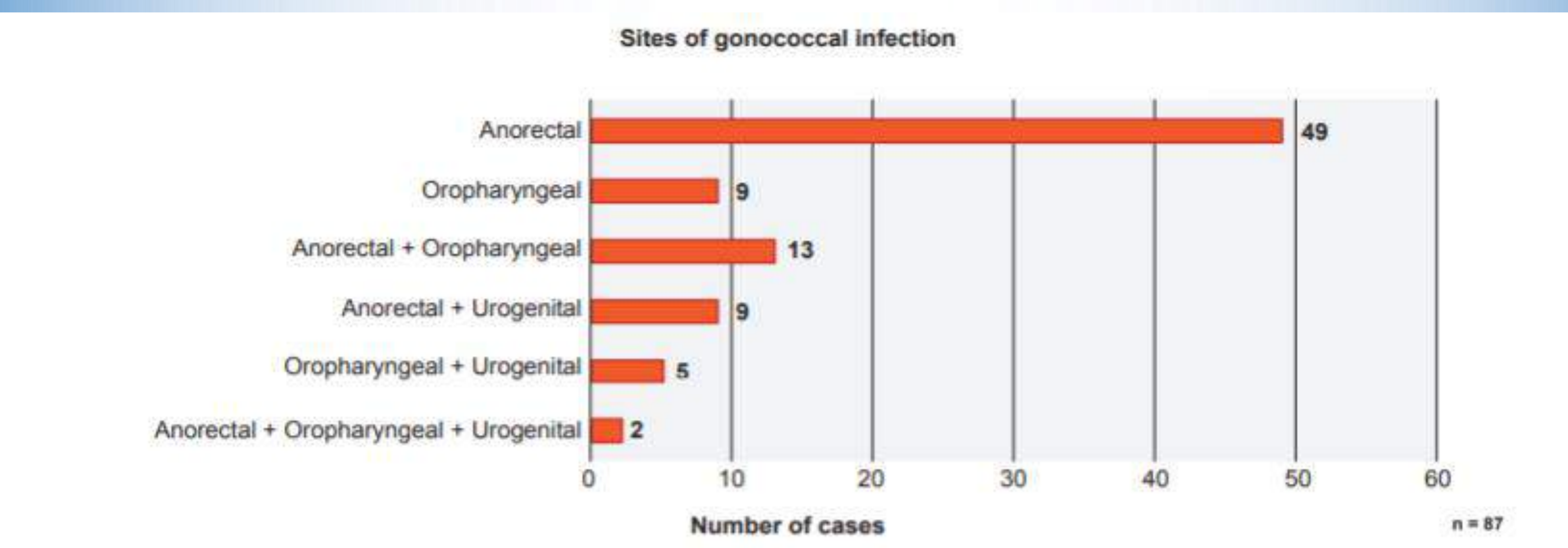


Figure 1 – Anatomical location of extragenital gonorrhoea. Distribution of gonococcal infections by site(s) (n = 87): exclusively extragenital infections accounted for the majority of cases (71), whereas the remainder 16 cases corresponded to mixed extragenital and urogenital infections.

Valejo Coelho MM, Matos-Pires E, Serrão V, Rodrigues A, Fernandes C.
Acta Med Port. 2018 May 30;31(5):247-253

Black and Latino MSM using mobile phones and internet for sex had ↑STI rates

(n=853 Black and Latino MSM)

- **23%** reported an STI in the prior year.
  - **29%** reported using a mobile phone app for sex.
  - **28%** reported using an internet site to meet sex partners
  - **22%** used both.

- MSM reporting using both mobile phone and computer-based sites were **more likely to report an STI** (AOR=2.59, 95% CI 1.75-3.83)

Allen, STD, 2017

Case Study 1: Continued

- Informs you that he has a primary male partner but they are not sexually exclusive.
- He was on PrEP but stopped because he was concerned about side effects and taking it daily.
- He tells you he and his partner started using meth when they have group sex.

What are his options and how would you handle this situation?

Is group sex a higher-risk setting for HIV/STI, compared to dyadic sex, for MSM?

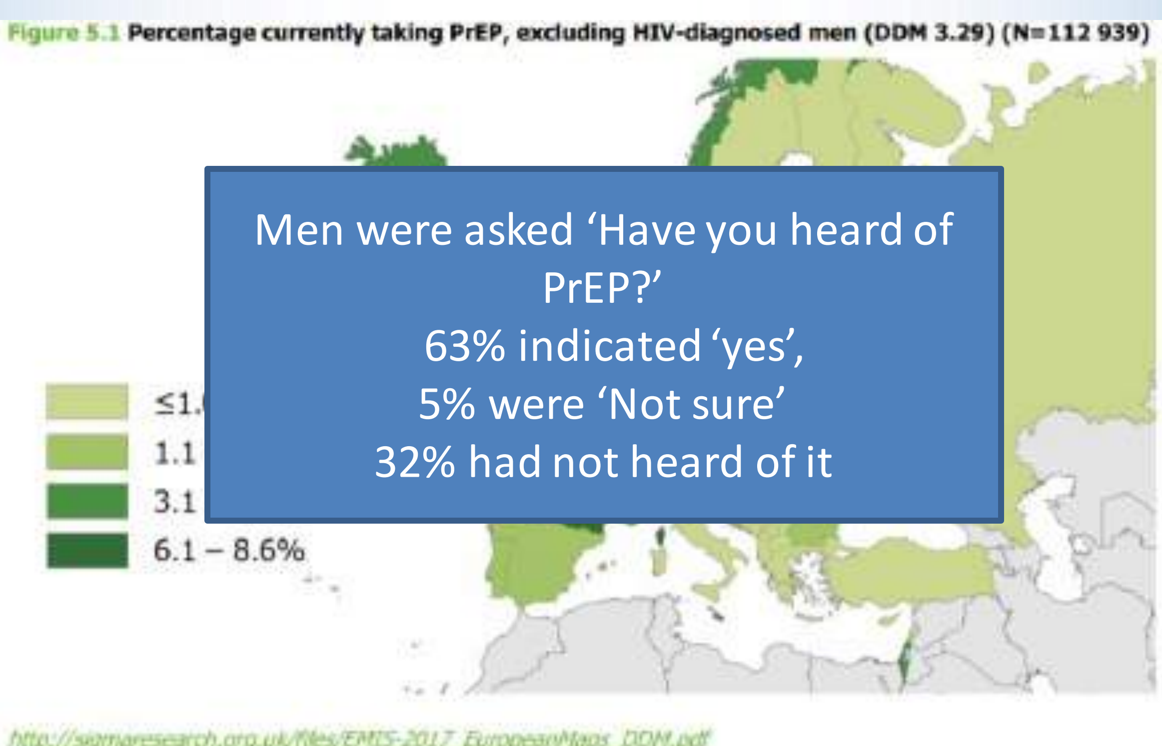
- 35% of 465 MSM participating in Amsterdam cohort studies reported some group sex
- Condomless sex was more often reported during dyadic than group sex, OR=3.6 (95% CI 2.57-5.16)
- **Men who reported group sex were more likely to be diagnosed with gonorrhea compared to those who only reported dyadic sex**, OR= 1.71 (95% CI 1.08-2.97) but this did not persist in multivariable model
- Paradox: **more condom use in group sex, but greater STI risk, possibly because of more partners and inconsistent condom use**

van den Boom, STI, 2016

Pre-Exposure Prophylaxis

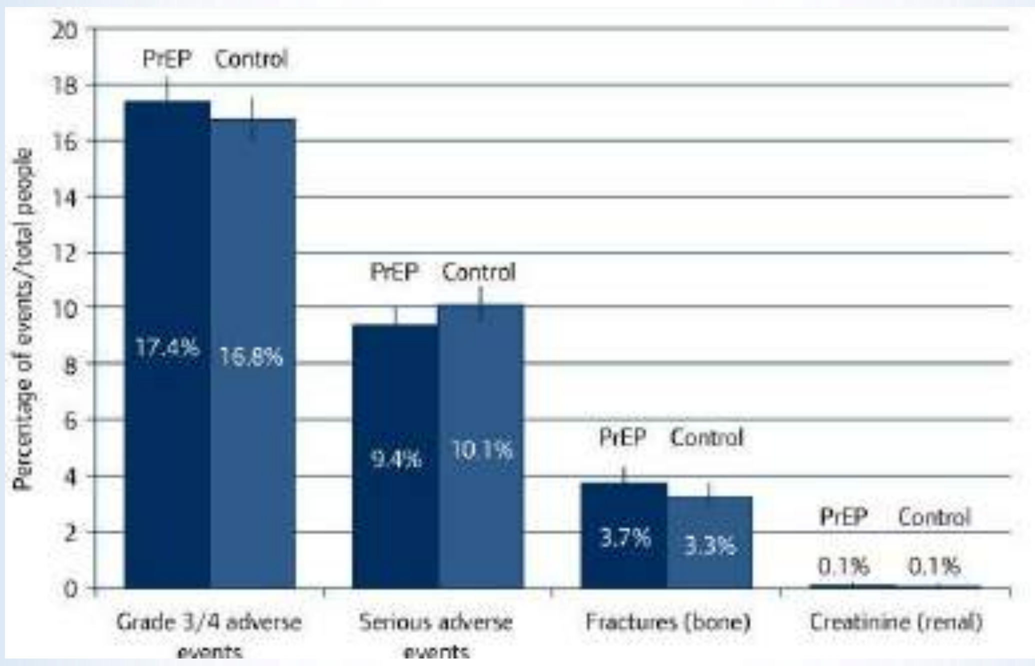
- Uptake has been slow in the U.S., but continues to increase
- Access
- Provider knowledge
- Stigma
- Cost

PrEP Use



Men were asked 'Have you heard of PrEP?'
63% indicated 'yes',
5% were 'Not sure'
32% had not heard of it

Safety of TDF/FTC



Pilkington V, Hill A, Hughes S, Nwokolo N, Pozniak A. How safe is TDF/FTC as PrEP? A systematic review and meta-analysis of the risk of adverse events in 13 randomised trials of PrEP. *J Virus Erad.* 2018;4(4):215–224. Published 2018 Oct 1.

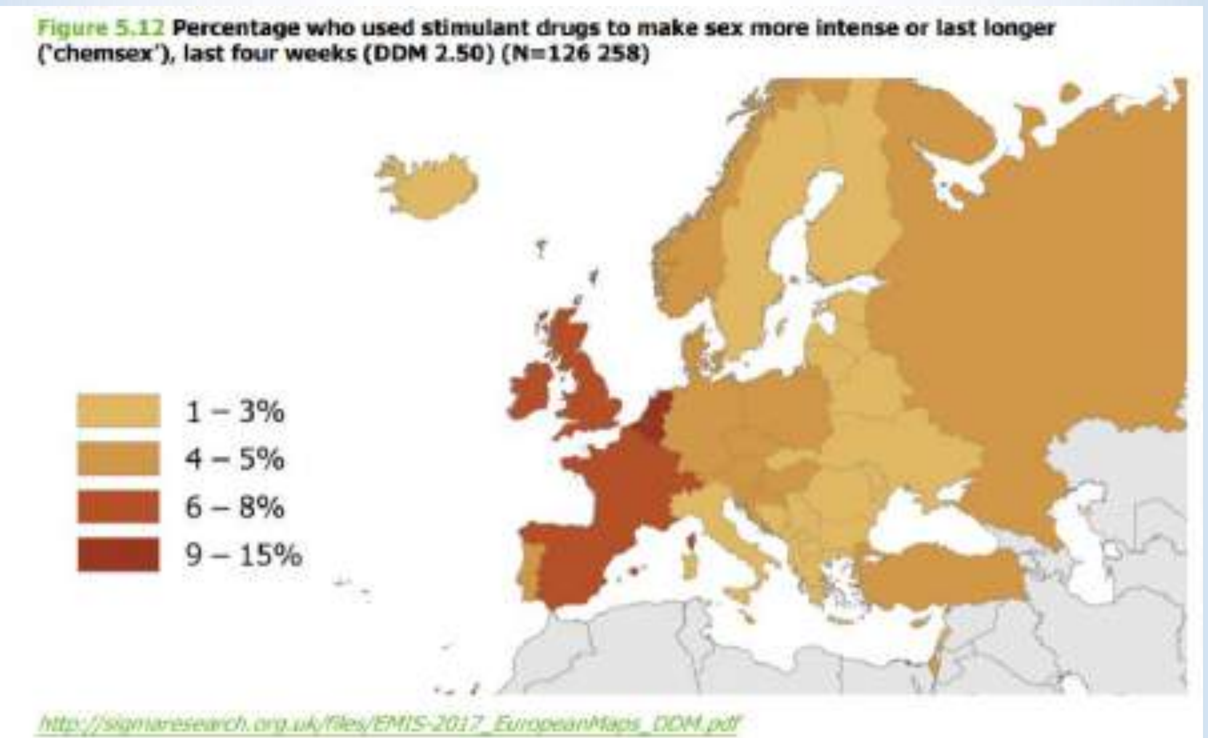
Event Driven vs Daily PrEP

Table 2. When ED-PrEP could be considered

For whom is ED-PrEP appropriate?	For whom is ED-PrEP NOT appropriate?
• a man who has sex with another man: – who would find ED-PrEP more effective and convenient – who has infrequent sex (for example, sex less than 2 times per week on average) – who is able to plan for sex at least 2 hours in advance, or who can delay sex for at least 2 hours	• cisgender women or transgender women • transgender men having vaginal/frontal sex • men having vaginal or anal sex with women • people with chronic hepatitis B infection.

https://apps.who.int/iris/bitstream/handle/10665/325955/WHO-CDS-HIV-19.8-eng.pdf?ua=1

Stimulant drugs and Sex (Chemsex)

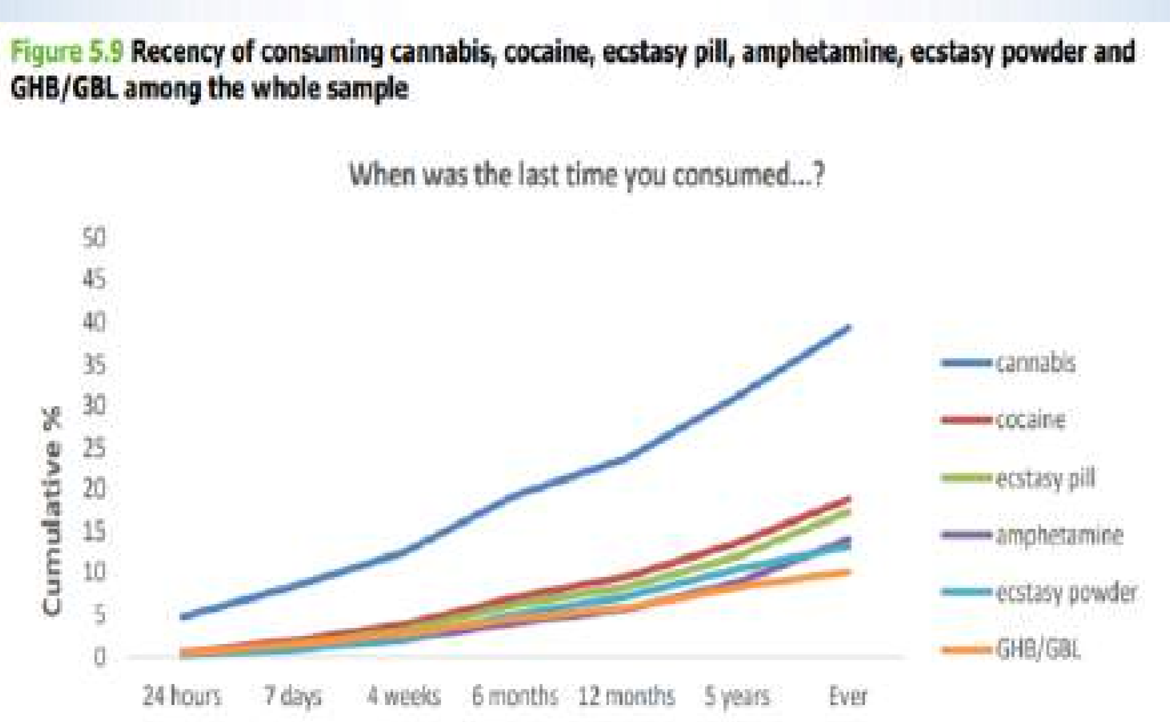


Chemsex associated with higher rates of GC

- MSM who used crystal methamphetamine and GHB/GBL in previous year had **1.92- and 2.23-fold** higher odds of GC
-
- MSM reporting the use of all three chemsex drugs had the highest increased odds (aOR **3.58**; P < 0.0001; n = 15 174).

Kohli, Manik; Hickson, Ford; Free, Caroline; Reid, David; Weatherburn, Peter; (2019) *Cross-sectional analysis of chemsex drug use and gonorrhoea diagnosis among men who have sex with men in the UK.* Sexual Health. DOI: https://doi.org/10.1071/SH18159

Substance Use



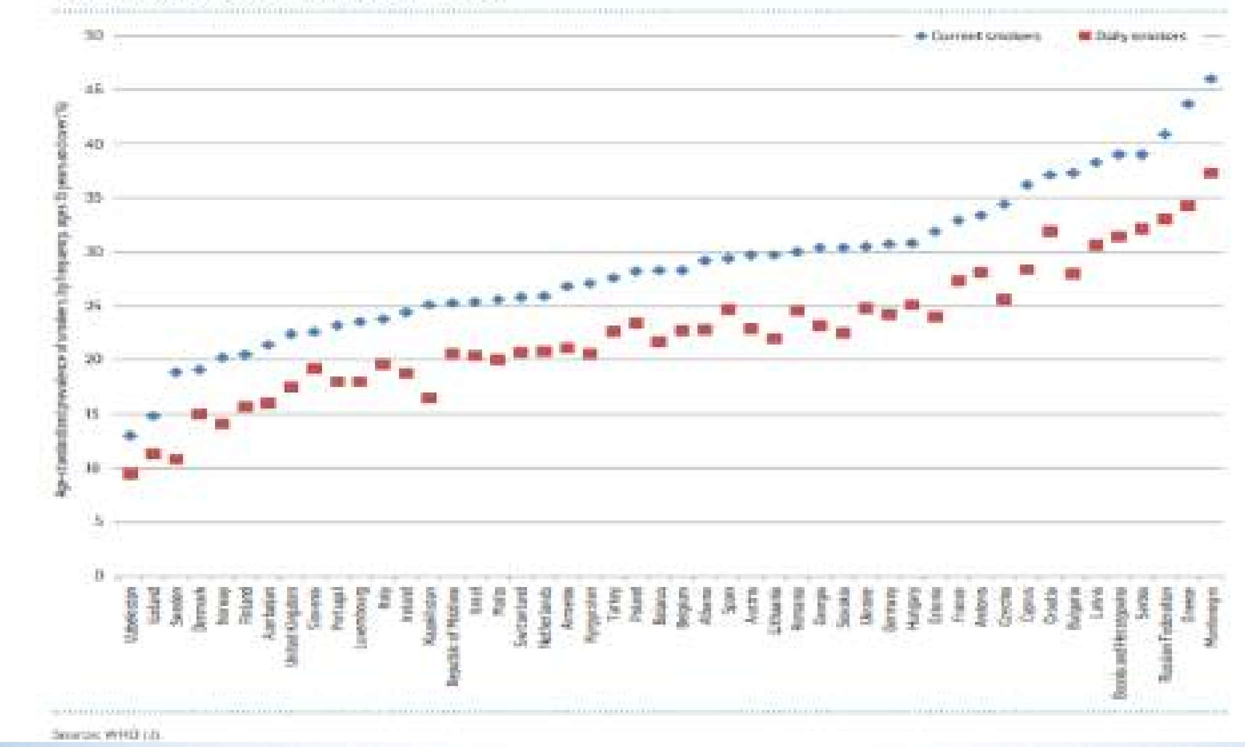
Alcohol Dependency

Figure 4.3 Percentage with potential alcohol dependency (CAGE4) (N=126 146)

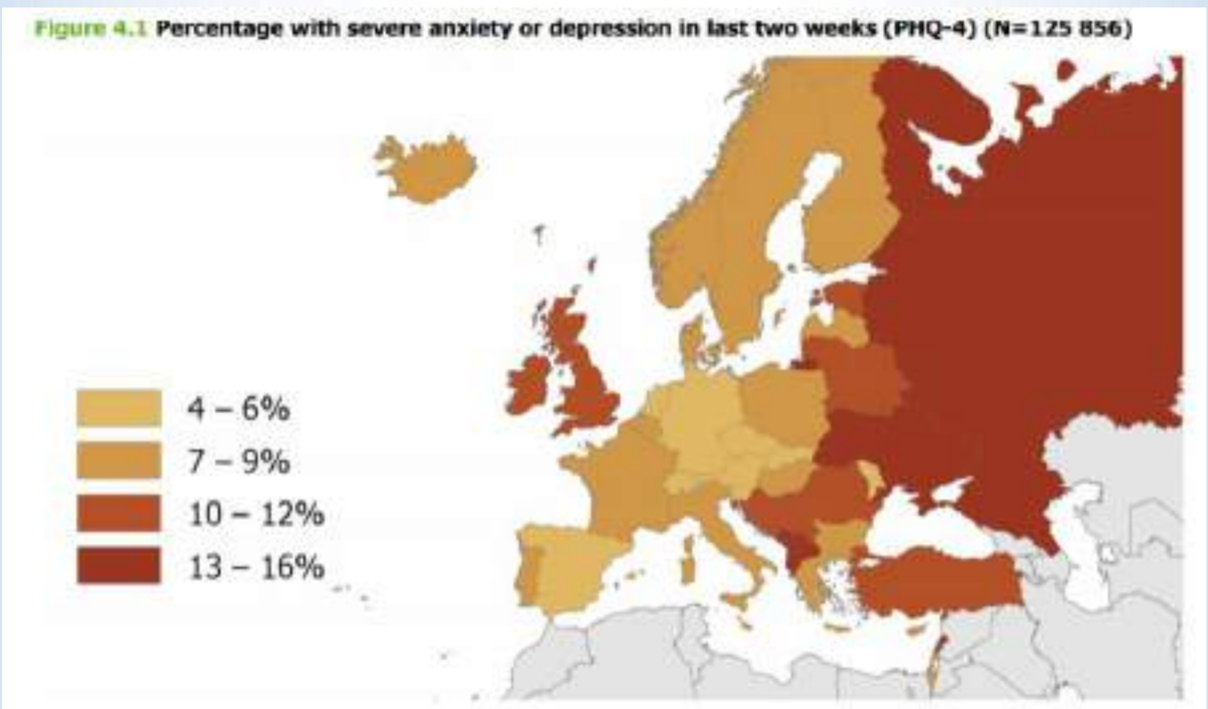
9 – 18%
19 – 26%
27 – 34%

http://sigmaresearch.org.uk/files/EMIS-2012_EuropeanMaps_DDM.pdf

Tobacco Use



Anxiety or Depression



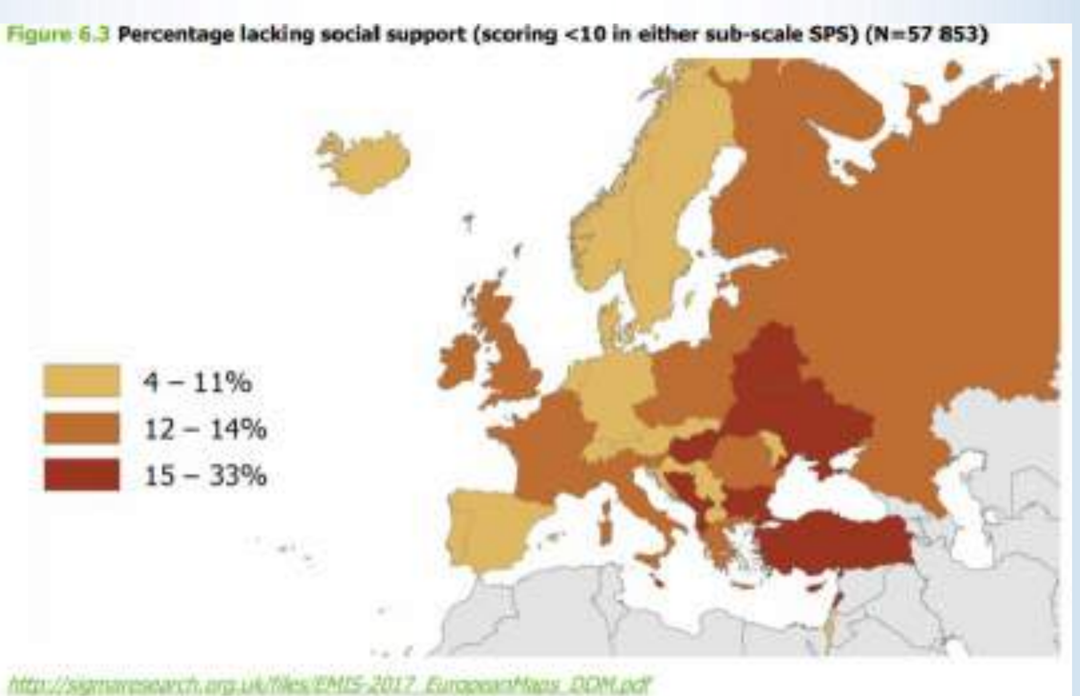
https://www.ecdc.europa.eu/sites/portal/files/documents/European-MSM-internet-survey-2017-findings.pdf

Mental Health Issues

- 40% of **MSM become depressed**, 2X the lifetime rate of heterosexuals
- Predictors of major depression are:
  - not having a partner,
  - experiencing **anti-gay threats or violence**,
  - **non-identification** as gay
- Panic disorder, social phobia, generalized anxiety disorder are more common among MSM (**20% lifetime incidence**)
- **Culturally-tailored treatment** may involve groups that enhance community identification

(Sandfort, Arch Gen Psych, 2001; Gilman, AJPH, 2001; Lewis, Health Place, 2010; Safren, Health Psychology, 2012)

Social Support



Other Prevention Needs

- Vaccination for Hepatitis A and Hepatitis B
- Vaccination against HPV

41% of the respondents did not know that vaccination against hepatitis A and B is recommended for MSM.

Guidelines for implementing comprehensive HIV and STI programs with MSM

- Human Rights
- Access to quality health care
- Access to justice
- Acceptability of services is a key spect of effectivenesss
- Health literacy
- Integrated service provision
- Community empowerment
- Community participation and leadership

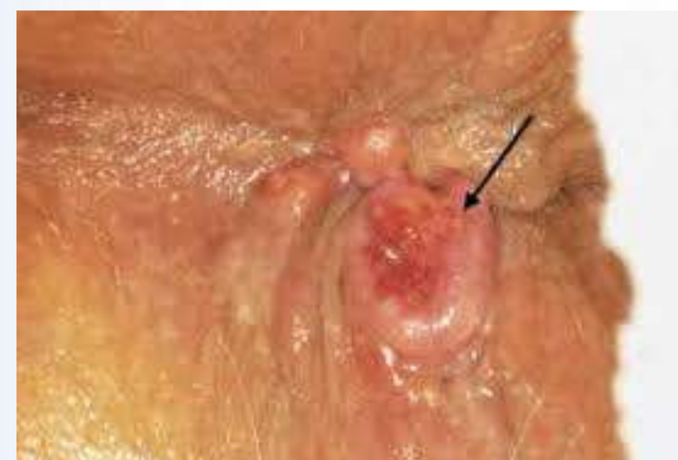
https://www.unfpa.org/sites/default/files/pub-pdf/MSMIT_for_Web.pdf

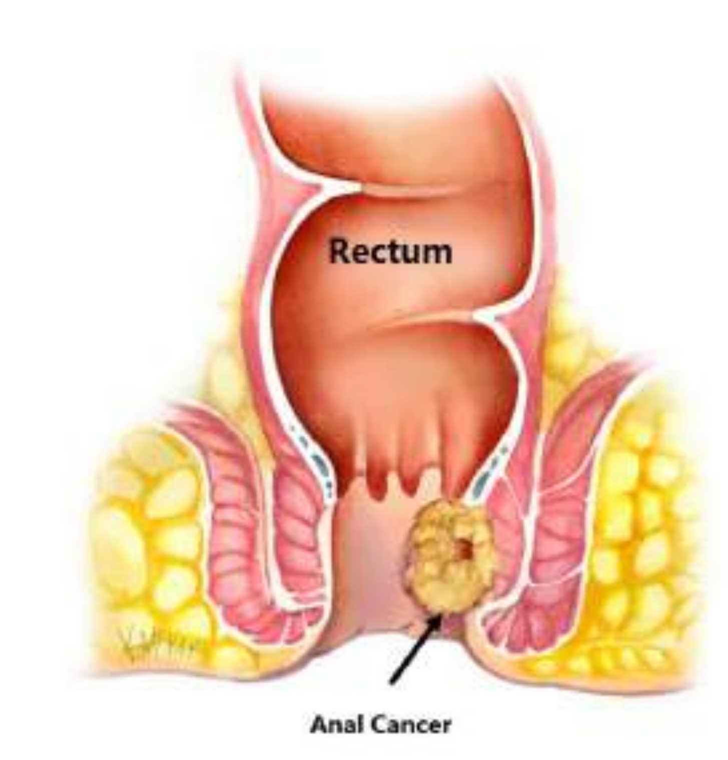
Case #2: KZ

- KZ is a 62 year old male living with HIV (dx in 2000)
- Presents with a complaint of rectal bleeding
- **Past Medical History**:
  - syphilis, GC proctitis, asthma, hypertension, hyper-lipidemia, depression
- **Medications**:
  - Tenofovir alafenamide/Emtricitabine/Bictegravir
  - Albuterol
  - Valsartan
  - Citalopram
  - Atorvostatin

Case #2: KZ

- On physical exam




Rectum
Anal Cancer

Anal Cancer

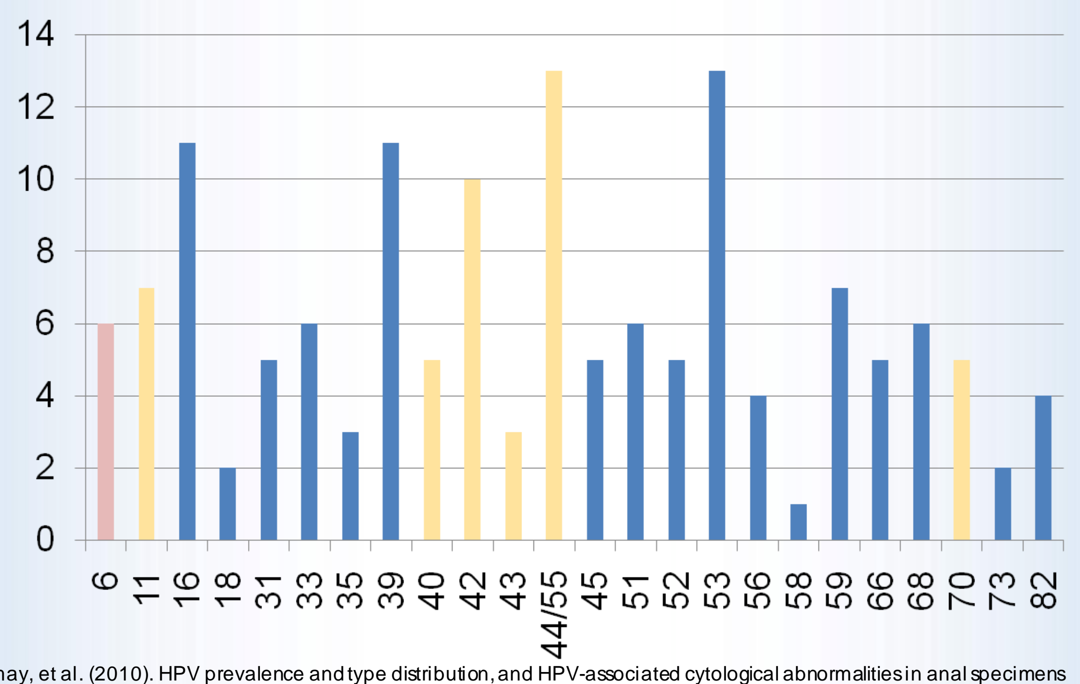
- HIV negative MSMs are **20 times** more likely to be diagnosed with anal cancer. Their rate is about 40 cases per 100,000.

- HIV-positive MSMs are up to **40-80 times** more likely to diagnosed with the disease, resulting in a rate of 80 anal cancer cases per 100,000 people.

https://cancer-network.org/cancer-information/gay-men-and-cancer/anal-cancer-hiv-and-gaybisexual-men/

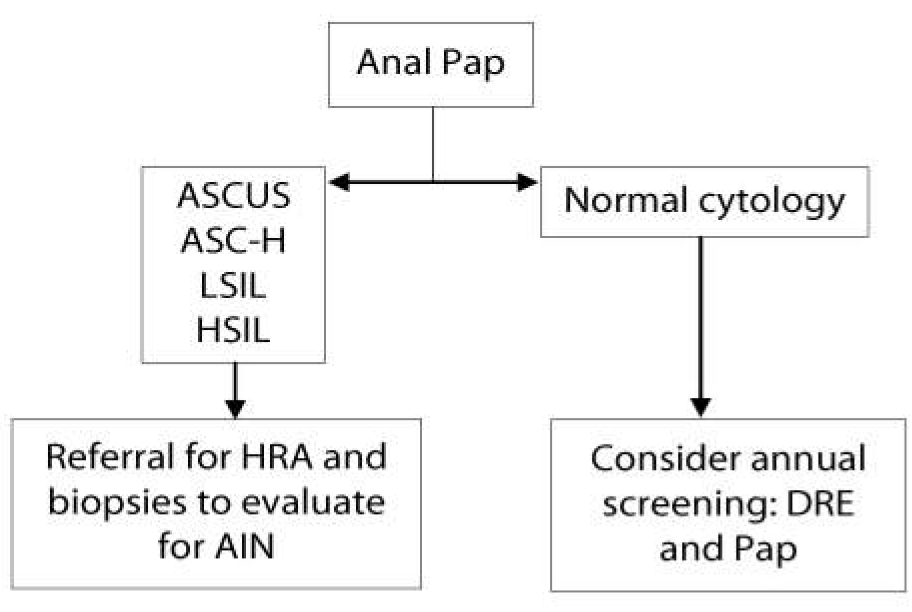
International_Anal_Neoplasia_Society_Guidelines.8.pdf

HPV Type in HIV+ MSM



Damay, et al. (2010). HPV prevalence and type distribution, and HPV-associated cytological abnormalities in anal specimens from men infected with HIV who have sex with men. *J Med Virol* 82:592-596

HPV screening algorithm



Digital Anal Rectal Exam

Group	Minimum[a] proposed DARE frequency
Those with symptoms suggesting anal cancer such as: bleeding, anal/perianal mass, tenesmus, pain, altered bowel habit (read, Read et al., 2013)[38]	Immediately, with referral for anoscopy, HRA, or to a colorectal specialist if the initial DARE is negative
HIV-positive MSM	At least annually in men ≥35 y
Those with demonstrated cytologic or histologic anal HSIL	At least annually
Those with a history of treated anal squamous cell carcinoma	Every 4 mo after completion of radiation for first 2 y, then every 6 mo for the next 3 y, then at least annually (Wright et al., 2010)[39]
Other immunosuppressed populations, such as other groups with HIV infection and recipients of solid organ transplants	At least annually in those ≥50 y
HIV-negative MSM	Every 2 to 5 y in those ≥50 y
Women with a history of cervical, vulvar or vaginal neoplasia or cancer	Every 2 to 5 y, depending on further risk assessment (Moscicki et al.,[15] 2015)

Colonoscopy may miss anal canal lesions and performing a DARE potentially provides an opportunity to assess the anal canal while the patient is sedated.

[a]Frequency may increase, depending on risk assessment, such as anal history, degree of immunosuppression, age, and smoking status.

https://journals.lww.com/jlgtd/Pages/articleviewer.aspx?year=2019&issue=04000&article=00008&type=Fulltext

Conclusions

- MSM are at **greater risk for health disparities** including HIV, other STIs, substance use, violence, and mental health issues.

- **MSM living with HIV** are also at **greater** risk for certain co-morbidities including HPV-associated **anal cancer**.

- **Nurses** play a critical role in recognizing, addressing disparities in care through the **provision of social, physical, and behavioral interventions that are re-affirming** and meet the **cultural needs of MSM**

THE EXPERIENCE OF AGING LIVING WITH HIV IN SPAIN:
A Phenomenological Study

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INTRODUCTION

RARE CANCER SEEN IN 41 HOMOSEXUALS

Outbreak Occurs Among Men in New York and California —8 Died Inside 2 Years

By LAWRENCE K. ALTMAN

Medscape® www.medscape.com

FIGURE. *MMWR* report on *Pneumocystis* pneumonia in five previously healthy young men in Los Angeles — June 5, 1981

CDC

MMWR

MORBIDITY AND MORTALITY WEEKLY REPORT

June 5, 1981 / Vol. 30 / No. 21

Pneumocystis Pneumonia — Los Angeles

Source: MMWR © 2006 Centers for Disease Control and Prevention (CDC)

Virology

Public Health

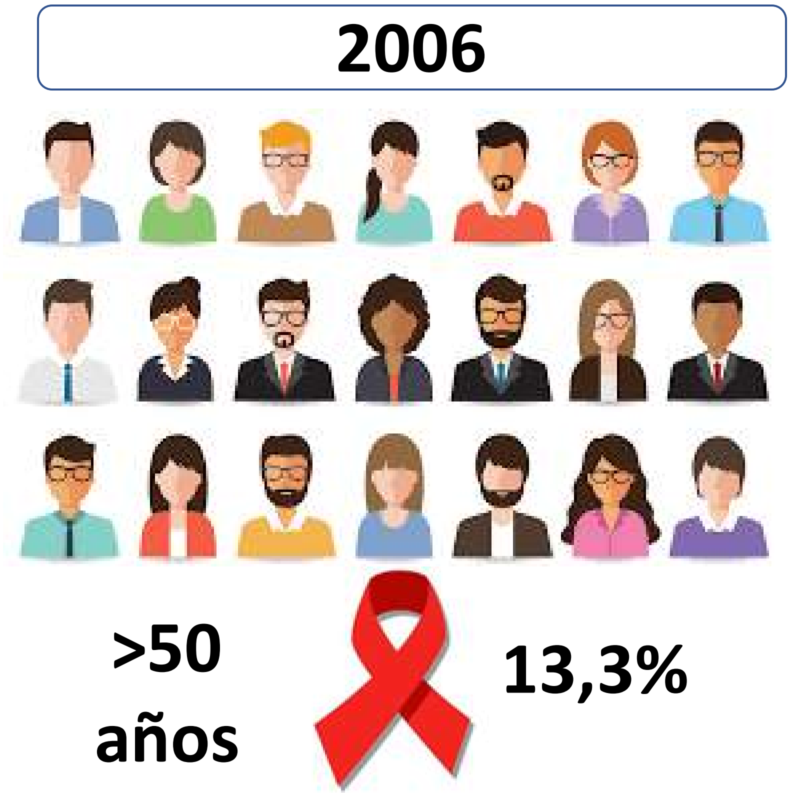
Pharmacology

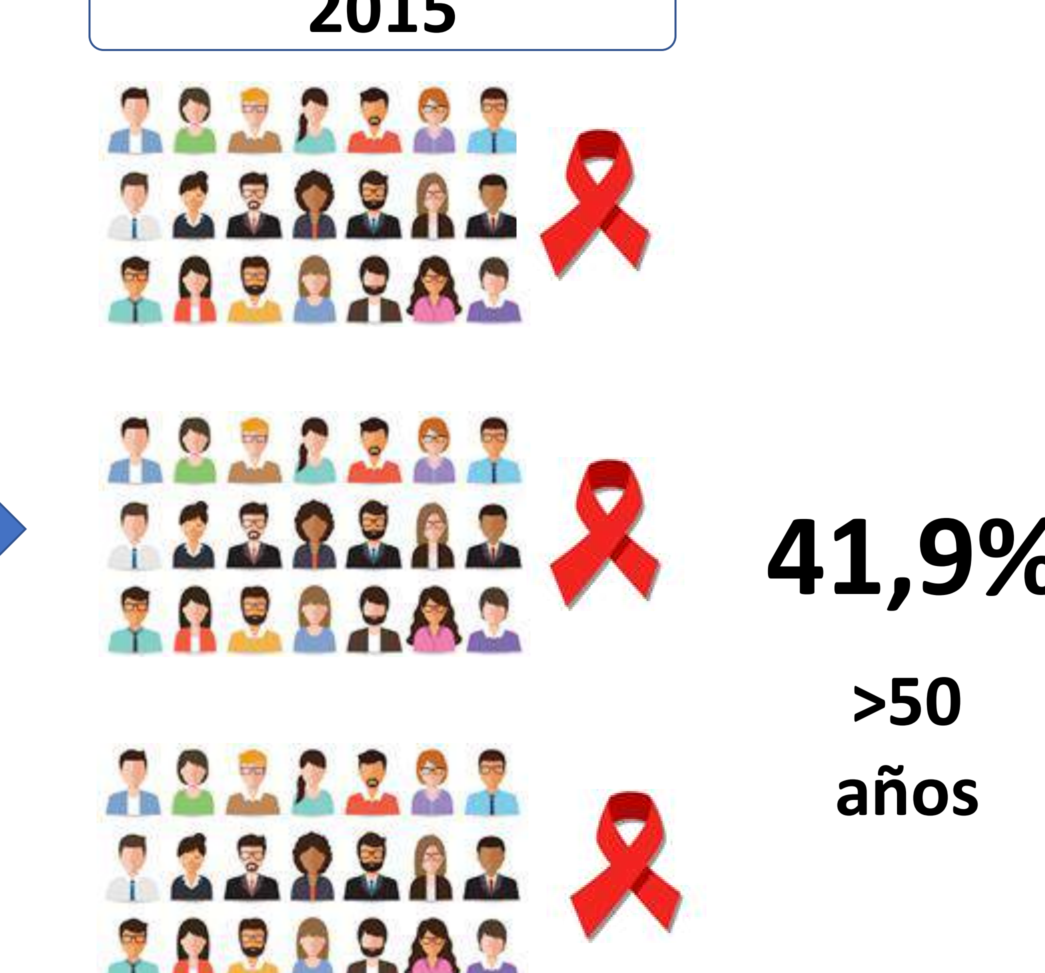
Mortal

Chronic

Sabin, C. A. (2013). Do people with HIV infection have a normal life expectancy in the era of combination antiretroviral therapy? *BMC Medicine*, *11*(1), 251. https://doi.org/10.1186/1741-7015-11-251

INTRODUCTIÓN





- Manzanares, F., Herrando, I., del Amo, J., Diaz, A., & Grupo de Trabajo de la Encuesta Hospitalaria de Pacientes con VIH. (2016). Caracterización del paciente con VIH de 50 o más años. Resultados de la encuesta hospitalaria, 2006-2015. In *VIII Congreso* Nacional GeSIDA (p. Poster 127).

AIMS

1. To describe the experiences of aging while living with HIV in Spain.
2. To detect unmet care needs.
3. To identify coping mechanisms

METHODOLOGY

- Qualitative
- Descriptive phenomenology
- Purposive sampling (>50 years old & >10 years living with HIV)
- Semi-structured interviews 2017
- Data saturation
- IRB approval
  - Anonymous, confidential, voluntary, informed consent.
- Data analysis: 7 steps Colaizzi method.

Table 2. Participant Characteristics

Key Informants (n = 24)	M (SD)
Age	$\bar{x}$ = 55.08 years (5.1)
Years living with HIV	$\bar{x}$ = 26.58 years (6.3)
Key Informants (n = 24)	***n* (%)**
Sex	
Male	17 (70.83)
Female	7 (29.16)
Sexual identity	
Men who have sex with men	11 (45.83)
Heterosexual	10 (41.66)
Not available	3 (12.5)
Financial situation	
Retired	17 (70.83)
Employed	6 (25)
Unemployed	1 (4.16)
Marital Status	
Single	12 (50)
Widowed	4 (16.66)
Engaged	4 (16.66)
Divorced	3 (12.5)
Not available	1 (4.16)
Children	
Yes	18 (75)
No	6 (25)
City of residence	
Valencia	5 (20.83)
Madrid	3 (12.5)
Cartagena	3 (12.5)
Bilbao	3 (12.5)
Gijón	3 (12.5)
Seville	3 (12.5)
Barcelona	2 (8.33)
Burgos	2 (8.33)

Note. SD = standard deviation.

FINDINGS

1. TOMORROW IS HERE

- Survivors
- New worries
- Loneliness
- Aging as a natural process
- Specialized care demands

"I did not expect to live so long, and look at me, I am 53 and I am still here" (Adam, male)

"I feel enormous loneliness and also a lack of love and affection. I have a solitary life. I would say that I am almost totally alone" (Abel, male)

"Very few interventions are specifically designed for us nowadays. We are a lot o people living with HIV for so many years; we are getting old" (Ángel, male)

FINDINGS

2. WE WERE DYING

- Death watermark
- Frail health
- 1st ART
- Non-regular adherence

"My friends with HIV were dying, all of them. This keeps you in a permanent state of fear" (Adela, female)

"I was like a dragon spitting fire out out my mouth" (Agustín, male)

"I stopped ART for three months and when I went to see the doctor, I screwed it! My viral load was very high again!" (Alejo, male)

FINDINGS

3. THE OTHERS

- Family (- Vs +)
- NGO's
- Society
- Health care providers

"When I said it at home… my mother kept being my mother, and so did my father, my brother and my sister" (Amadeo, male).

"When I came out of the doctor's office my parents told me that if I had it they did not want to see me again. They did not give me any support. Anything was the same again" (Adolfo, male)

FINDINGS

3. THE OTHERS

- Family (- Vs +)
- NGO's
- Society
- Health care providers

"Doctors' attention is excellent. Their human quality is just excellent. They are very involved with the cause" (Agustín, male)

"There are still doctors that have bad reactions when they treat a person with HIV" (Adela, female)

"I am nurse assistant. I can't say 'I am HIV+' because they will not accept it. HIV is … something classified (Alba, female)

FINDINGS

4. SELF-CARE

- Hope
- Emotional relief
- New ARTs
- Care strategies
- Normalization

“Now you just take a pill and it makes everything easier. You some hope” (Agustín, male)

“Everything has its own phases… I didn’t say it before but when I felt ready I asked myself ‘Why should I hide?’ If I am HIV+, I am, full stop” (Alba, female)

CONCLUSIONS

1. Aging living with HIV means to face intense vital experiences which threaten emotional, physical and social health.
2. Participants learnt to face it spontaneously, with lay care.
3. Analysis and discussion is needed to face new social and health care demands for old people living with HIV
4. Loneliness and its impact on patient's life must be systematically assessed in older people living with HIV
5. More research is needed

THANK YOU
MUCHAS GRACIAS

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REFUGEES, HIV AND SEXUAL HEALTH

Maja Erceg Tušek, MS (Psychologist)
Croatian Association for HIV and Viral Hepatitis (CAHIV)

HIV NURSING 2019, September 21-22, 2019, Rome

Terminology

- as defined by the Law on International and Temporary Protection (OG 70/2015)3, there are several terminologies used:

- INTERNATIONAL PROTECTION APPLICANTS
- ASYLEES
- FOREIGNERS UNDER SUBSIDIARY PROTECTION
- FOREIGNERS UNDER TEMPORARY PROTECTION
- FOREIGNERS UNDER TRANSFER
- VULNERABLE PERSONS

International protection applicants

- third-country nationals or stateless persons who express the intention to apply for international protection up until the final decision on the application.
- international protection includes asylum and subsidiary protection.

Asylees

- a refugee to whom the asylum is granted.
- Asylum shall be granted to applicants who are outside the country of their nationality or habitual residence and have a well-founded fear of persecution owing to their race, religion, nationality, affiliation to a certain social group or political opinion, as a result of which they are not able or do not wish to accept the protection of that country.

Foreigners under subsidiary protection

- a third country national or a stateless person who has been granted with the subsidiary protection.
- subsidiary protection shall be granted to an applicant who does not meet the conditions to be granted asylum, if justified reasons exist to indicate that if returned to his/her country of origin he/she would face a real risk of suffering serious harm and who is unable, or, owing to such risk, is unwilling to avail himself/herself of the protection of that country.

Foreigners under temporary protection

- a third country national or a stateless persons who have been granted protection of an urgent and temporary character, introduced pursuant to the Decision of the Council of the EU on the existence 7 of a mass influx of displaced persons.
- temporary protection is initially approved for a period of one year and it can be extended to no longer than three years.

Foreigners under transfer

- a third-country national or a stateless persons who is in the process of handover to the responsible member state of the European Economic Area (EEA) for consideration of his/her application.

Vulnerable persons

- deprived of legal capacity, minors, unaccompanied minors, elderly and infirm persons, seriously ill persons, persons with disabilities, pregnant women, single parents with minor children, persons with mental disorders and victims of trafficking in human beings, victims of torture, rape or other psychological, physical and sexual violence

Loss, trauma, stress

- BEFORE TRAVELLING (country of origin)
  - war, life in danger, uncertainty, poverty…
  - leaving their homes and at least part of their family behind, without goodbyes
  - many of them lost family members and valuable assets.

Loss, trauma, stress

- DURING TRAVELLING
  - travelling is for most of them very long (several months or years)
  - it is exhausting (lack of water, food, sleep, exposed to dangers
  - travelling afoot or by unsafe means of travelling, unprotected, until they reach the destination where they seek asylum
  - they meet people with different intents: from activists who help refugees to criminals who want to use the fact they are in need and unprotected, which is sometimes very hard to distinguish so they become distrustful
  - on their way they witness painful things happening
  - conflicts with border police forces and army

Loss, trauma, stress

- AFTER TRAVELLING
  - completely new and different culture (economicaly, politicaly, language, socialy)
  - longterm uncertainty concerning their legal status (can last for several years)
  - challenges: learning new language, finding a job, meeting new friends, housing, education...
  - some of them are less motivated for integration because of the unsolved legal status
  - adapting to new culture and new ways of being is particulary hard while future of their families is not legaly solved so the level of uncertainty is huge, and the meaning of adapting is questionable.

Reception and detention centres in Croatia

- there are reception and detention centres with the capacity of around 700 places for migrants operating under the supervision of Ministry of Interior:
- PORIN - in Zagreb - asylee, asylum seekers, illegal migrants (detention replacement) - as a temporary accommodation
- KUTINA - approximately 80 km from Zagreb; vulnerable groups - women, unaccompanied children, families with children
- JEŽEVO - under the Border Administration of the Ministry of Interior Affairs; detention and deportation centre for foreigners

Upon arrival

- Families are kept together, while vulnerable persons i.e. single women, unaccompanied children and traumatised applicants are accommodated in separate rooms.
- The centre for foreigners in Ježevo is under the competence of the Ministry of Interior and it serves as a detention and deportation centre. This is primarily centre for irregular migrants, but among them there are sometimes foreigners who express the intention to file an application for international protection while accommodated there, so they can stay there for a limited period of time.
- After this period elapses, they are transferred to the Reception Centre for Asylum Seekers (i.e. applicants for international protection).
- Upon arrival measures of personal hygiene (washing and changing clothes) and disinfestations of clothing should be performed.

Medical examination

- Upon admission to the centre, the reception staff or physician should perform the health status examination to detect clear signs of illness, such as fever, rash or diarrhoea and, where needed, to refer the person to the doctor or relevant medical institution
- BASIC MEDICAL EXAMINATION
  - during the first seven days of stay at the shelter, asylum seekers should check immunization status and receive the necessary vaccines. After the examination, a person should receive a written confirmation of the medical examination and guidance on health monitoring procedure. Asylum seekers should be subjected to the 21-days health monitoring at the centre during which some infectious diseases (e.g. yellow fever, measles) would manifest in case the person arrived infected but without symptoms. Also, during that period, person would get lab results from the performed analysis and receive vaccinations if necessary.
- ADDITIONAL MEDICAL EXAMINATION
  - after the medical examination, health certificate is issued to the asylum seeker in two copies, of which one is submitted together with other documents as part of the submission of request for status, and the other copy person keeps it for himself. A positive finding of a chronic disease can not influence the decision about obtaining status.

In the case of medical emergency…

- In the case of medical emergency, every person irrespective of his/her legal status in Croatia has the right to medical emergency examination and emergency treatment.
- they should inform about emergency situation the person on duty in the Centre who will call an ambulance.
- if hospital treatment is indicated, person needs a referral from primary care physician.
- in case of medical emergency, person is admitted to the hospital immediately and without a referral.

Croatian health system guide

- Croatian health system navigation guide for international protection applicants, asylees and persons under subsidiary protection (2016)
- Published by Croatian Institute of Public Health (CIPH)
- https://www.hzjz.hr/wp-content/uploads/2017/12/CARE-brosura-EN.pdf
- this booklet is part of the project / joint action ‘717317 / CARE ’ which has received funding from the European Union’s Health Programme (2014- 2020)

CARE

- **C**ommon **A**pproach for **RE**fugees and other migrants' health
- aimed to promote a better understanding of refugees and migrants' health condition as well as to support the adaptation of the appropriate clinical attitude towards refugees and migrants' health needs and in particular towards the health needs of fragile subgroups, such as minors, pregnant women and victims of violence.
- its main results included more appropriate health care deliveries, increased control of infectious disease risk at the early phase of migrant's care and better taking care of migrants' health over the European territory will have been obtained.
- http://careformigrants.eu/the-project/

Sexual health in refugees

- many overlaping risk factors affecting this population also reflect upon their sexual health
- higher risk for infectious diseases, including HIV and other STDs
- poor living conditions lead to poor health
- prostitution, sex without protection, history of sexual violence…
- poor sexual education
- diagnostics and treatment

Needs and challenges

- need to educate and support people working with refugees
- need to provide material support for the refugees
- need to provide better medical support to the refugees
- need to provide psychological support to the refugees
- dealing with traumatic experiences
- dealing with language barriers (working with a translator)
- integrating in society (school, job...)
- legal challenges
- stigma and discrimination

Organizations supporting refugees in Croatia

- Croatian Red Cross
- Center for Peace Studies (CMS)
- JRS (Jesuit Refugee Service)
- Are You Syrious
- Society for Psychological Assistance (DPP)
- Rehabilitation Centre for Stress and Trauma - RCT
- Croatian Law Center
- Médecins du Monde – MDM
- Croatia Association for HIV and Viral Hepatitis
- lokalne vjerske zajednice
- lokalni volonterski centri
- UNHCR
- UNICEF

Thank you for attending and for attention

THE ROLE OF THE NURSE IN HARM REDUCTION

ARD LLUÍS COMPANYS-CREU ROJA

HIV Nursing 2019

Sara Riba Venanci- sara.riba@creuroja.org

Himalaya Vallejo Cañete- himalaya.vallejo@creuroja.org

Cada cop més a prop de les persones

WHAT IS HARM REDUCTION?

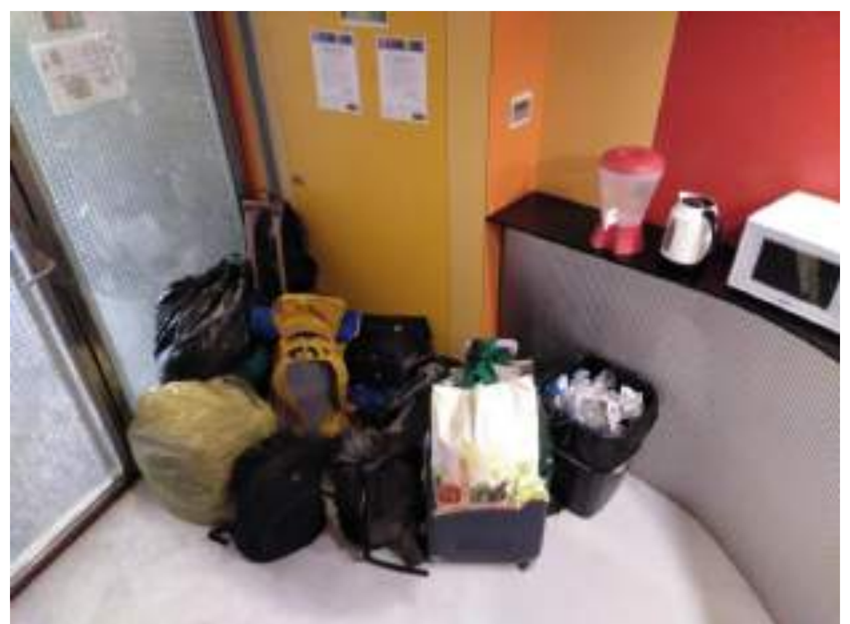
Set of policies and programs that aim to reduce the negative consequences of drug use.

General objectives:

- Prevent overdoses derived from drug use.
- Reduce mortality and morbidity.
- Prevent infectious diseases.
- Linking to the health public system and adherence to treatments.
- Reduce social exclusion.
- Improve Life Quality.

WHO DO WE ATTEND TO?

- People who use active drugs.
- Population at risk of social exclusion (homeless, prostitution, squatters ...)



WHERE WE WORK

Entry

WHERE WE WORK

The club

Cada cop més a prop de les persones

WHERE WE WORK

Shower and laundry area

WHERE WE WORK

Consumption room

WHERE WE WORK

Nursery

WHERE DO WE WORK?

Workshop room

THE NURSE IN ARD

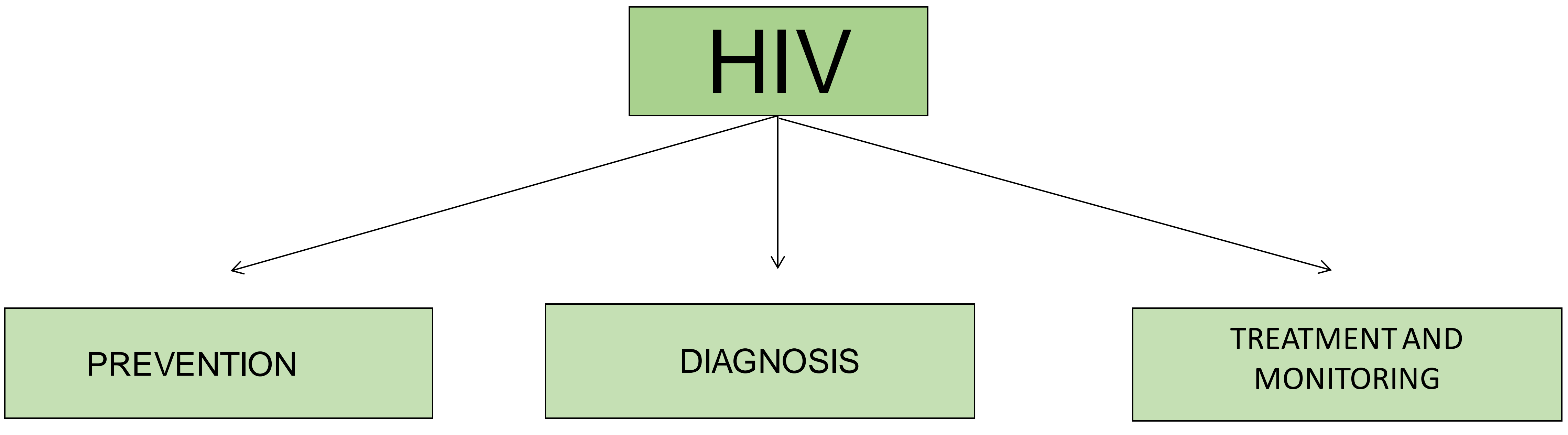
Nursery:

- Blood test.
- Rapid test (HIV, HCV and Syphilis).
- Vaccines.
- Supervised medication: HIV, HCV and chronic treatment.
- Tuberculin test.
- Basic nursing cures: abscesses, wound sutures etc.
- Individual and group health education as hygienic venipuncture workshops and overdose prevention workshops.

THE NURSE IN ARD

Consumption room:

- Supervision of consumption.
- Help in the search for venous access.
- Overdose attention.
- Hygiene consumption education.


HIV
PREVENTION
DIAGNOSIS
TREATMENT AND MONITORING

PREVENTION

Needles delivery and collection program: provide sterile needle and other items necessary for hygienic injected consumption and encourages the return of used syringes.
During 2018, 22354 syringes were delivered and returned to our 6884 service.

PREVENTION

Consumption room: Socio-sanitary space for hygienic users of drugs, where the person can consume with intimacy and under nursing supervision. Nurse can offer help in case of need and thus improve the practice of hygienic venipuncture to prevent infections and organic complications.

During 2018, 2284 people used the room, of which 397 needed help in the search for venous access.

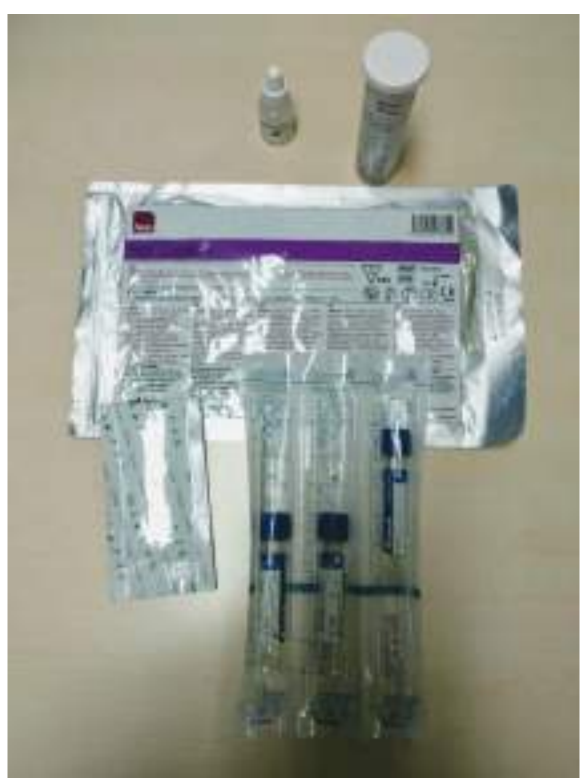
PREVENTION

Health Education:

- Safe sex.
- Workshops of hygienic venipuncture.
- Programs snowball.
- Interactive activities related to HIV.
- Assemblies to solve doubts.

DIAGNOSIS

Rapid test

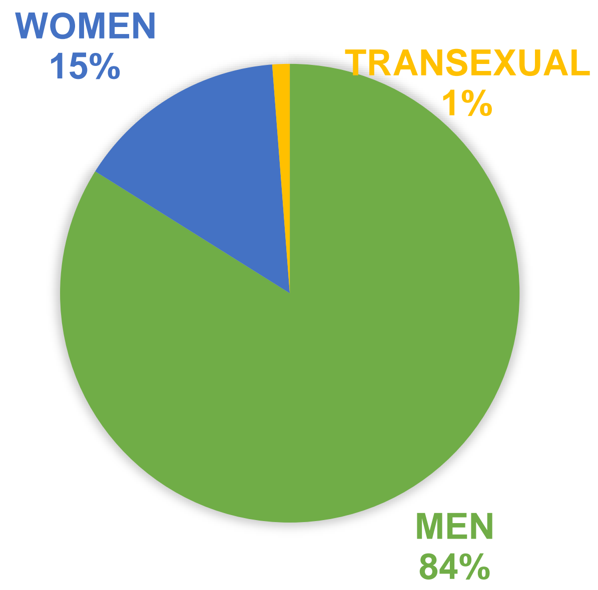


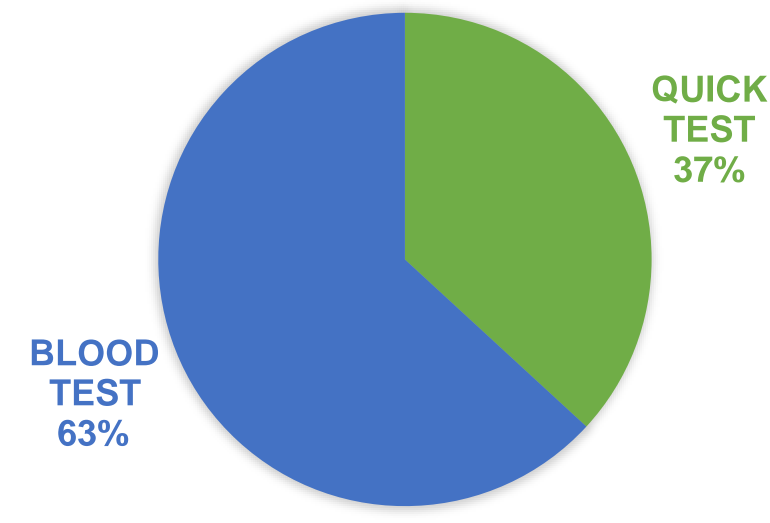
DIAGNOSIS

Blood test: serology and viral load

DIAGNOSIS

In 2018, a total of 114 HIV screenings were performed, two of them with a POSITIVE diagnosis.





TREATMENT AND MONITORING

Treatment:

- Confirmation of diagnosis and viral load.
- Referral to Infectious Medicine unit.
- Adherence treatment.
- Supervision of treatment taking.
- Side effects control.
- Accompaniment to visits with specialists and for the collection of drugs.

TREATMENT AND MONITORING

During 2018, 3639 nursing visits were made, with a total of 713 due to STD and Infectious Medicine. 261 visits were for delivery and supervision of TARGA treatment.

CONCLUSION

The existence of harm reduction resources is of vital importance, since the population we work with has a high incidence of HIV infection and from these centers access to early diagnosis and treatment follow-up is facilitated.

Injecting drug use should not be seen as a criminal act, but as a major public health issue. We have a responsibility to safeguard the well-being of drug users and allow them to minimize harm to themselves and others by offering simple life-saving services and continuous support.

Thank you

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Women living with HIV in Clinical Research

Christina Antoniadi, RN, Chelsea and Westminster Hospital
NHS Foundation Trust
Co-opted member of the NHIVNA Executive Committee

Disclosures

- All views are my own.
- This presentation is based on the research of others.

What we know

Every cell has a sex, and all bodies are influenced by gender. Integrating these factors into medical education, training and clinical practice will improve health care for all.

Sex and Gender Women's Health Collaborative http://sgwhc.org/

What we know

TED Ideas worth spreading WATCH DISCOVER

Alyson McGregor | TEDxProvidence

Why medicine often has dangerous side effects for women

Share

Add to list

Like

Recommend

ALYSONMCGREGOR

15:16

September 2014

Dr. Alyson McGregor

Sex and Gender Women's Health Collaborative

A couple of questions:

- Are there different signs of heart attack in men and women?
- Which are they?

What we know

Discomfort or tingling in arms, back, neck, shoulder or jaw

Sudden dizziness

Heartburn-like feeling

Most common IN MEN...

Watch for THE SIGNS

Additional symptoms, most common IN WOMEN...

Chest pain

Cold sweat

Shortness of breath

Nausea or vomiting

Unusual tiredness

The Heart foundation: https://theheartfoundation.org/2017/03/29/heart-attack-men-vs-women/

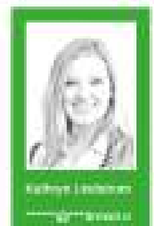
What we know

CONCLUSIONS:

Many of the trials that have established the efficacy and safety of statins were conducted predominantly or entirely in men, with results extrapolated to women. **Additional research is needed** to guide clinical recommendations specific to women.

Key points

- When it comes to CVD, a typical presentation may not be accurate for half of the population
- In CVD, sex and gender differences contribute to a lower perceived risk of morbidity in women than in men
- A typical presentation of CVD must be further defined to include the sex that it describes
- We need to reclassify typical and atypical presentations of CVD as this terminology contributes to bias that may lead to incorrect diagnoses



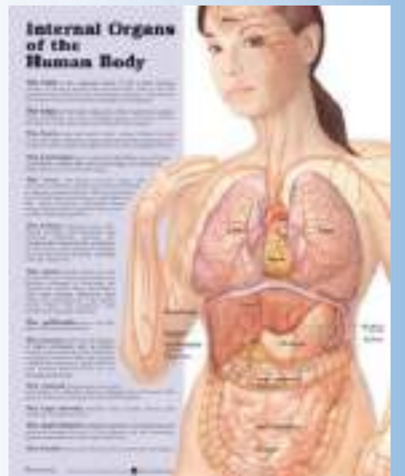
HealthManagement, Volume 19 - Issue 4, 2019

Sex & Gender Impacts in Cardiovascular Disease: A "Typical" Presentation of Cardiovascular Disease?

Share

Are there differences?

- **Biological Differences:**
- Hormonal profile: affects the absorption, binding and distribution of medication
- Smaller organs: affects the metabolism and elimination
- More % fat: affects distribution
- Varying plasma volume: affects distribution
- **Socio-economic differences:**
- Costs (time off work, child care, travel expenses)
- Knowledge + Referral
- Recruitment from appropriate sites
- Child bearing potential
- Carer duties



Anatomical Chart Company

Women living with HIV worldwide

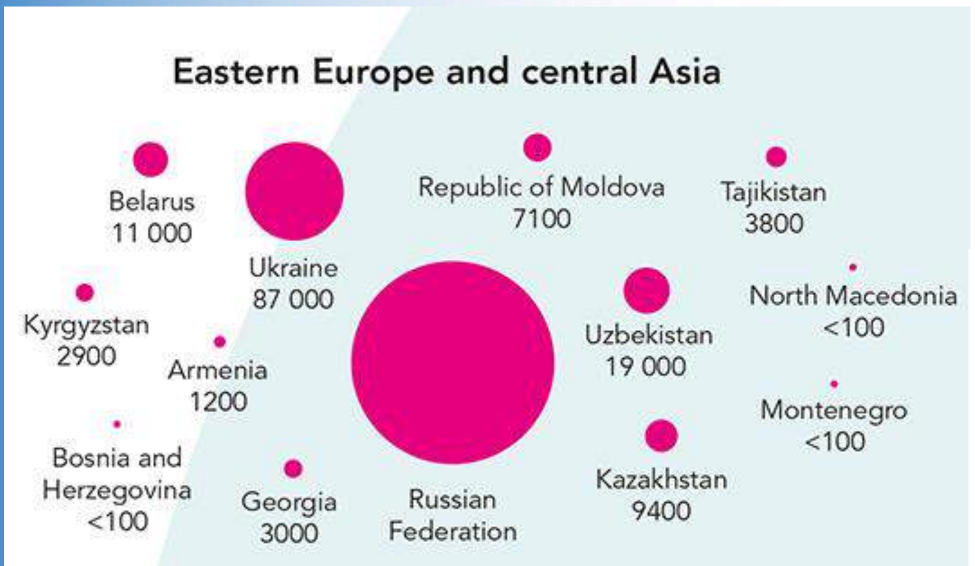
19.6 MILLION GIRLS AND WOMEN LIVING WITH HIV

Global
19 600 000

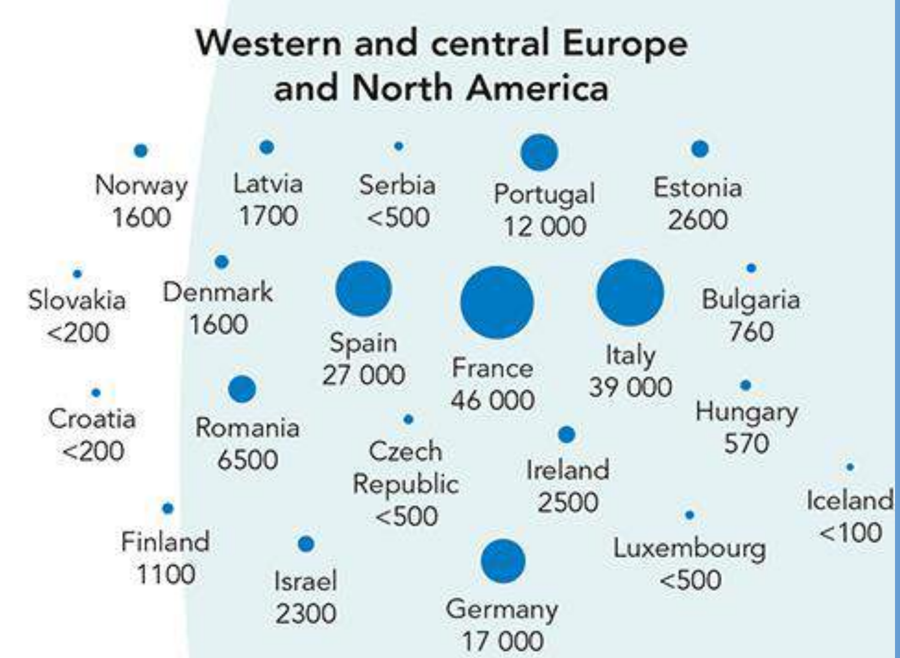
UNAIDS

UNAIDS: 37.9 million [32.7 million–44.0 million] people globally were living with HIV in 2018

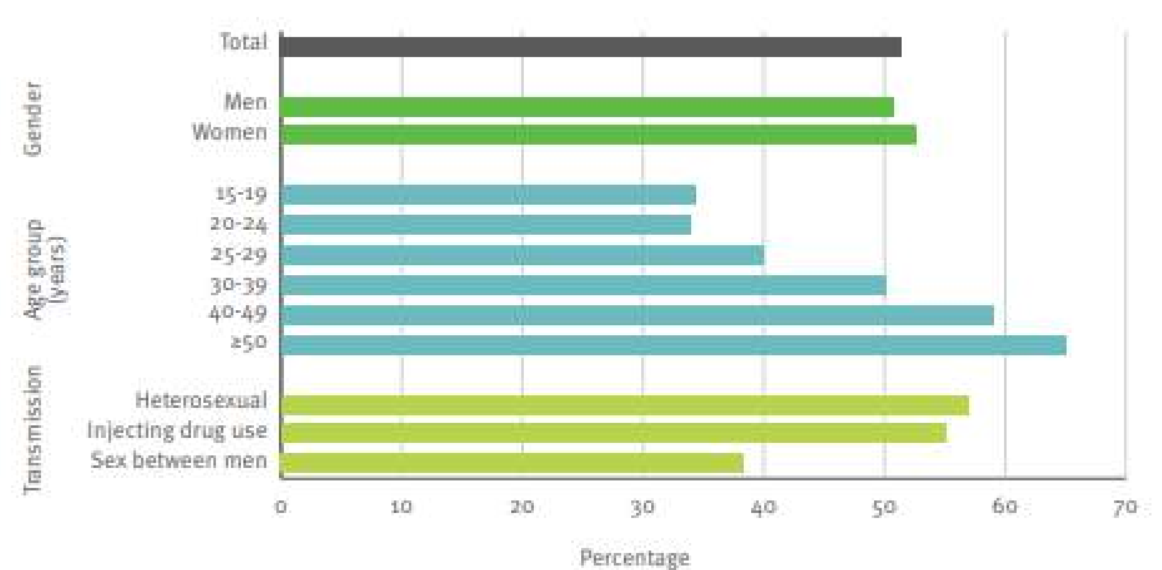
UNAIDS: Infographics, 09/2019



UNAIDS: Infographics, 09/2019



Late presenters



ECDC – WHO HIV/AIDS surveillance in Europe 2018 - 2017 data

HIV : leading cause of death in women

EASTERN EUROPE AND CENTRAL ASIA

New HIV infections among young people (15-24) - by sex

AIDS-related illnesses are the leading cause of death among 15–49-year-old females globally (hundred thousands)

Cause	Value
HIV	302.7
Maternal conditions	298.2
Ischaemic heart disease	182.3
Self-harm	164.1
Road injury	154.5
Tuberculosis	152.4
Stroke	143.4
Breast cancer	140.9
Cirrhosis of the liver	89.2
Diarrhoeal diseases	87.1

Source: Global health estimates 2016: deaths by cause, age, sex, by country and by region, 2000– Geneva, World Health Organization; 2018.

Of every five new HIV infections among young people (15–24 years), three are among young women.

UNAIDS (2019) '[Women and HIV — A spotlight on adolescent girls and young women](#)

HIV Specific research

Representation of Women and Pregnant Women in HIV Research: A Limited Systematic Review

2011

- 38% of study participants were women
- 81% of studies did not mention pregnancy
- 4% of participants were pregnant

A Systematic Review of the Inclusion (or Exclusion) of Women in HIV Research: From Clinical Studies of Antiretrovirals and Vaccines to Cure Strategies

2016

Women represented 23% of participants in 544 studies

WOMEN'S PARTICIPATION BY TYPE OF HIV RESEARCH

Antiretroviral therapy

Vaccination

Cure

0% 20% 40% 60% 80% 100%

Female Male

Dr. Shema Tariq, 2018

Barriers and opportunities

Conclusions

- The number of women in trials is still disproportionate to that of men.
- Higher incidence of women participating in observational rather than interventional trials.
- Lack of information available
  - Recruited v Enrolled

Recommendations

- Women's needs can no longer be ignored.
- Hard Paternalism / Over protectionism is no longer a tenable position.
- Need for legislative changes which push for greater inclusion of women.
- Further research on additional barriers

M.J.Rapa et al., The participation of women living with HIV EATG 2018

Where are we now?

- **GRACE Study**: A Study to Compare the Effectiveness, Safety and Tolerability of PREZISTA (Darunavir)/Ritonavir by Gender and Race When Administered With Other Antiretroviral Medications in Human Immunodeficiency Virus (HIV) Positive Women and Men. (First results 2010) **67% women participants**

- **PRIME Study** - Positive transitions into the menopause : To explore the impact of the menopause on health and wellbeing of women living with HIV. (First results 2018)

- **ECHO Study**: Evidence for Contraceptive options and HIV Outcomes (first results 2019)

Is it a movement?

- **HIV activism**: research led by the needs of PLWHIV, Patient experts participating in research boards and as protocol reviewers
- **How many women among them?**
- **Is research relevant to women? Is it guided by their needs?**
- **Are protocols being developed to include women?**

- **Women's groups**: Sophia Forum, Women's Action Group (Gilead), SWIFT, WAVE, International Community of Women living with HIV, Salamander Trust

Next steps

Women's Involvement In Research

WiiR

Patients Advocacy Alliance

A training program open to activists who want to develop their knowledge about participation in clinical trials. Priority will be given to women (cis and trans) with an aim of 75% participation to the training.

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Acknowledgements

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- **Damian Kelly**, Patients Advocacy Alliance

Thank you

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Co-opted member of the NHIVNA Executive Committee

Contacts Details: Christina.Antoniadi@nhs.net

21-22 September 2019 • Rome, Italy

HOSTED BY:

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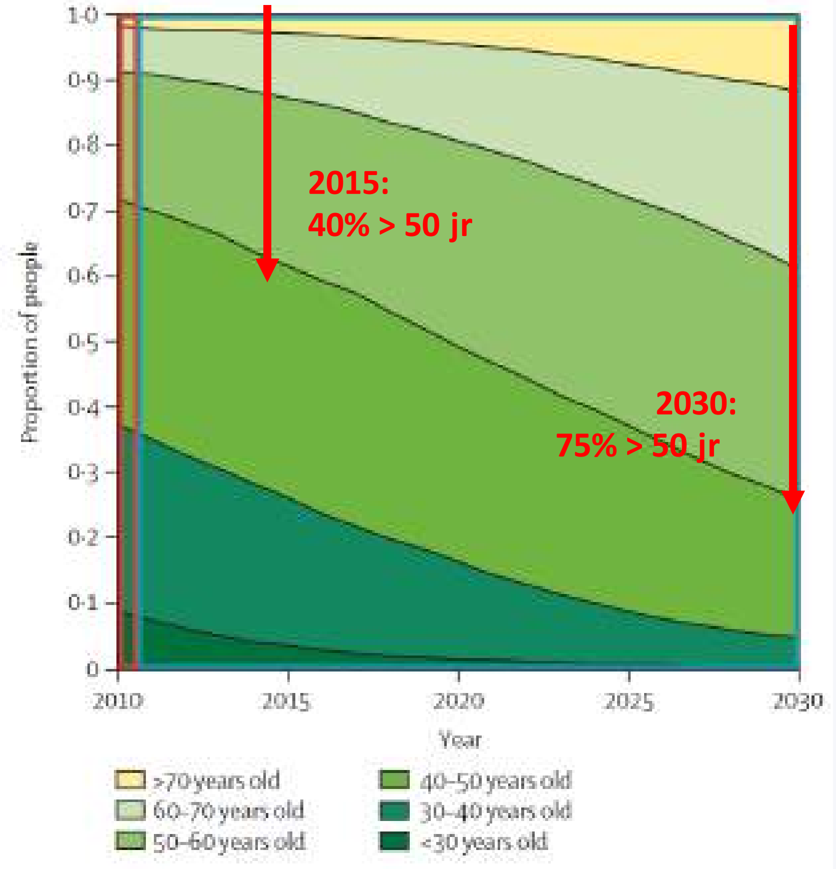
HIV and Frailty

Nienke Langebeek, PhD, MANP, MSc, RN
Nurse Practitioner Infectious Diseases
Rijnstate Hospital Arnhem
The Netherlands



1·0
0·9
0·8
0·7
0·6
0·5
0·4
0·3
0·2
0·1
0
Proportion of people
2015:
40% > 50 jr
2030:
75% > 50 jr
2010
2015
2020
2025
2030
Year
>70 years old
60–70 years old
50–60 years old
40–50 years old
30–40 years old
<30 years old

Age
Non-frail
Pre-frail
Frail
Disabled

Frailty

Frailty:

A clinical syndrome with multiple causes and contributors, resulting in enhanced vulnerability to stressors and increased risk of adverse outcomes.

Phenotype of Frailty

- Undesirable weight loss of ≥5% body weight in the previous year
- Self-reported exhaustion
- Weak grip strength
- Slow Walking speed
- Reduced physical activity

Fried et.al 2001, J.Gerontology A Biol.Sci.Med.Sci;56;M146-156

Clinical Relevance

- Increased risk of falls, hospitalisation,nursing home admission and mortality
- A predictor of occurrence of new disabilities independent of age, burden of disease and psychosocial characteristics.
- Better predictor of mortality than age
- Higher risk of post-operative complications
- Higher risk of dementia

Measurements

- Self-reported
  - Weight loss
  - Physical activity
  - Exhaustion
- Measurements
  - Max. hand grip strengths
  - Walking speed

Early identification of onset of frailty with targeted interventions

PROMOTING HEALTHY AGING

- Optimize sensory options (hearing, vision)

- Assess cognition and mood

- Exercise

Even into his nineties, John was determined to stay fit!

- Fall prevention

- Nutrion supplements

- Optimizing vitamin D and Calcium

Questions

- Who are the (pre)frail subjects
- Why is there a need to identify frail elderly and proposing such a approach
- What approach should be considered

Take home messages

- Be aware of (pre) frailty in your patients
- Start measuring all your patients ≥ 50 years
- Prevent co-morbidities by promoting healthy lifestyle

Healthy Aging In Place

21-22 September 2019 • Rome, Italy

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WHAT NURSES KNOW ABOUT PrEP

Riccardo RONDINA
Azienda Ospedaliero-Universitaria di FERRARA

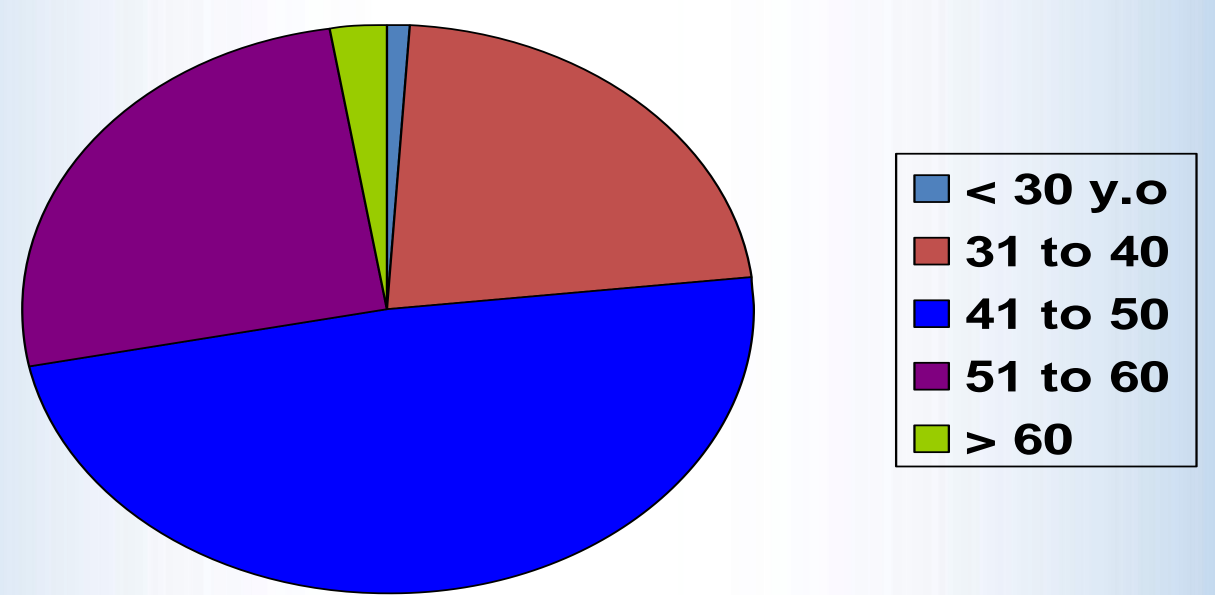
THE AIM

- The aim of this survey was to discover how much healthcare workers (non doctors) know about PrEP.

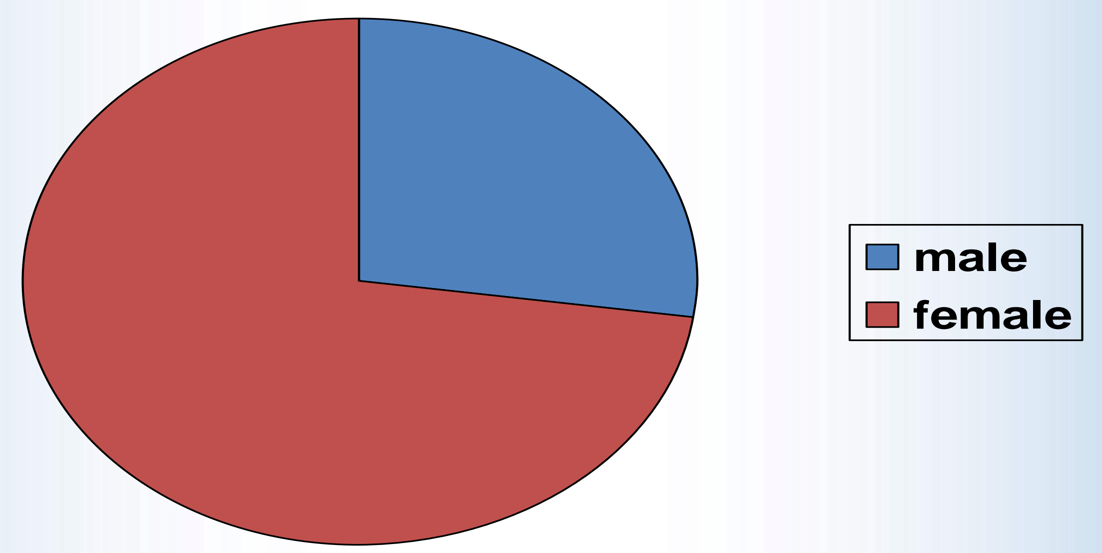
PREAMBLE

- Note: in Italy, there is **NO** advanced level course available for nurses in HIV care.

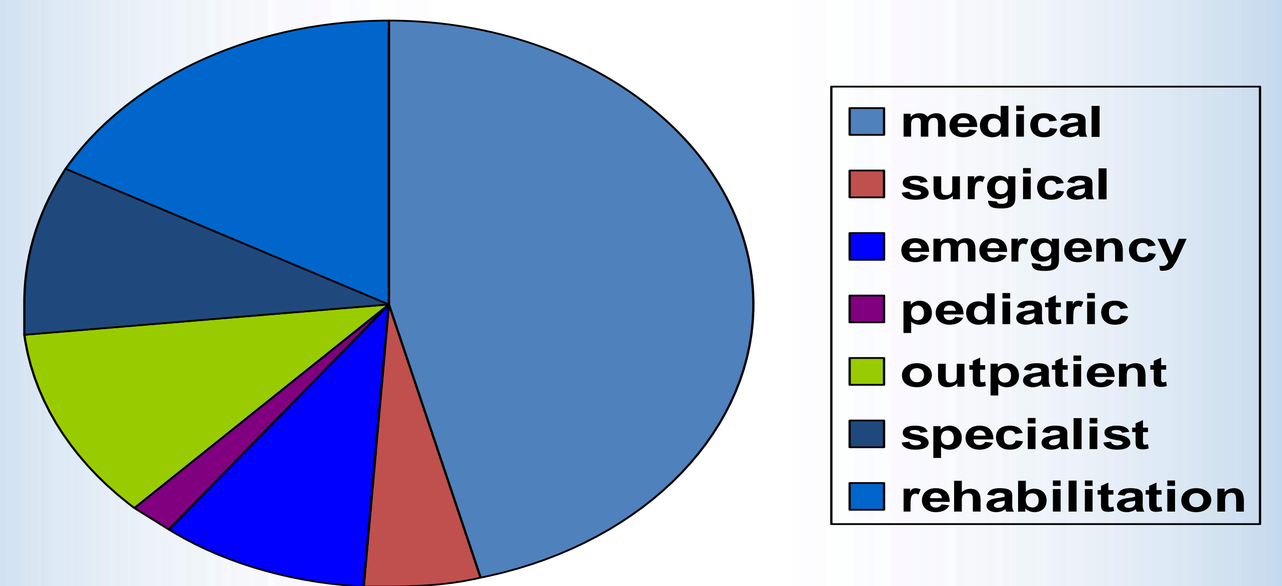
AGE



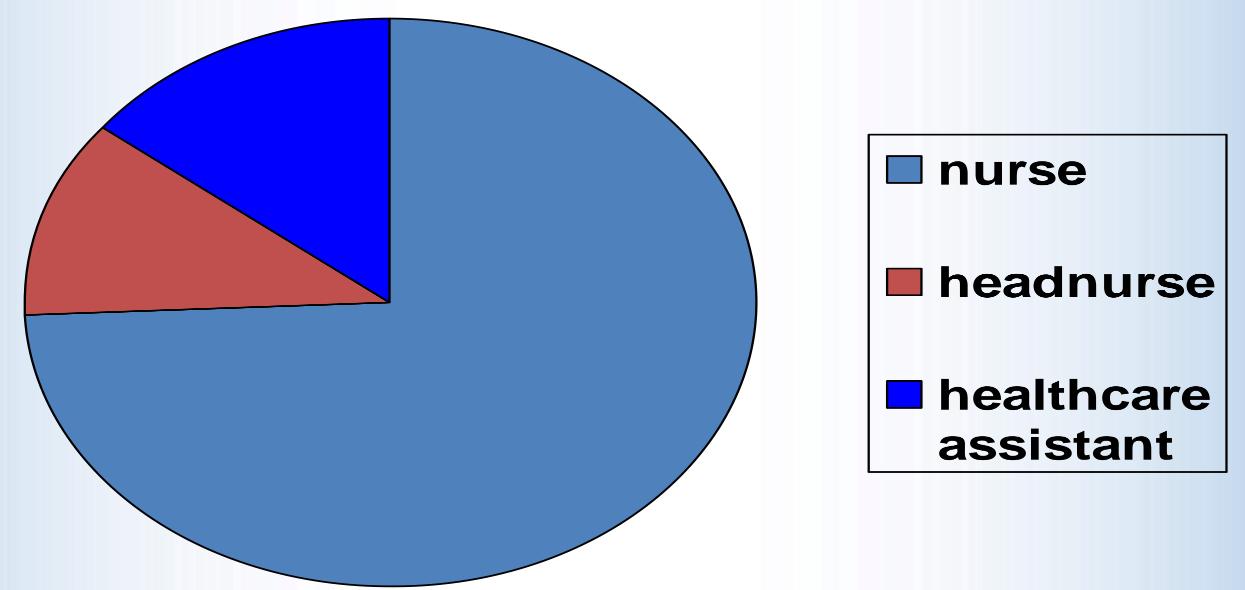
GENDER



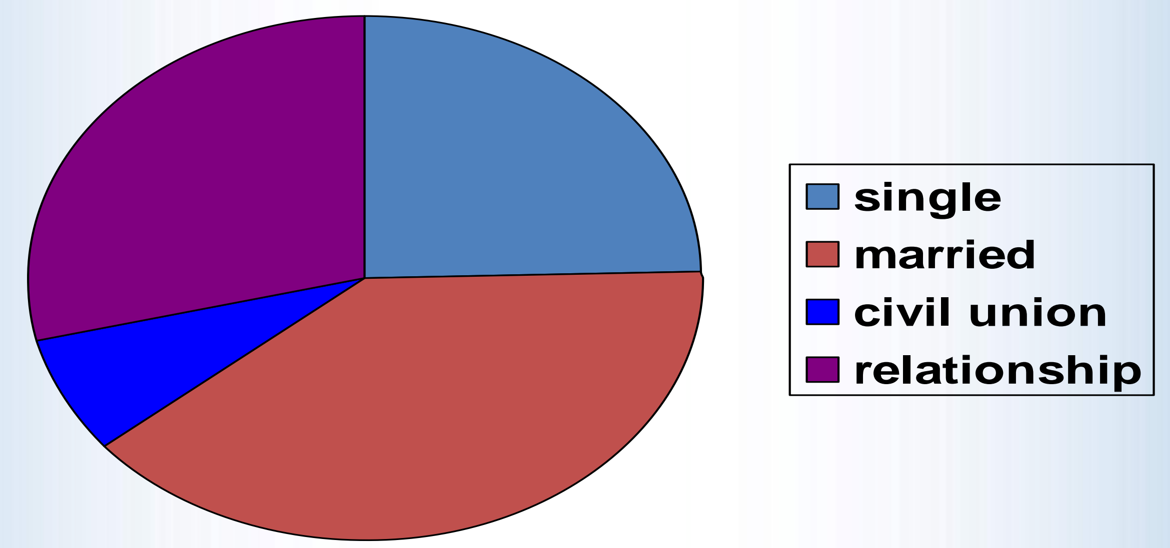
WORKPLACE



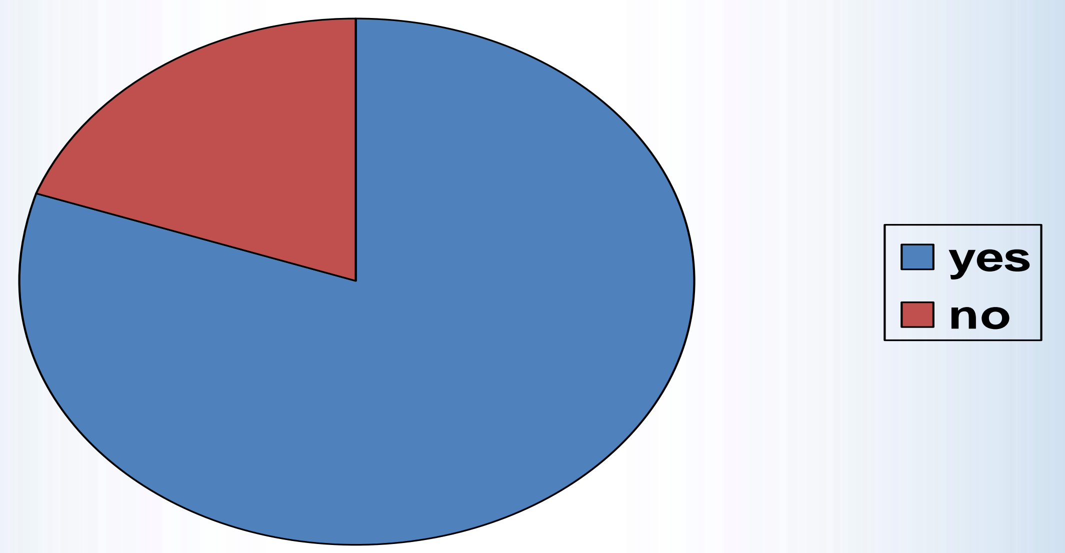
PROFILE



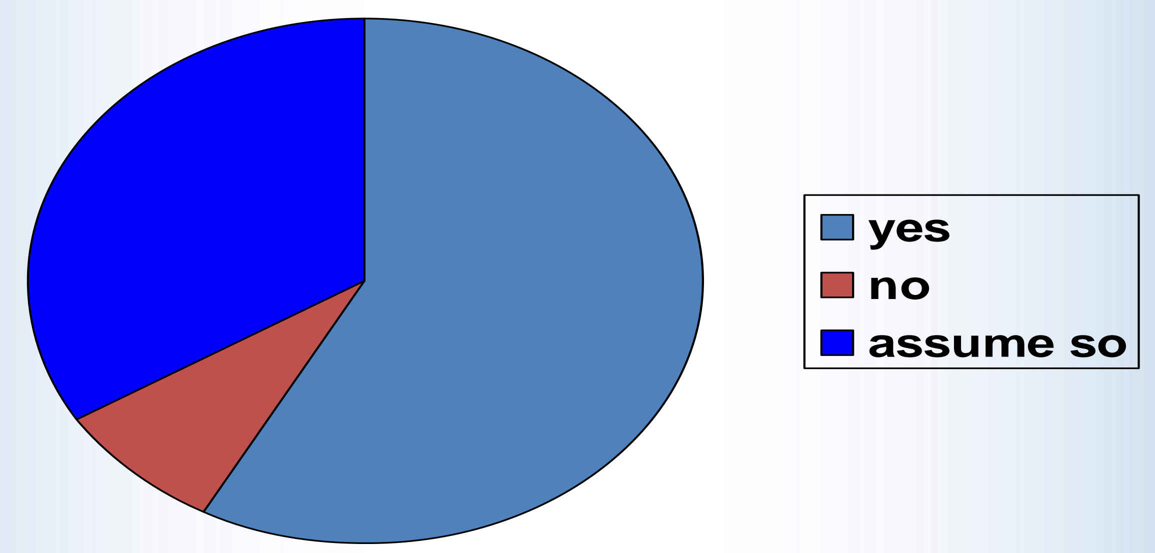
STATUS



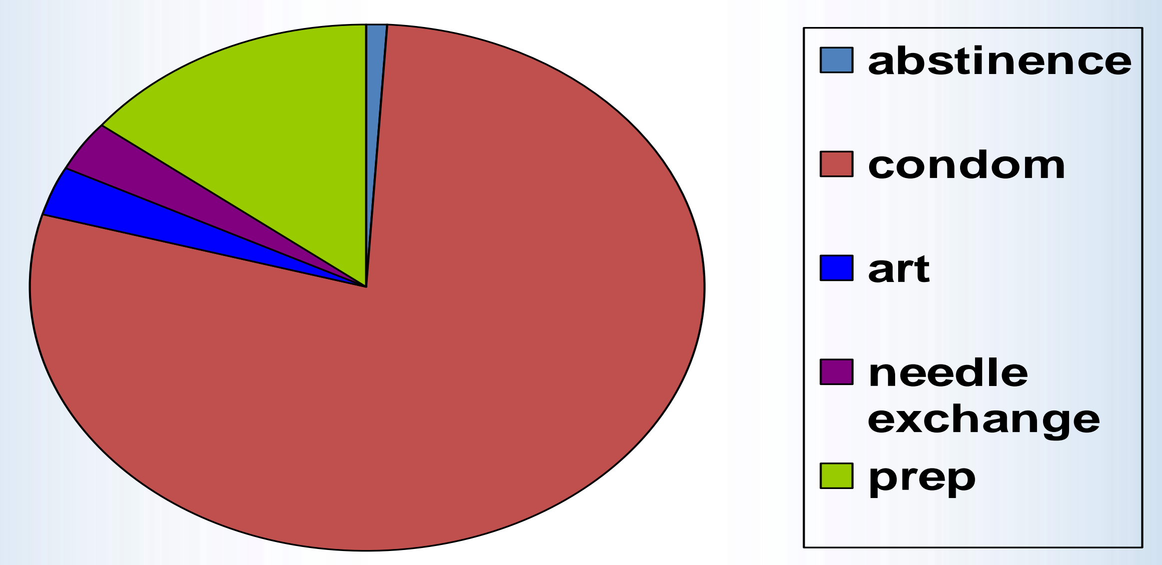
EVER TESTED?



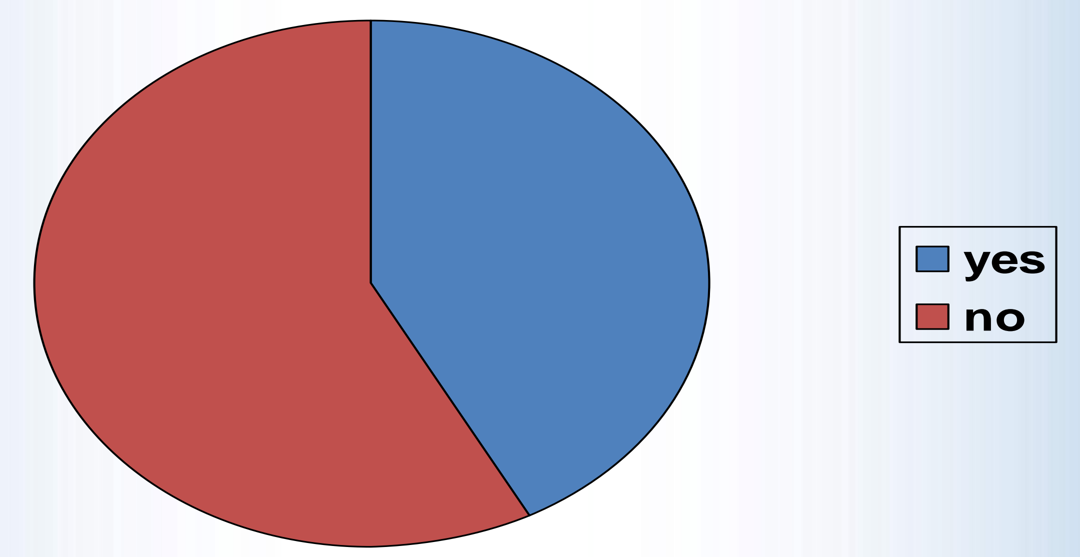
KNOW YOUR STATUS



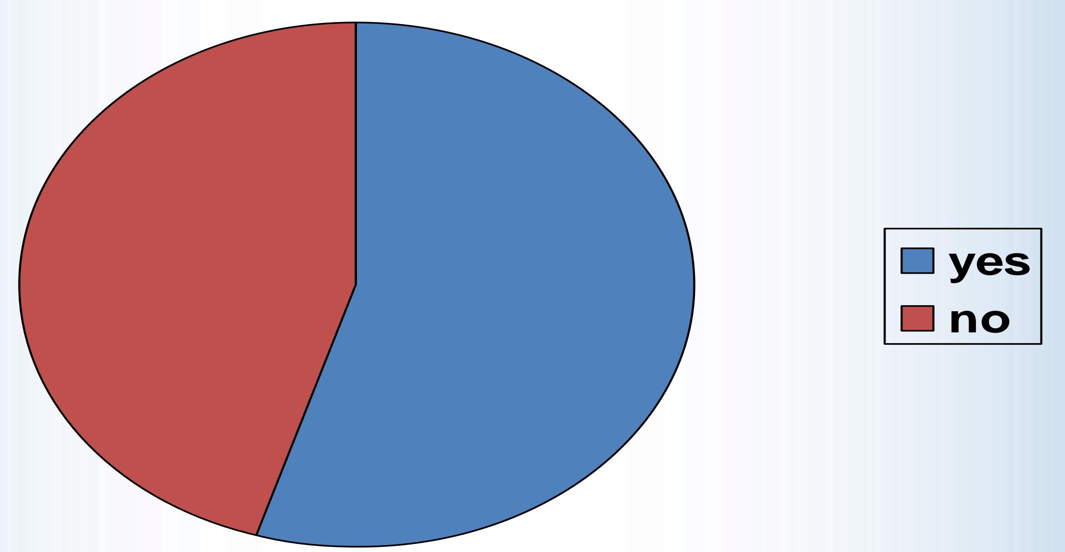
RECOMMENDATIONS TO PREVENT



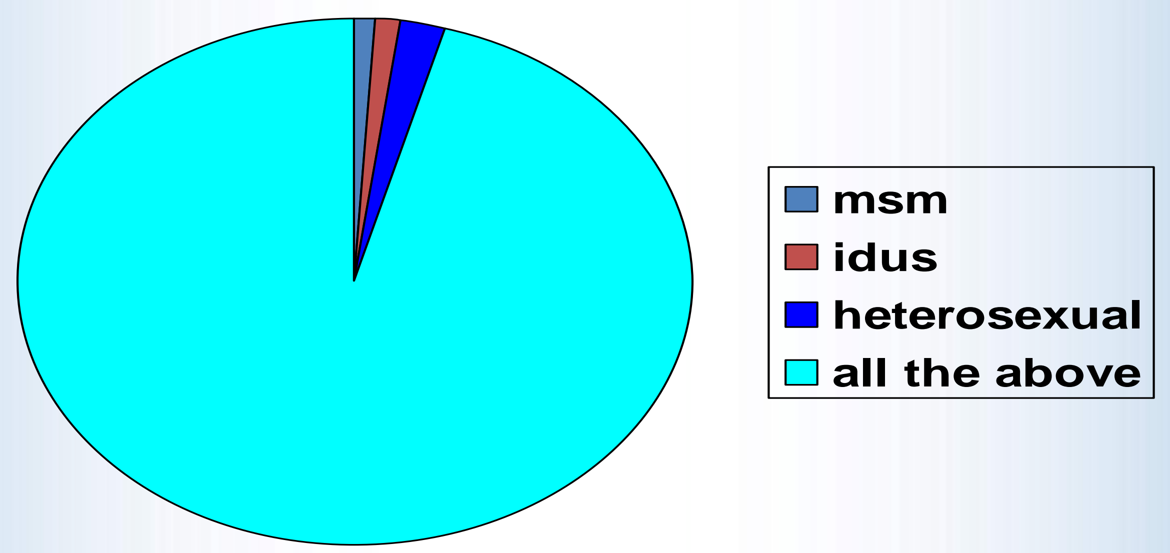
EVER HEARD OF PrEP



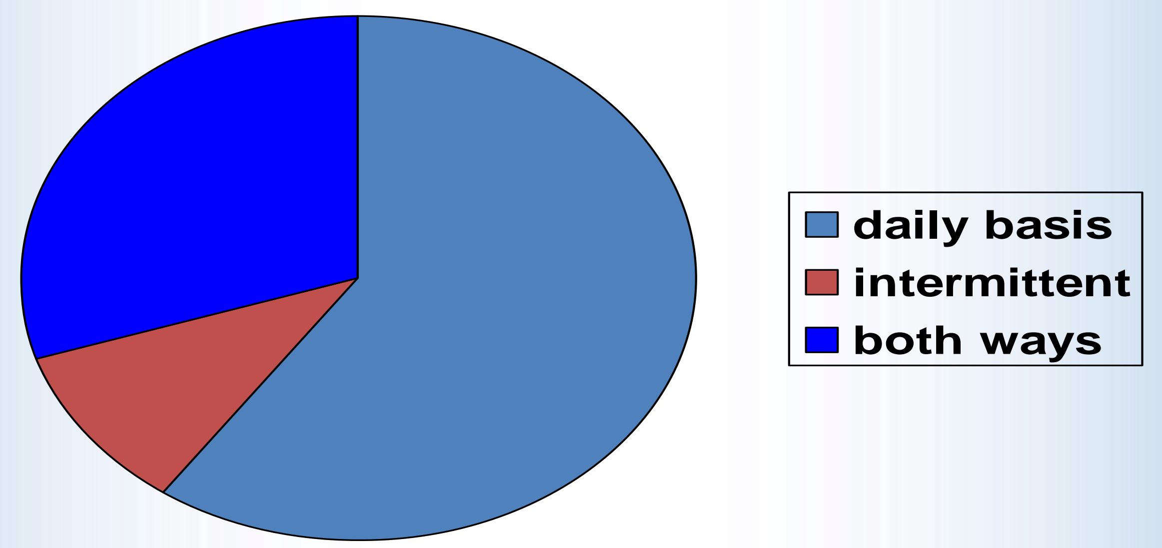
KNOW WHAT IT IS



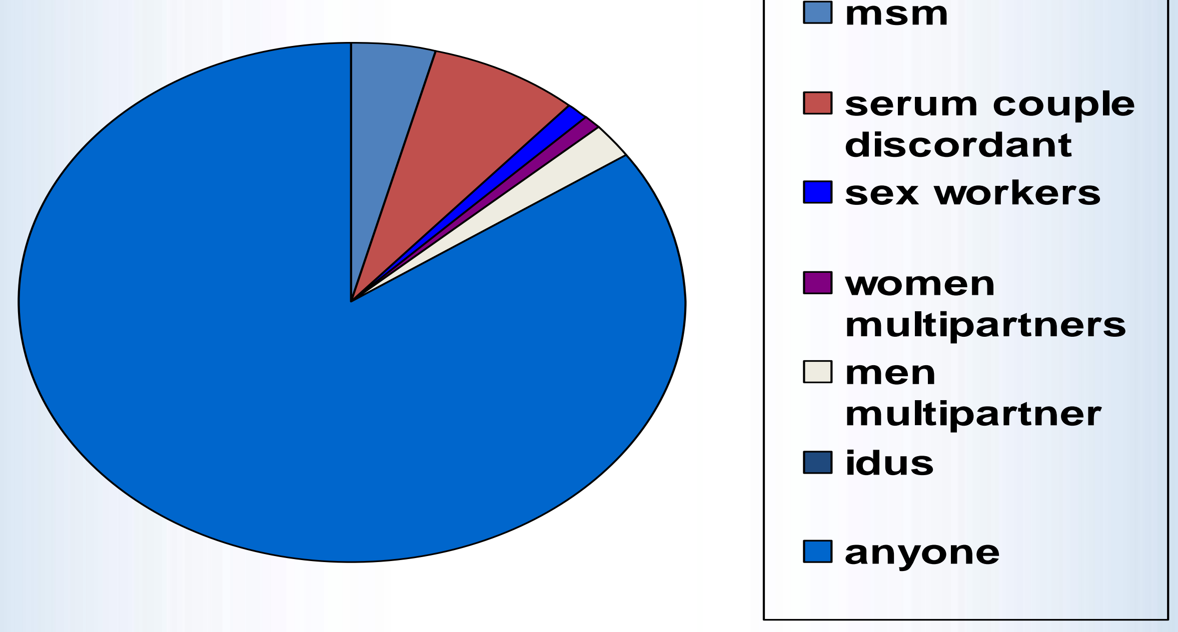
IF YES IT'S FOR



HOW TO TAKE IT



RECOMMENDED FOR



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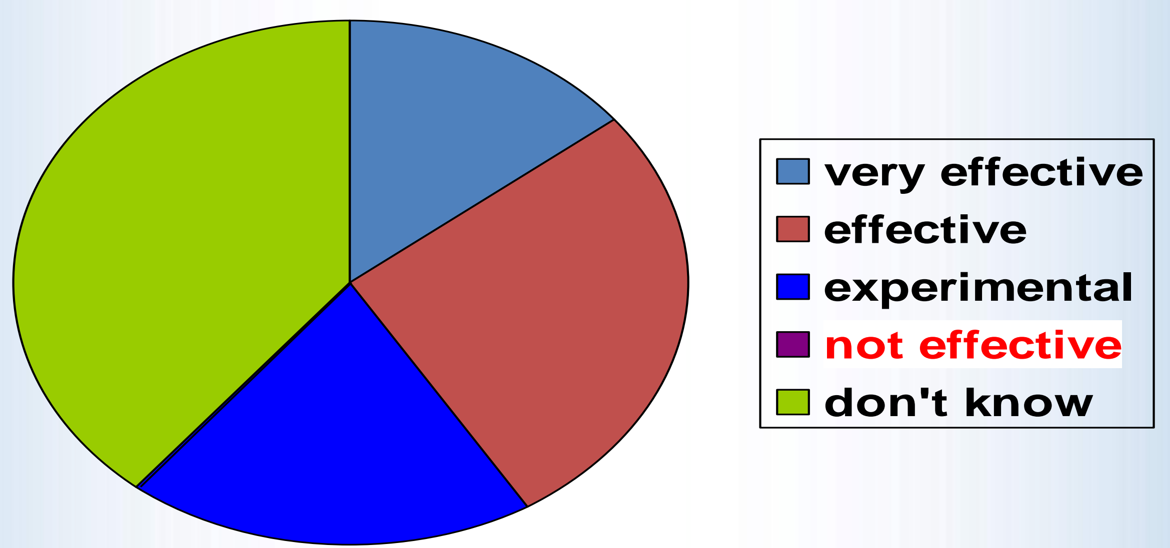
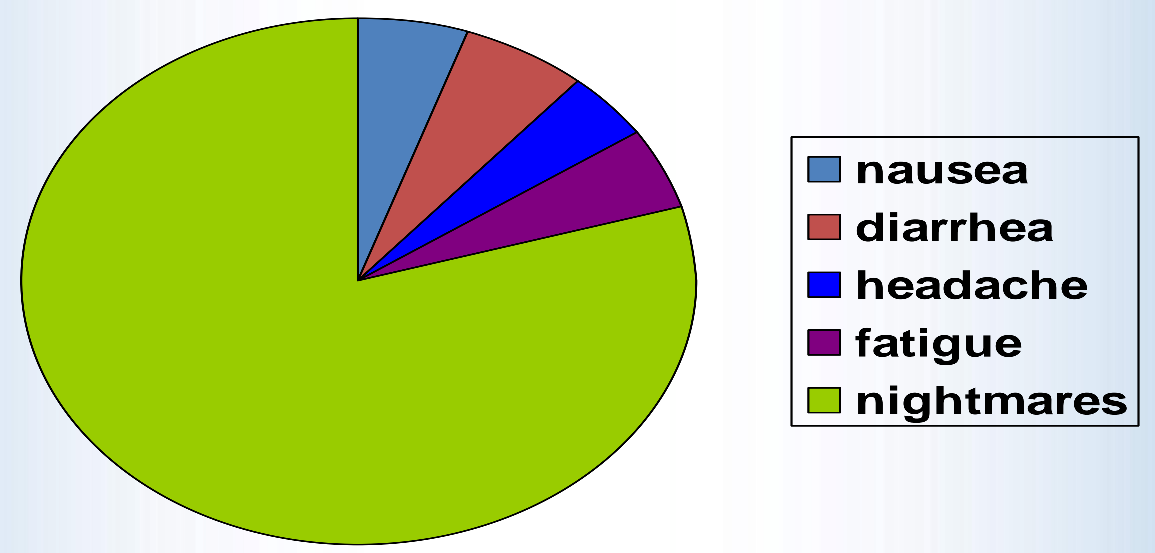
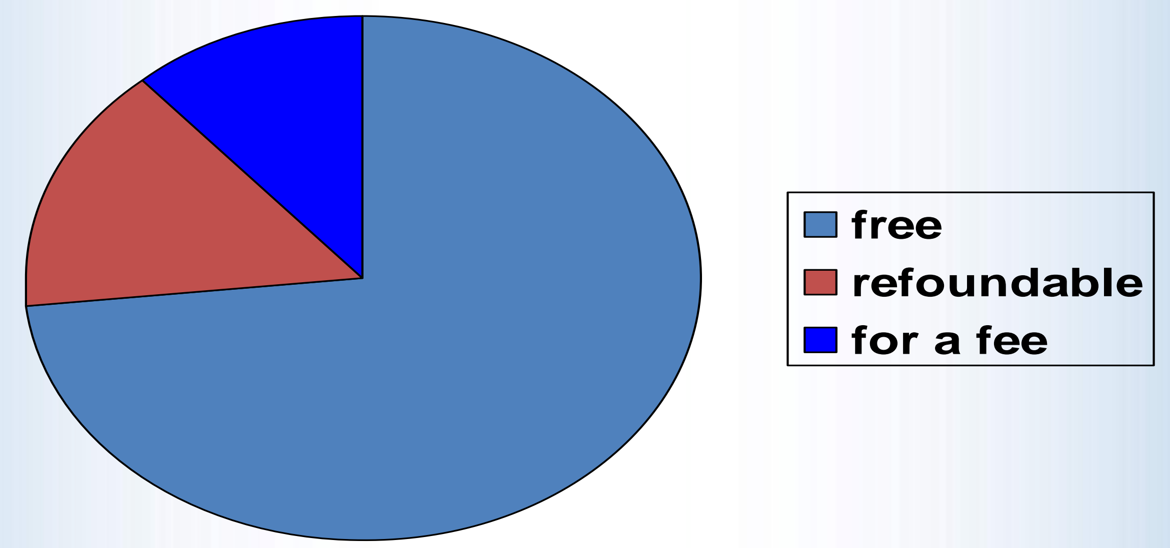


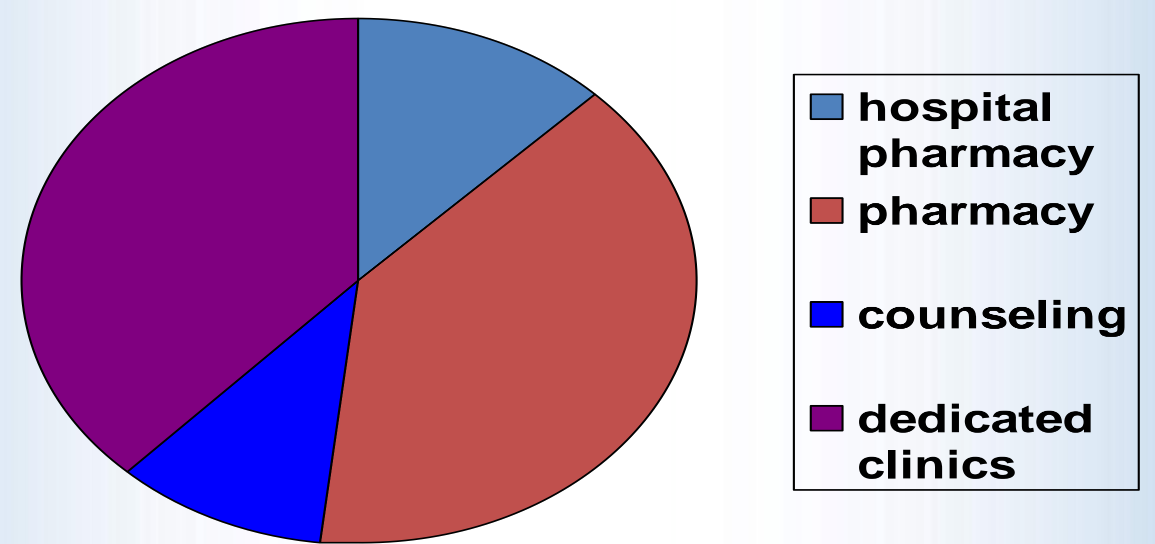
NOT A SIDE EFFECT



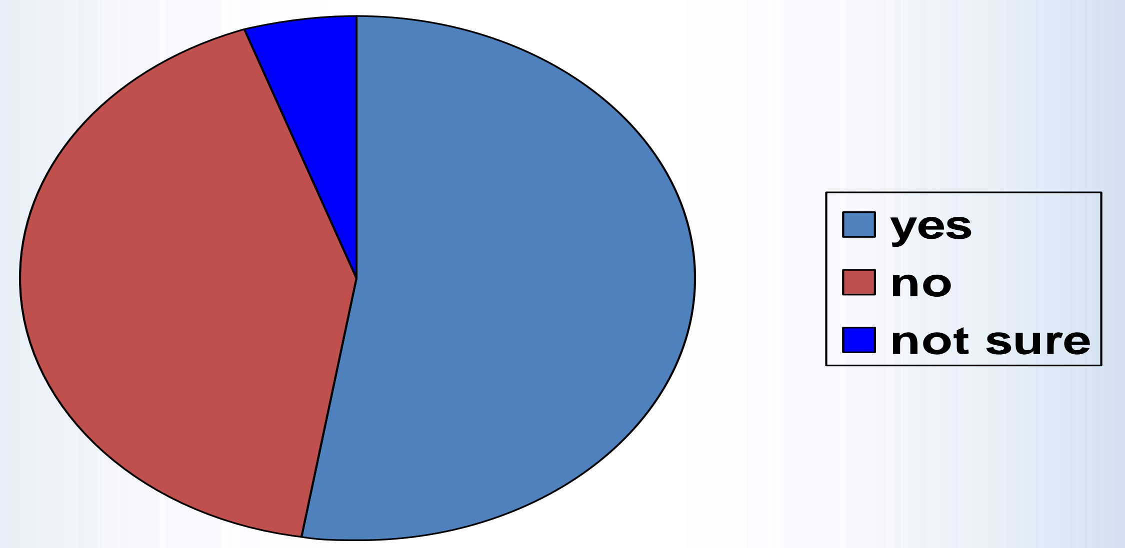
DISPENSED



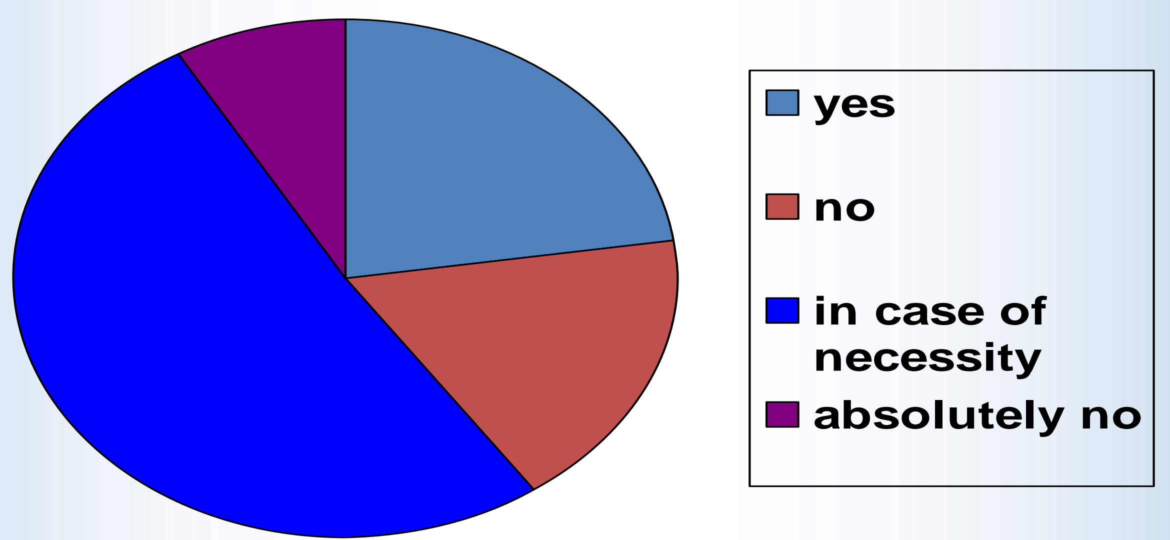
WHERE SHOULD ONE WITHDRAW



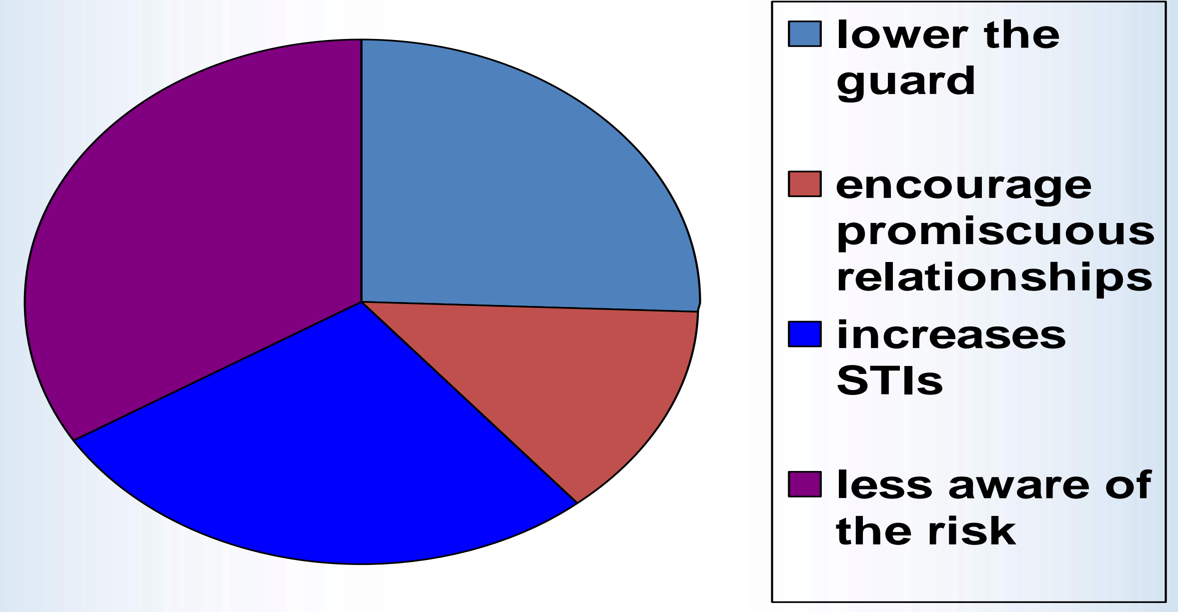
YOU RECOMEND IT



YOU HIRE IT



PROPOSING PrEP COULD MEAN



SOME COMMENTS

- More information is needed from the competent Institutions
- Decrease the incidence in the most affected Countries
- I didn't answer all the questions because I don't know the subject
- I would like to know if my answers are right and where I should read up
- I would like more information with dedicated meetings in the various Units inside my Department
- It must not weigh on the NHS
- All this is certainly positive but we must also act on discrimination and stigma

NEXT STEPS

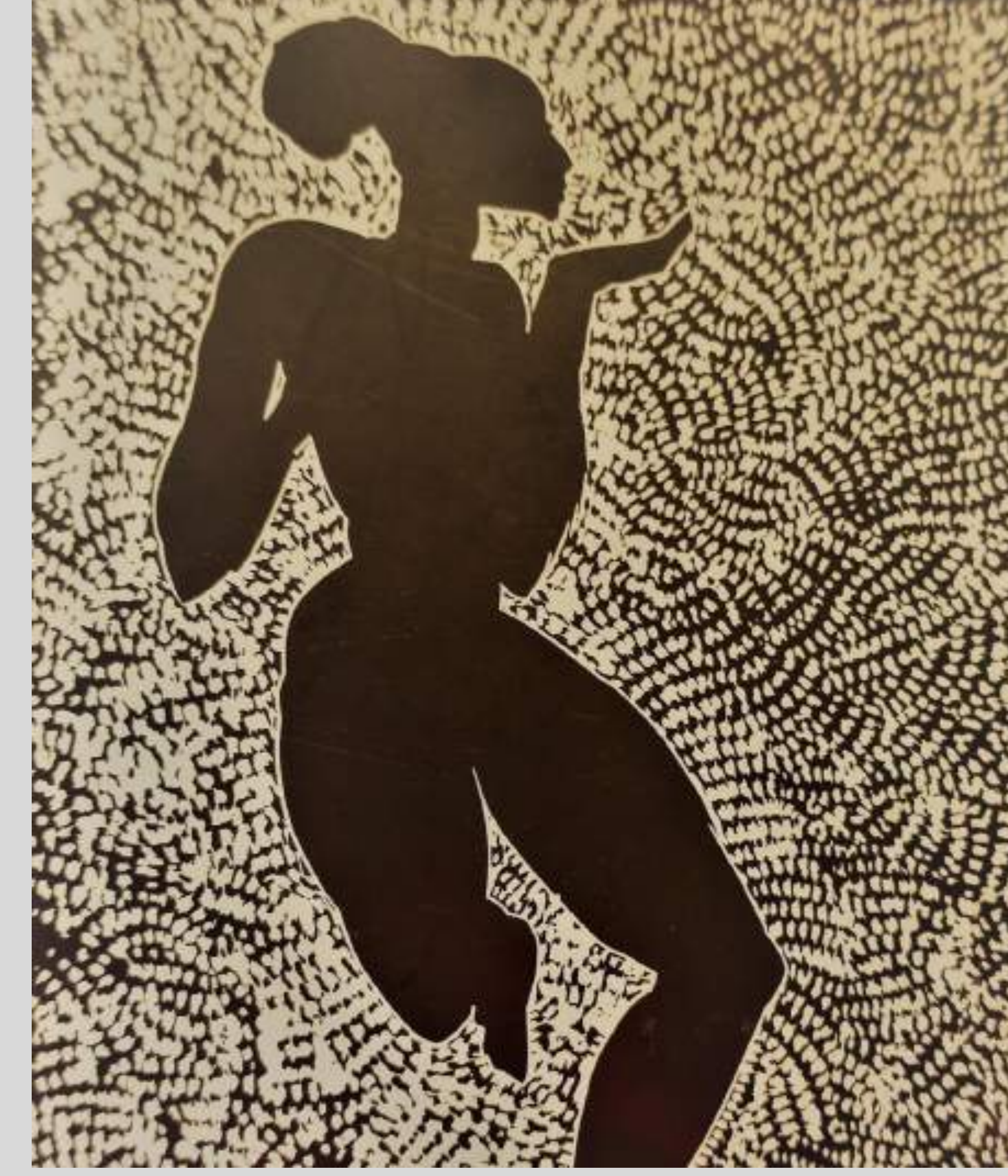
- First, show the data to the Management
- Agree with the Manager if and how to organize one or more meetings on the topic, maybe even just to comment on the answers, or if trying to build a " hospital paper/document" type flow chart to consult in case of need, to respond immediately to the request
- Try to be able to propose again, but this time with adequate support from the Management, this short questionnaire to all staff, doctors and specialists including, in order to assess the actual knowledge and then give them the information they need
- What else? Tips ?

THANKS FOR YOUR ATTENTION

REPRODUCTIVE HEALTH

Riikka Teperi RN, Sexual Therapist

Finland



TOTAL NUMBER OF DIAGNOSED HIV CASES IN FINLAND=4150 (100-200 NEW CASES PER YEAR)

1980 first HIV case

1983 first female HIV case

Until 1999, 40-80 cases (all) per year

From 2000 onwards, 40-70 female cases per year

<u>1980 - 2019</u>

Men: 2994 (72%)

Women: 1156 (28%)

Pregnancies of HIV-positive women 1983 - 2013

National Infectious Diseases Register

Medical Birth Register

Finnish Maternity Cohort Register

212 HIV-positive mothers diagnosed before or during the pregnacy

12 mothers diagnosed HIV-positive <2 years after the pregnacy

0 HIV-positive children

290 HIV-negative children

3 HIV-positive children

9 HIV-negative children

SEXUAL AND REPRODUCTIVE HEALTH OF WOMEN LIVING WITH HIV IN FINLAND

Studies at Inflammation Center / Division of Infectious Diseases,

Helsinki University Hospital 2012-2016

- Study I: 560 WLWH from Helsinki University Hospital and largest outpatient clinics from Denmark.
- Study II: including all women attending the Helsinki University Hospital´s outpatient clinic for HIV care at least two times during 2002-2013.
- Study III and IV: including all women having delivered at least one child after HIV-diagnosis in Finland 1983-2013.

LIST OF ORIGINAL PUBLICATIONS

I. Wessman M, Aho I, Thorsteinsson K et al.

Perception of sexuality and fertility in woman living with HIV: questionnaire study from two Nordic countries.

J Int AIDS Soc 2015 Jun 1; 18:19962.

II. Aho I, Kivelä P, Haukka J et al.

Declining prevalence of cytolocigical squamous intraephithelia lesions of the cervix among women living with well controlled HIV…

Acta Obstet Gynecol Scand 2017 Nov; 96 (11):1330-1337.

III. Aho I, Kivelä P, Kaijonmaa M et al.

Comprehensive nationwide analysis of mother-to-child HIV transmission in Finland from 1983 to 2013.

Epidemilogical Infect 2018 Jul;146 (10):1301-1307.

IV. Aho I, Kajonmaa M, Kivelä P et al.

Most women living with HIV can deliver vaginally - national data from Finland 199´3-2013.

PLoS One 2018 Mar 22;13(3):e0194370.

CONCLUSIONS OF THE STUDIES

- HIV- infected women in Denmark and Finland are in good physical health with good treatment response to HIV treatment.
- 2002-2013 improved results: at the end of study period, 87% of PAPA smears showed normal findings.
- Of 2012 pregnant women with HIV, 46% were diagnosed during pregnancy (outside HUCH 65%).
- Of all deliveries, 75% were vaginal. The low level of cesareans in Finland will protect their childbearing possibilities in the future.

PERCEPTIONS OF HIV POSITIVE WOMEN ON SEXUALITY

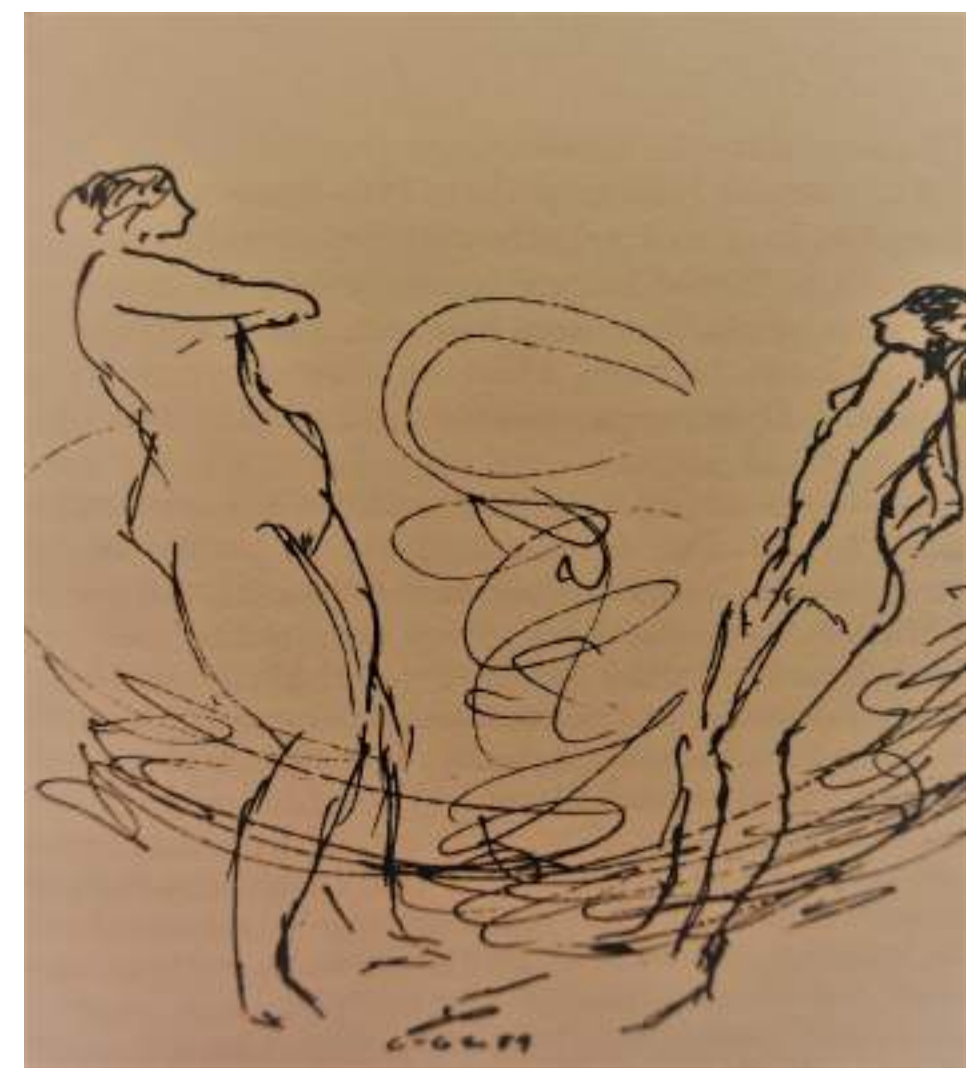
50% thought HIV diagnosis had changed their sex life.

25% felt isolated and

40% did not dare to have sex.

94% of the women had disclosed their dg to someone outside healthcare (mostly partners;also to siblings,friends and children).

One-third had disclosed their diagnosis to less than three people.



CHILDBEARING INTENTIONS

- Two-thirds live in steady relationship, mainly with an HIV-negative partner.
- One-third of them were sexually inactive: age, HIV-treatment response, or partner´s HIV status were not associated with amont of sexual activity.
- Majority of the women had children, 25% desired to have children.
- 15 % overestimated the risk of MTCT.

DELIVERIES BY HIV+ WOMEN 1993 - 2019

- Deliveries in HUCH:
  - 1993 - 1999 – about 4 deliveries per year (n=26)
  - 2000 - 2016 – about 10 deliveries per year (n=162)
  - 2017 - 2019 about 30 deliveries every year

  - Until 2019, 450-500 children in all in Finland.

- Type of deliveries in HUCH 2006 – 2013
  - Vaginal deliveries 77%
  - Caesarean deliveries 23 %
    - emergency operations (8%)
    - others (15%; obstetric reasons, high transmission risk of HIV or HCV viruses)

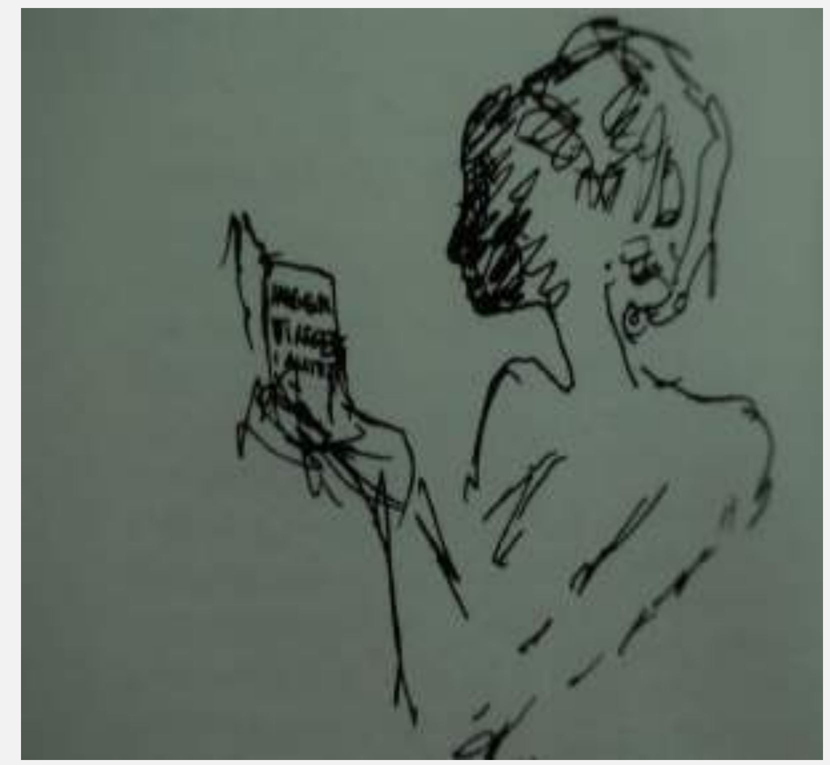
TREATMENT OF HIV+ WOMEN IN FERTILE AGE - NURSE’S ROLE

1) Giving correct information

2) Helping reach realistic understanding of
- Pregnancy
- Childbirth
- Recognize own resources

3) Encouraging women to fulfill their dreams

4) Helping to plan ahead
- Living in a relationship
- Becoming a mother



GYNECOLOGICAL FOLLOW-UP OF HIV+ WOMEN

- Goals:
  - Effective contraception
  - Identifying abnormal papa smears
  - Identifying other gynecological symptoms
- Every new HIV+ woman referred to a gynecologist
  - Gynecological history and status
  - First pap smear, next one after 1 year, then every 3rd year
- Gynecology control visit every 1-3 years

- Risk of abnormal pap smears 2,9-5 % (higher than among all women)
- Other risk factors:
  - Smoking, HPV-infection, bacterial vaginosis, STD's, low CD4 cell counts

CONTRACEPTION

Aim: All HIV+ women's pregnancies are planned

- Contraception:

First choice is hormonal intrauterine device (In HUCH, free to HIV patients)

- does not change HIV medication effectiveness

- does not induce higher HI-virus counts in the genital tract

Other good options:

- Copper intrauterine device
- Contraceptive pill (very few trials)
- Subdermal contraceptive capsule (possible interaction with HIV medication)

HOW WE TREAT - TEAMWORK AT HUCH (HELSINKI UNIVERSITY CENTRAL HOSPITAL)

Infectious disease polyclinic

- HIV follow-up and care co-ordination during / after pregnancy

Ob & Gyn polyclinic

- antenatal follow-up, childbirt

Pediatrics polyclinic

- meeting women & family before delivery
- information to mothers and obstetrics department personnel about newborn medication
- 2-year follow up

Co-ordination meetings of the polyclinics every 6 weeks

PLANNING FOR PREGNANCY

1) Both woman and man HIV+, no drug resistant virus strains (virus loads of both need to be low, HIVNh < 50)
   - normal intercourse

2) Serodiscordant couples told: Swiss statement, WHLW PARTNER- trials foundings

PLANNING FOR PREGNANCY

Earlier protocol (not used anymore)

HIV+ women, HIV- man

- start HIV medication to women before pregnancy
- teach to identify ovulation time

- Home insemination. ´Mumincup`- syringe treatment.
- (If sperm taken from condom, condoms without spermicide)

HIV+ WOMEN AND PREGNACY

- Ensure optimal HIV medication
- Start medication as soon as possible (For fertile aged women it is usually started soon after the HIV diagnosis)
- If poor medication adherence, start DOT (Directly Observed Therapy)
- HI virus load control 1-2 times in every 2 months, copies need to be <20.
- Glucose tolerance test recommended. Check the vaccination: German measles, measles.
- No breast feeding. (If woman wants to breastfeed, monthly HI-virus load check. Pediatric opinion for HIV medication of the child)
- Very important to have a control visit at week (34)- 36
  - Planning the type of delivery
  - Vaginal birth is the primary choice

HIV+ WOMAN AND DELIVERY

- If mother has ART at week 36 and HIV virus load < 200, vaginal delivery planned
- Elective caesarean section at week 38, if it´s because of HIV
- In other cases Zidovudine infusion during the pregnancy (in caesarean delivery start 3 hrs before)
- Avoid invasive procedures (No intrauterine registering or micro blood samples, avoid episiotomy)

- If woman hasn´t been attending a prenatal clinic, and no HIV test has been done, while there is strong suspicion of HIV infection :
- Start same zidovudine protocol as above, but immediately

FOLLOW-UP OF CHILDREN TO HIV+ WOMEN

Before delivery:

New born baby:

2 days old baby:

3 weeks time:

- Meeting with mother, medication planning
- Big blood count, check contra-indications to start medication, no breastfeeding
- HI –virus load
- Big blood count (anemia, symptoms of primary infection)
- Anemia? Any symptoms of primary illness - need to raise dose of medication. Plan to stop HIV medication in week 4

FOLLOW-UP OF CHILDREN TO HIV+ WOMEN

- 2 months:
  - Big blood count, HI- virus load. Any symptoms?
- 4 months:
  - HI-virus load (big blood count).
  - If HI- virus load negative x 3 child is not infected
  - Give a BCG vaccination
- 18 months:
  - If HIV AgAb antibodies have disappeared stop the follow up, contact only when needed

MENOPAUSE

- HIV+ women reach menopause earlier than average women
- Hormonal replacement therapy (HRT): same goals as among other women
- Because HIV medication might reduce treatment effect, possible need to increase the dose
- Sexuality should be discussed with women of all ages

THANK YOU!

Inka Aho. Sexual and reproductive health of women living with HIV in Finland. Doctoral Programme in Clinical Research, University of Helsinki. Helsinki, Finland 2018

- Nuno Nobre. Quality of Life of People Living with HIV/AIDS in Finland. Department of Public Health, Faculty of Medicine. Doctoral Programme in Population Health, University of Helsinki, Finland 2018
- www. Arvosta.fi, 2019
- www. HIV-hoitotyön käsikirja. 2017, Helsinki
- www. THL, HIV-tilastot 9/ 2019

Graphics: Carl-Gustaf Lilius

CASE STUDY EXPLORATION OF THE IMPACT & PSYCHOLOGICAL UNDERPINNINGS OF CHEMSEX

DR SARAH RUTTER
CLINICAL PSYCHOLOGIST

SESSION OVERVIEW

- **To use a case example to think about:**
  - The psychological impact of chemsex participation
  - The psychological underpinnings of chemsex participation
  - What can we do?

  - Details of the case have been altered to protect anonymity

DISCLAIMERS

Not claiming expertise

MSM as focus – but may be more complex

Chemsex engagement not always problematic

Difficult/sensitive topics – take care of yourselves

NATHAN'S STORY

- Nathan is a 32 year old gay man
- He works full time for a marketing firm
- He is currently single
- His family live in a small town in the UK, but he has lived in the city for over 10 years
- He has a good size social circle, made up friends he has had for many years
- Nathan would love to find a partner and settle down

NATHAN'S STORY

- **The start of Nathan's participation in chemsex**

- Nathan always liked to have a good drink when out socialising
- Helps to manage social anxiety
- One night he met a guy when out, who introduced him to sexualised drug use
- One night turned into a weekend
- Nathan had a great time
- However, he had call in sick for work on the Monday

DEFINING CHEMSEX ACTIVITY

- Use of certain drugs ('chems') by MSM to enhance sexual experience (intensity & longevity)

CHEMS	EXAMPLES OF OTHER DRUGS
• Crystal Methamphetamine • Mephedrone • GHB/GBL	• Ketamine • Cocaine • Viagra • Amylnitrate • Viagra • Alcohol

Is it such a new phenomenon?

Literature makes distinction between sexualised drug use and chemsex

THE EFFECTS OF CHEMSEX

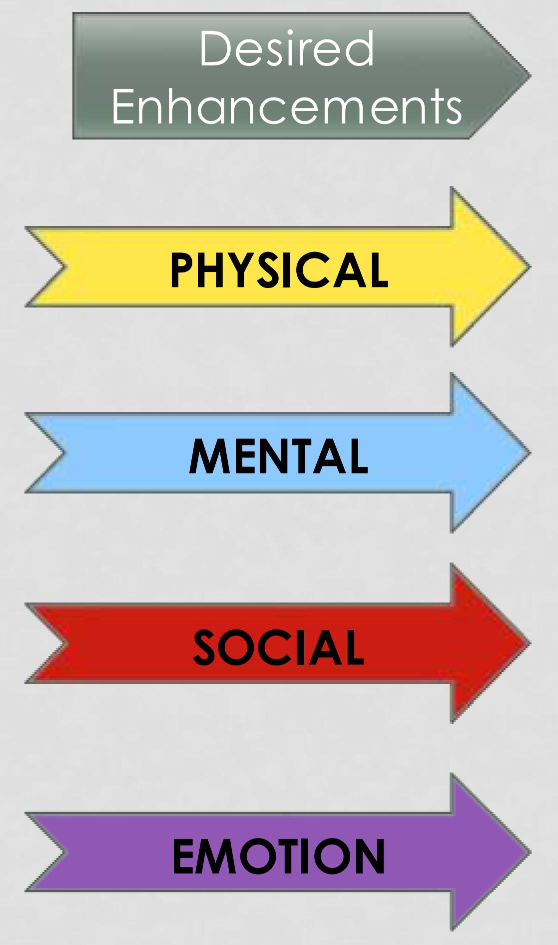
Drug Effect

Decrease inhibitions

Alter cognitive pathways

Muscle relaxant effect

Increase energy



Sexual Experience

Facilitate receptive anal intercourse/esoteric acts and maximise sexual performance

Alter perception which intensifies the ‘in the moment’ sexual acts/experience

Increased confidence and enhanced ability to engage with partners

Intensify self-emotion awareness and shared experience with partners

Maxwell et al (2019)

CHEMSEX ACTIVITY & PREVALENCE

- Practiced predominantly in Western Europe
  - **Rosinska et al (2018) – 13 European cities**
  - 23% sexual performance enhancement drugs
  - 8.4% party drugs
  - 3.4% chemsex drugs (higher in HIV+)
- Who is participating?
  - MSM of all ages and backgrounds
  - Different sub groups- different needs
- Geographical differences
  - Chemsex concentrated in certain areas

Bourne et al (2018); Evans (2019); Public Health England (2015)

NATHAN'S STORY CONTD…..

- Nathan began to practice chemsex more regularly
- He would use hook up apps to access most weekends
- He began to miss more and more days off work – which resulted in a disciplinary
- A 'slamming site' became infected, and even with anitbiotics the wound took time to heal
- He acquired gonorrhoea

NATHAN'S STORY CONTD…..

- Nathan witnessed many disturbing events
- He felt ashamed of his behaviour
- He began to withdraw from friends and family
- His mood became very low
- He did not wish to socialise with people he met on the scene outside of it

HARMS ASSOCIATED WITH CHEMSEX

- **Biological** (O/D, STI's, physical health, interactions with medications)
- **Indirect** (impact on functioning: self-care, employment, housing, loss of partners/friends/networks)
- **Mental health and well-being issues**
  - **Anxiety**
  - **Depression**
  - **PTSD**
  - **Low self esteem…….**
- **HIGH RISK OF TRAUMA**
  - To self/witness of
  - Re-triggering previous trauma
  - Consent issues & criminal aspects

(Maxwell et al., 2019, Morris, 2019)

A QUESTION CLINICIANS MIGHT ASK?

So why does Nathan keep going back when it was having such a negative impact on his life?

NATHAN'S STORY CONTD…..

Early life

- Nathan was an only child and came from a stable family environment
- His mother was very anxious, father did not really discuss emotions
- Between the ages of 7-9 his uncle sexually abused him on many occasions
- The uncle said that people would think he was dirty and bad if he told them
- He never told anybody
- When feeling worried/distressed as a child he would go to his room (so nobody would notice)

NATHAN'S STORY CONTD…..

- **Adult experiences and values**
- Nathan did not share his sexuality with anyone until he was 25
- He had some brief relationships, but was not comfortable with casual sex
- He was then with a long term partner for five years
- They split up when he was 31
- Nathan is drawn to traditional values
- He wants to own his own home with a partner
- He would like to adopt children

PSYCHOSOCIAL UNERPINNINGS

- **Historical personal and social context**
- Higher levels of trauma and emotional distress in LGBT community
- Homophobia – internalised self-stigma
- **Escape**
  - From societal attitudes, judgment…....

  (stigma, layers of toxic shame – marginalised groups, HIV status....)
  - From aspects of gay culture

  (perfect body, perfect sex)
  - From own sense of shame – shame free space?
  - From loneliness

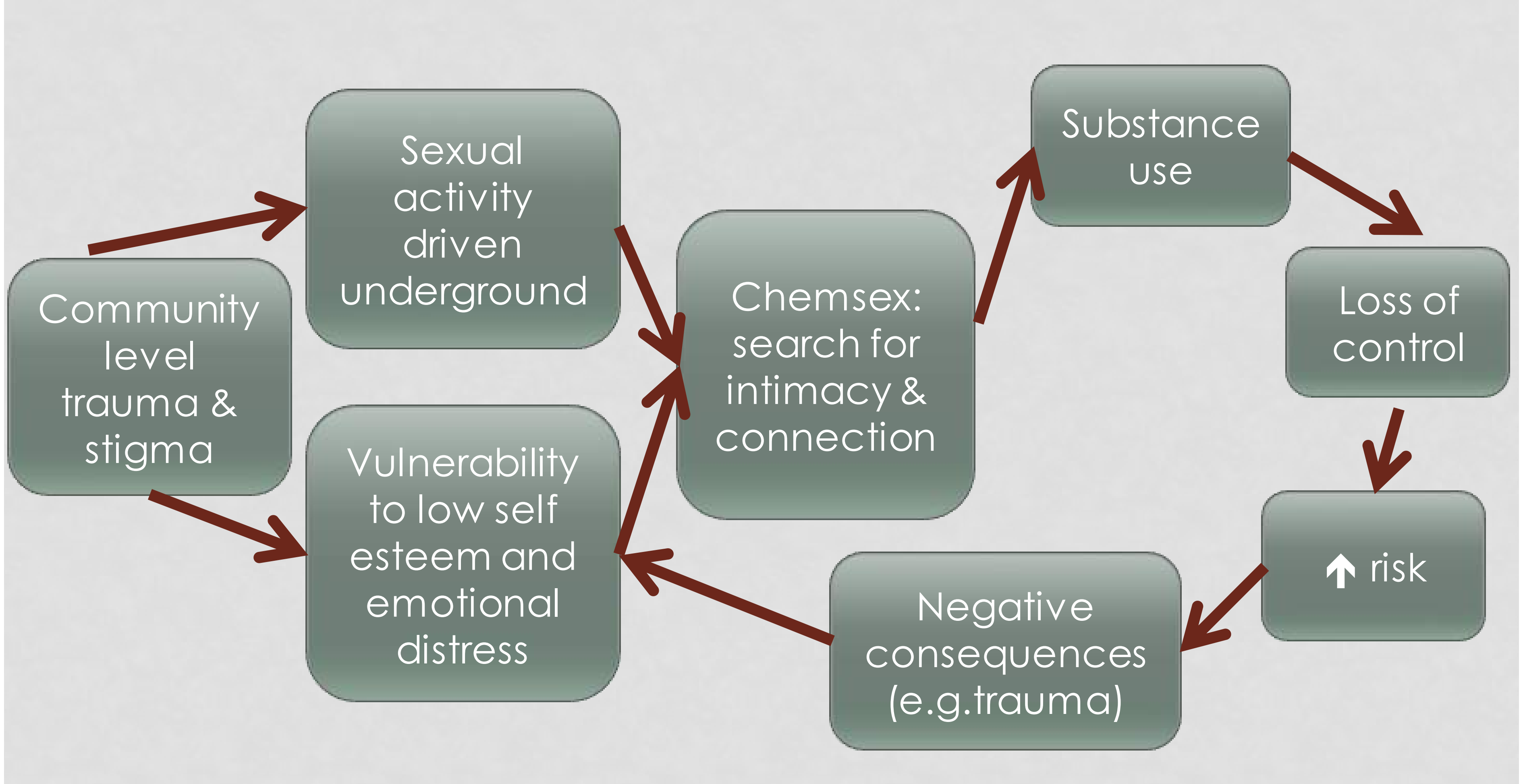
Evans (2019); Lloyd & Operario (2012); Morris 2019; Pollard et al (2018); Stuart (2019)

PSYCHOSOCIAL UNDERPINNINGS

- **It can be about the sex OR the drugs - (or of course both)**
- Great sex –
  - strong reinforcer (problem of sober sex)
  - Drugs can facilitate sense of connection/intimacy
- Chems offer relief from emotional distress
  - Historical and/or recent trauma
  - Self medication to reduce distress or reduce numbness

Evans (2019); Lloyd & Operario (2012); Morris 2019; Pollard et al (2018); Stuart (2019)

AN ON-GOING CYCLE



A COMPLEX PICTURE

- Although chemsex can offer shame free space, connection and uninhibited sex – it comes with consequences, and often inadvertently reinforces the issues MSM are trying to escape

HOW CAN SERVICES RESPOND?

- **Call for chemsex-related issues to become a public health priority**
  - A need for an integrated, holistic, Multi/interdisciplinary approach with local and national support pathways and partnership working
  - Shared social, political and institutional responsibility

- **Important elements of chemsex intervention:**
  - Sex positive
  - Harm reduction
  - Hollistic Ax (substance use, sexual needs and mental health)
  - Community involvement

Elliott et al. (2017); Glynn et al. (2018); McCall et al. (2015); Pollard et al (2018); Pufall et al. (2018); Sewell et al. (2018).

HOW CAN SERVICES RESPOND?

- Non-judgmental approach
- Be aware of language and non-verbals (curious vs shocked)
- Provide space for exploration if person wishes
- Space to understand self – may facilitate integration (chemsex used compartmentalise aspects of self)
- Utilise existing relationships - connection can begin to heal trauma
- Hollistic assessment (including risk Ax)
- Signposting to relevant services
- Ask consent to liaise with involved services
- Explore alternative community connections
- Foster hope by recognising resilience (survival skills)

Thank you for listening

Any thoughts? questions? reflections?

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21-22 September 2019 • Rome, Italy

HOSTED BY:

IN PARTNERSHIP WITH:

Complexity in HIV Care

Shaun Watson
Clinical Nurse Specialist (HIV Community)

Disclosures

I have undertaken paid advisory work and speaking invitations for:

ViiV, MSD, Gilead and Pfizer

It’s just a pill once a day what the big deal?

- **“What’s the problem? You take a pill once a day and that’s it. So get off benefits, get back to work and lead a long and healthy life with HIV”**
- “You just go in, get your bloods, the doctor says the numbers are OK, get the pills and get on with life”
- **”Just call your doctor” “Just book and appointment”**
- **“At least you’re alive!”**

The Modern Complex Patient

- The presence of multiple, well-defined chronic illness with various complications
- Treatment with multiple medications
- Highly specialized treatment and highly effective invasive procedures both for diagnosis and treatment
- A peculiar combination of resiliency and fragility
- Unexpected responses to common medications and minor illnesses
- Longevity (living highly functional lives into the 80's and 90's)

(http://www.moderncomplexpatient.org/category/the-modern-complex-patient/)

What Makes Complexity in HIV?

- **Multiple disease means multiple professionals with multiple appointments (Case management/Integrated Health)**
- **Potential poly-pharmacy and the drug interactions.**
- **Social issues – care packages, social worker input (adult & child), vulnerabilities, safe-guarding and protection issues.**
- **And….ageing, alcohol/drug use (recreational, street and chem sex), housing, finance, immigration status, language, literacy, capacity…**
- **Then add…stigma and discrimination, relationships, family dynamics, personalities, culture, history, experience, motivation!**

What Would I Say?

- **Physical complexity** – multiple diagnoses, co-morbidity, disability, issues of ageing, polypharmacy.
- **Psychosocial complexity** – drugs/alcohol use, language, culture, experience, confidentiality, stigma & discrimination
- **Socioeconomic complexity** – finances, benefits, housing, immigration
- **Professional complexity** – ‘it’s not our role/problem’…”oh they have HIV”
- **It’s everything!**

Complex or Complicated

- **We need to look at the complexities of health & social care not just how complicated it is to manage.**
- **Complex care needs skilled case management which requires a multidisciplinary team approach from the HIV team, GP, social services, palliative care, district nurse, support worker, drug/alcohol worker, psychologists, psychiatry, etc, etc, etc.**

Who's who?

- Partner, friends, family
- GP, practice nurse, district nurse
- Other specialist consultants – ageing, renal, cardiac…
- Psychiatrist, psychologist, psych. nurses, drug & alcohol workers, crisis team, support workers.
- Social worker (child & adult), carer's, housing workers, advice agencies
- HIV Voluntary services, respite care, palliative care, peer support.

Case Study - Sam

- Sam, 83, gay man, widowed (19 years)
- HIV positive for 25 years, controlled on TAF/NVP
- Ischaemic heart disease, dyslipidaemia, renal impairment, mild haemophilia, hypertension
- Admitted to hospital after falling in the street
- Referred for ‘support around ARV’s and concerns re. memory and complexity.
- Would he be classified as complex?

UK Payment by Results

- **Complexities (as devised in 2009) are listed as:**
  - Current TB co-infection on anti-tuberculosis treatment
  - On treatment for chronic viral liver disease
  - Receiving oncological treatment
  - Active AIDS diagnosis requiring active management in addition to ARV (not inpatient care)
  - HIV-related advanced end-organ disease
  - Persistent viraemia on treatment (> 6 months on ARV)
  - Mental Illness under active consultant psychiatric care
  - HIV during current pregnancy

UK Payment by Results

- The nature of HIV disease means that patients may have an additional range of complex psycho social needs, which go beyond the remit of the hospital, based HIV team to meet. The cost of meeting such needs is not included in the tariff development to date.
- However, in developing the HIV Currency it is acknowledged that there are a number of patients with complex psycho-social needs who may inappropriately rely on the HIV clinic to meet those needs
- One of the fields in the data set allows both providers and commissioners to monitor the impact of patients being under the care of social workers.

Sam on Assessment

- Lives alone (with his cat) 5th floor, no lift
- States he is lonely and isolated, all other property in his building are offices, closed at weekends/holidays
- Fall 2 months ago, feels dizzy all the time
- Care package (2 x 2 hours a week –cleaning/shopping)
- Lives on sandwiches – doesn't cook (too time consuming)
- Numerous hospital appointments needing transport
- Discharged from hospital – asked to leave by security after the ward lost his wallet, discharged home with no money/food on a Thursday evening
- Agreed to visit weekly!

Sam weekly visits

- Stopped ART – weeks ago “do you know the side-effects are dizziness”
- In pain, won’t take paracetamol “it can kill you”.
- Attended hospital three times in one week, out of the house 6 hours each day, fed up and angry
- Has volunteer visitors 5 days a week, feels he needs more “they are always on holiday”, “she’s leaving London” seems to be very angry about it.
- Good relationship with GP – home visit last week stopped medications (can’t remember which)

What are the issues?

Recurrent falls have kept him a ‘prisoner in his home’.

Hyperchondriac – watches TV thinks he’s ill, highly anxious, reading side-effects. Numerous appointments in 3 hospitals.

HIV – controlled by TAF/NVP

Care is sporadic – different people, different times. Relies on volunteers who may or may not visit. Very angry about lost friendships

Poor self care – eats poorly, last saw a dietician in 2000.

Sam – Further Visits

- 10 calls to speak to his GP – took 2 weeks to respond
- Called Social Worker to clarify care package (he's been discharged). Called care agency to request continuity and timings. Carers encouraged to buy meals not sandwiches
- Confirmed medications with GP and HIV clinic, consolidated hospital appointments (HIV and falls clinic)
- Discussed issues with volunteers and rationalized visits
- Saw a TV programme about super gonorrhea – wants to know how he can be checked!

Sam Further Visits (2)

- Flood in flat caused by leaking roof
- Cinnamon trust now visiting his cat (and him) 5 days a week
- Feels his foreskin is too tight, doesn’t want a circumcision but now anxious he”ll need one.

What’s the Healthcare Professional’s Problem?

1. Referral – what we’re told versus what the patient thinks.
2. Communication -
   - Electronic notes on different systems
   - No easy telephone access with anyone.
   - No emails, fax only.
3. Interpretation on the case – one person’s manic is another persons eccentricity.
4. Happy to let others do the work – who is best place to lead…most involvement, pressing need, longest involvement.

Capacity

- **In English Law, an adult has the right to make decisions affecting his or her own life, whether the reasons for that choice are rational, irrational, unknown or even non-existent. This right remains even if the outcome of the decision might be detrimental to the individual**
- **However, such a right to self-determination is meaningful only if the individual is appropriately informed, has the ability (capacity) to make the decision and is free to decide without coercion (Grisso, 1986).**
  - **Grisso, T. (1986) Evaluating Competencies: Forensic Assessments and Instruments. New York: Plenum.**

What Can I Do?

- Prioritise – compare your 'vs' your patients top 10 problems – is there a match?
- Work with the patient – it's easier than you think, if they can make them take the lead.
- Offer to lead the care if no one else is willing to (or fight to lead it if you feel you know the patient best)
- Do what 'you' need to do and ensure others know their roles and stick to them.
- Consolidate & rationalize!
- Communication – find a way around it, safe emails, direct lines, mobile numbers, text, fax…whatever works easiest & best.

Who Leads Care?

Who Really Leads the Case?