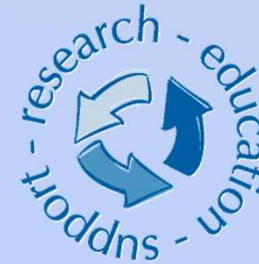


15<sup>th</sup> Annual Conference of the  
National HIV Nurses Association (NHIVNA)



National HIV Nurses Association

# Dr Ian Hodgson

## Independent HIV Researcher and Advocate

*27-28 June 2013- The International Convention Centre, Birmingham*

# HIV stigma and nursing: a European Perspective

*Ian Hodgson*

NHIVNA 2013  
Birmingham, UK

# This presentation

- Outline the current state of HIV in the European region
- Highlight prevalent forms of stigma
- Identify relevance to health policy and nursing
- Make recommendations

This is a detailed political map of Europe and its surrounding regions. The map uses a color-coded system to distinguish between different countries and territories. Major cities are marked with black dots and labeled. The map includes the following features:

- Geographical Features:** The map shows the North Atlantic Ocean, Norwegian Sea, North Sea, Baltic Sea, Adriatic Sea, Tyrrhenian Sea, Mediterranean Sea, Aegean Sea, Black Sea, and the Barents Sea. It also depicts the Arctic Circle and the Strait of Gibraltar.
- Political Entities:** Countries and territories shown include Greenland (Denmark), Iceland, Faroe Islands (Denmark), Shetland Islands, Orkney Islands, Hebrides, United Kingdom, Ireland, Jersey (U.K.), Guernsey (U.K.), France, Netherlands, Belgium, Luxembourg, Switzerland, Germany, Denmark, Norway, Sweden, Finland, Estonia, Latvia, Lithuania, Poland, Czech Republic, Slovakia, Austria, Slovenia, Hungary, Croatia, Bosnia and Herzegovina, Serbia, Montenegro, Albania, Greece, Turkey, Bulgaria, Romania, Moldova, Ukraine, Belarus, Russia, and parts of Morocco, Algeria, Tunisia, and Malta.
- Major Cities:** Numerous cities are labeled, including Reykjavik, London, Paris, Berlin, Moscow, Warsaw, Prague, Vienna, Budapest, Rome, Athens, and many others.
- Scale and Projection:** The scale is 1:19,500,000. The map uses the Lambert Conformal Conic Projection, with standard parallels at 40°N and 56°N. A scale bar at the bottom right shows 300 Kilometers and 300 Nautical Miles.
- Annotations:** A note at the top center states: "Serbia and Montenegro have asserted the formation of a joint independent state, but this entity has not been formally recognized as a state by the United States." Another note below it says: "F.Y.R.O.M. - The Former Yugoslav Republic of Macedonia".



# Where in Europe is the best beer?



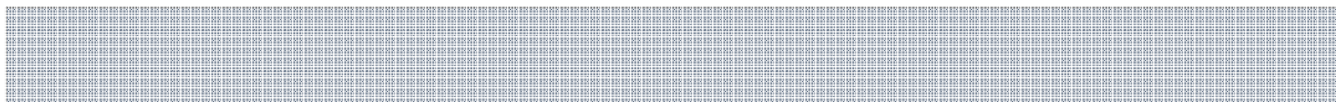
# How many countries are in the WHO European Region?

① 15



20%

② 27



60%

③ 53

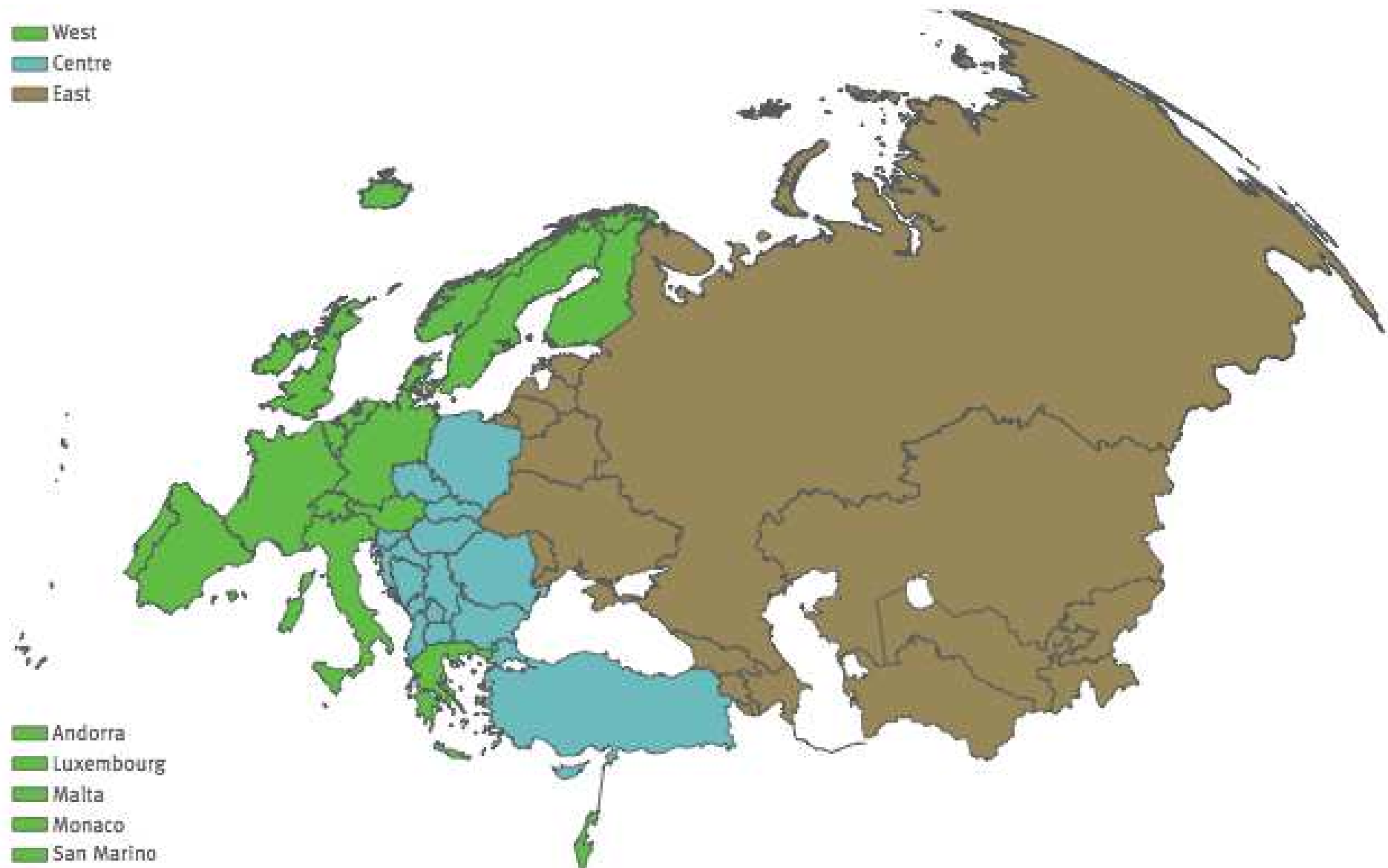


20%



# WHO European Region:

West, Centre and East



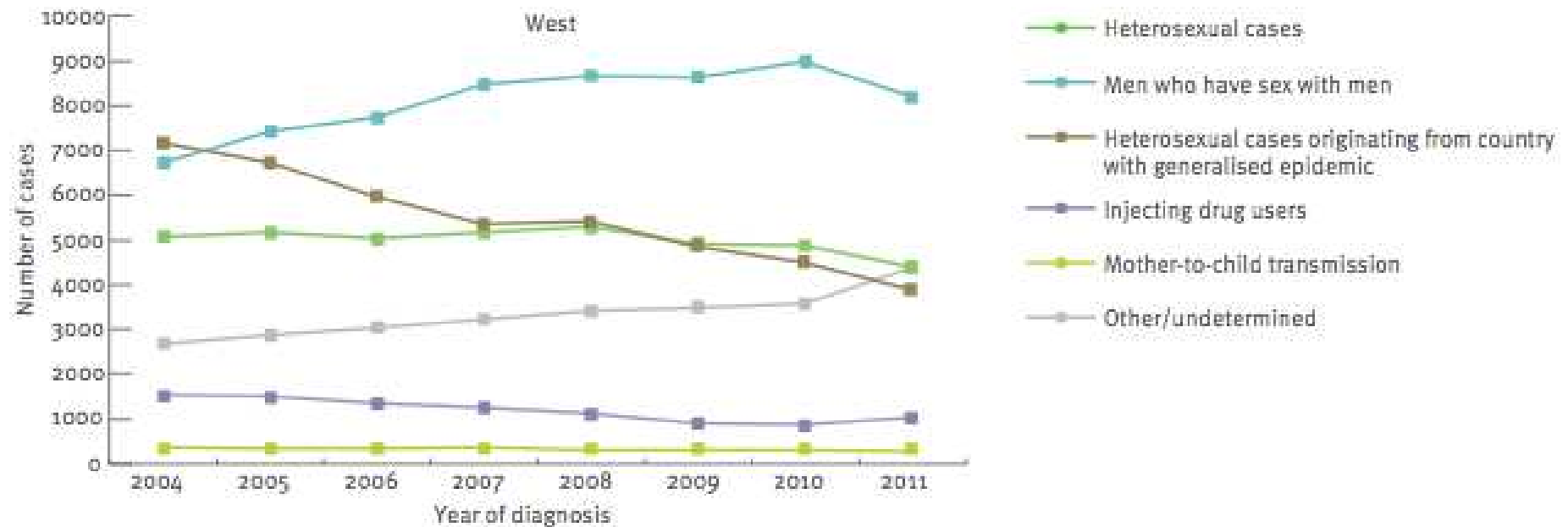
# HIV in Europe: summary

- People living with HIV (2011)
  - Worldwide: 31m
  - ALL Europe: 2.3m
  - West and Central Europe: 900,000
  - Eastern Europe (including Central Asia): 1.4m
- New HIV infections in 2011
  - Worldwide: 2.5m (20% lower than 2001)
  - West and Central Europe: 30,000
  - Eastern Europe and Central Asia: 140,000
  - AREA OF CONCERN: Eastern Europe and Central Asia



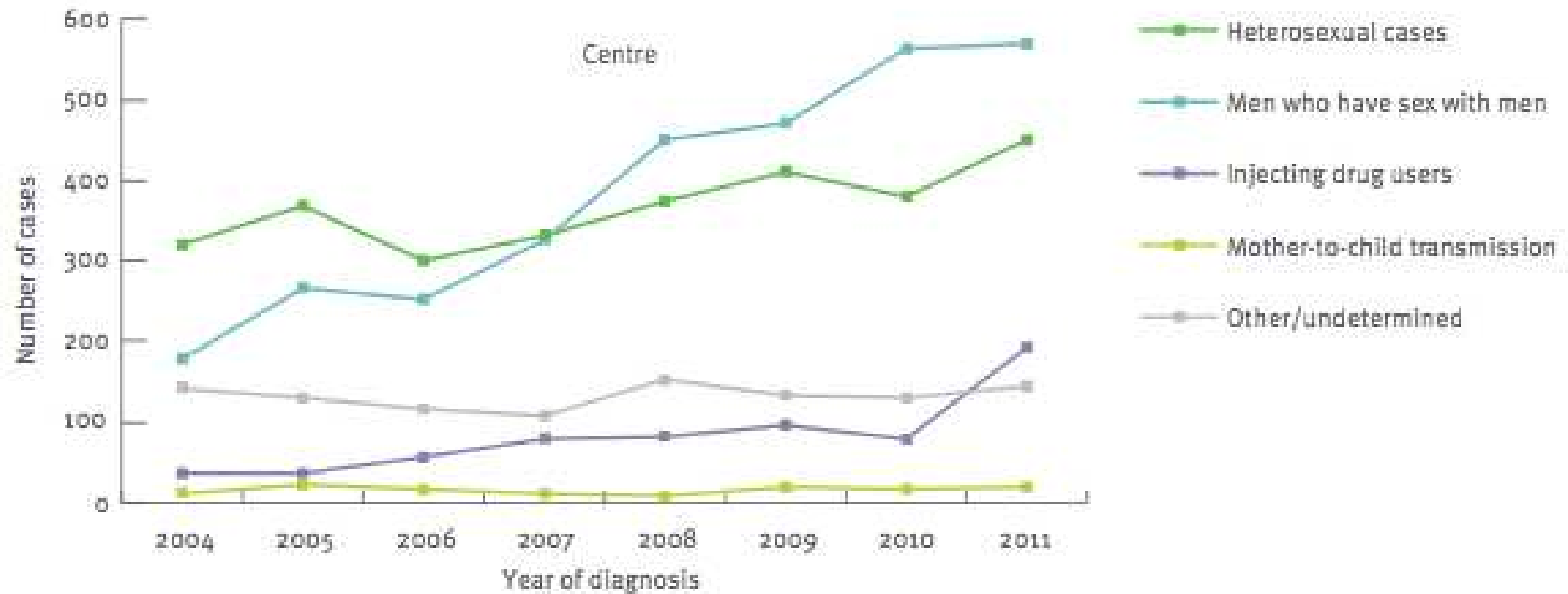
# HIV transmission (West)

## Mature epidemic



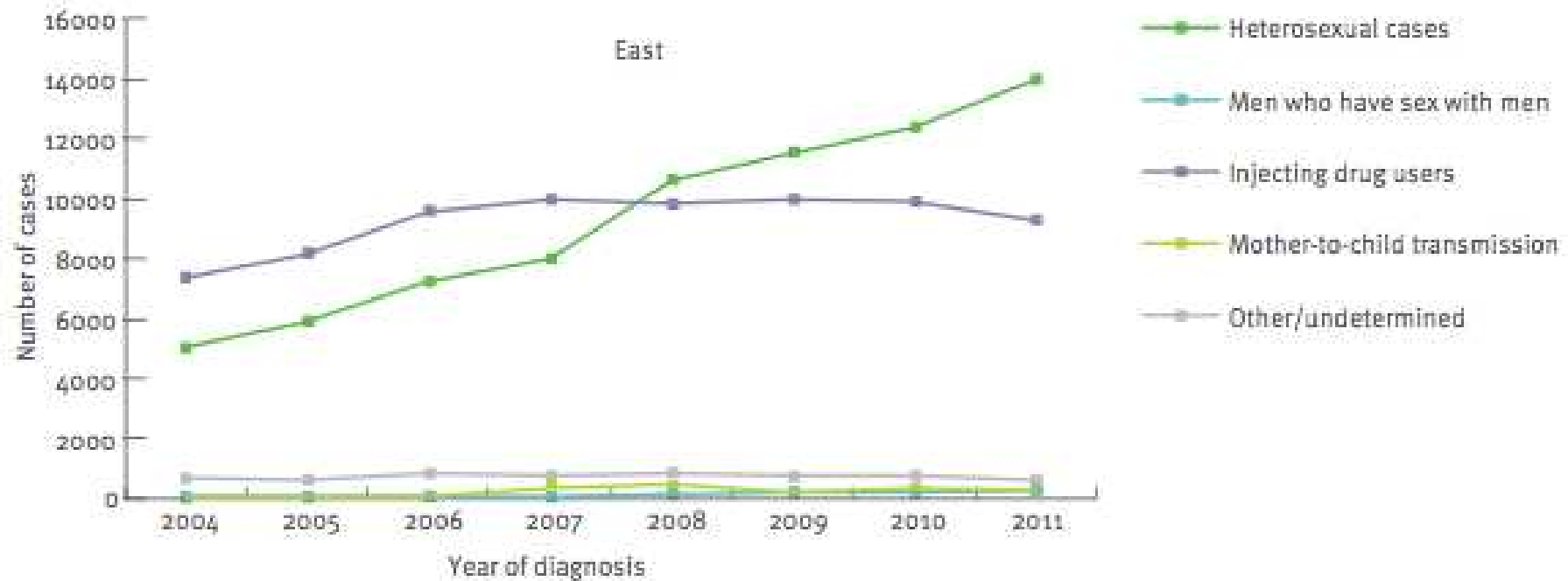
# HIV transmission (Centre)

## Stable epidemic



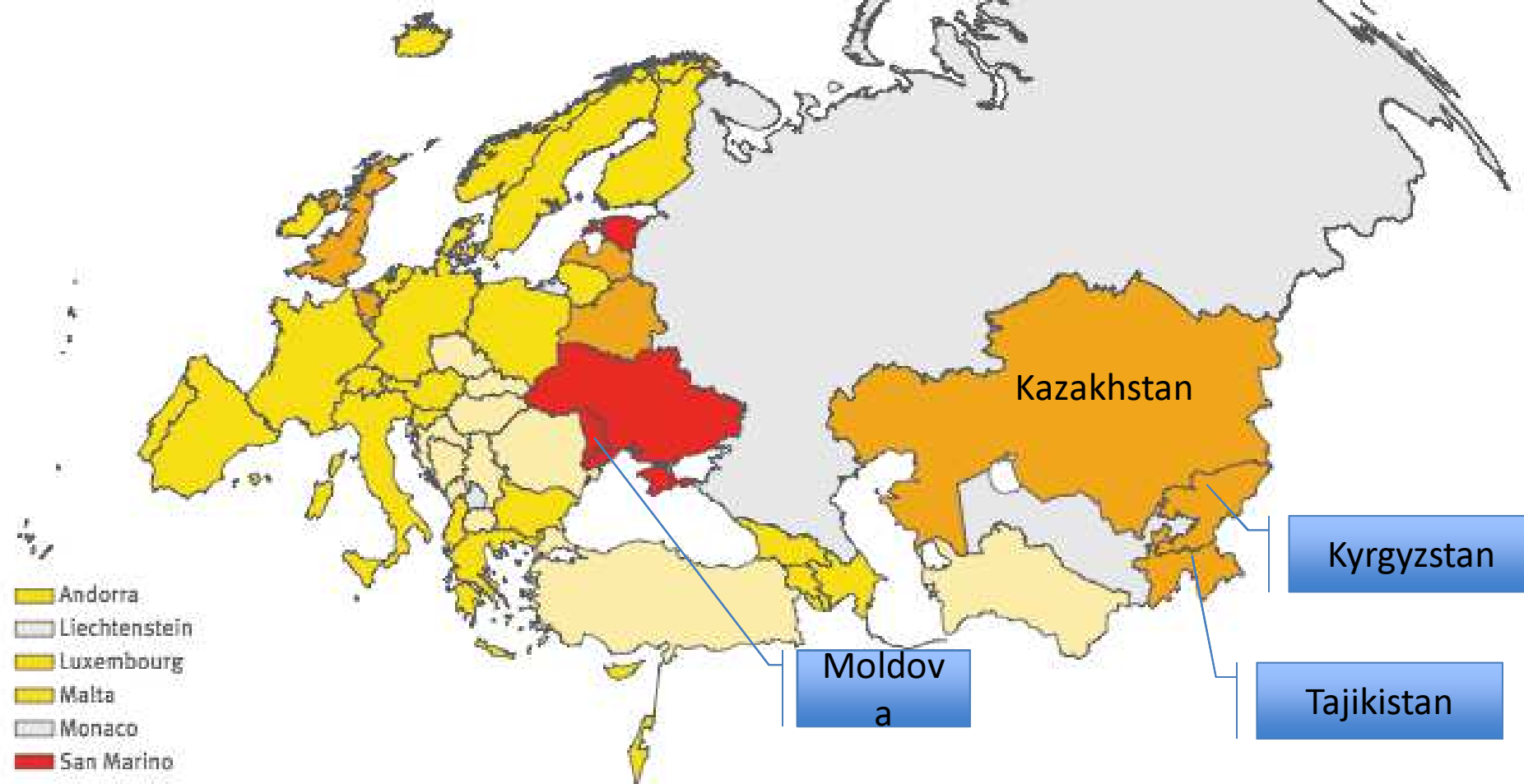
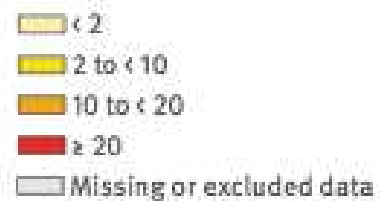
# HIV transmission (East)

## Concentrated, shifting to mature epidemic



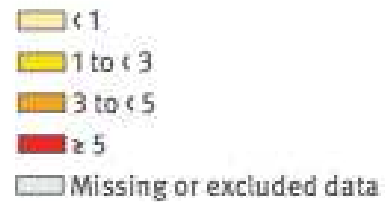
Including Russia (when stats available) and Central Asia

**Map:** HIV infections, per 100 000 population, reported for 2011: All cases



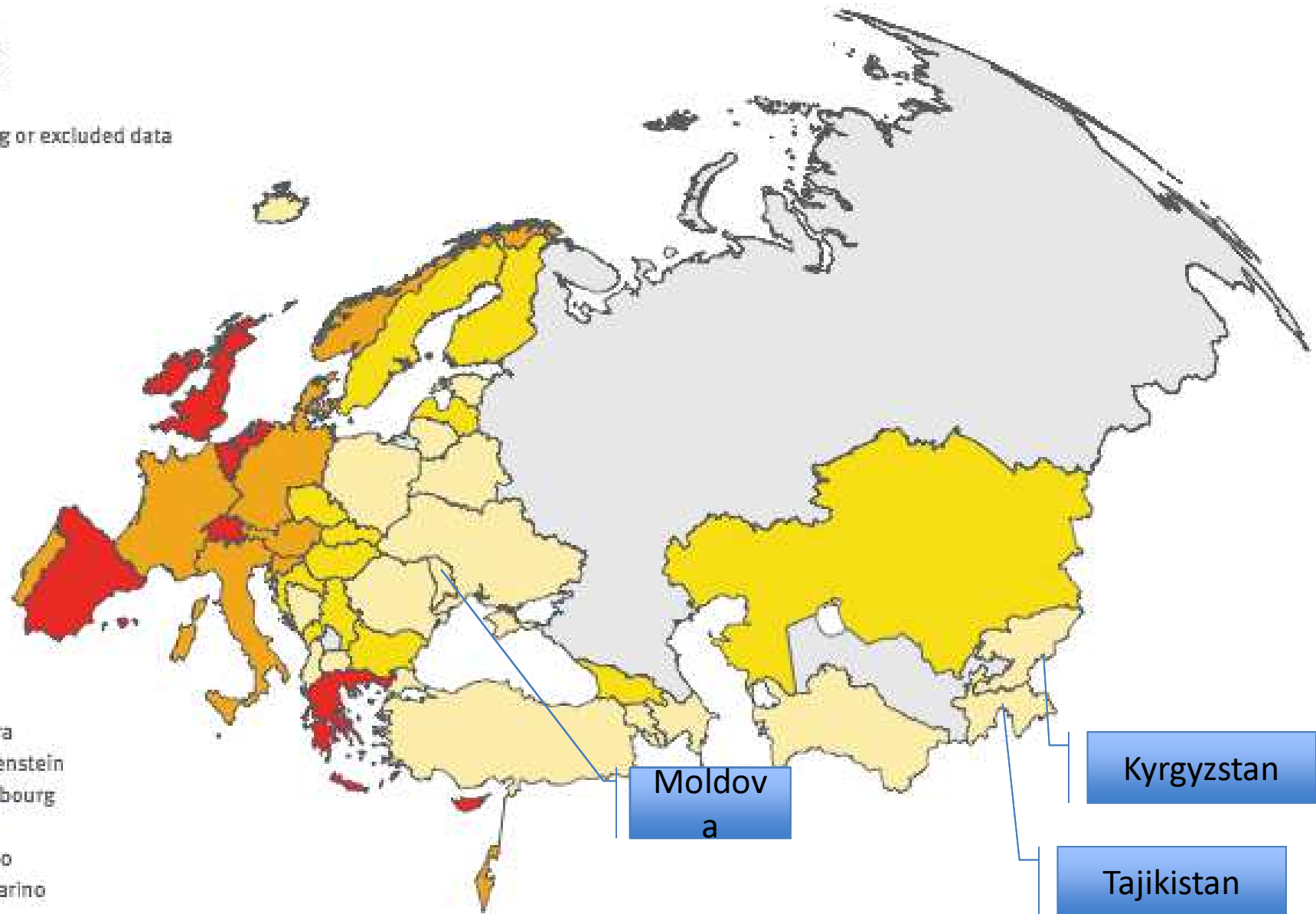
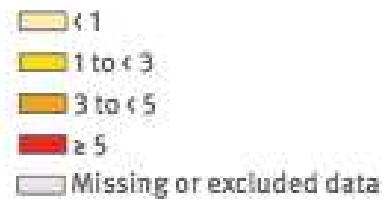
Source: WHO, 2011

**Map:** HIV infections, per 100 000 population, reported for 2011: Injecting drug users cases



Source: WHO, 2011

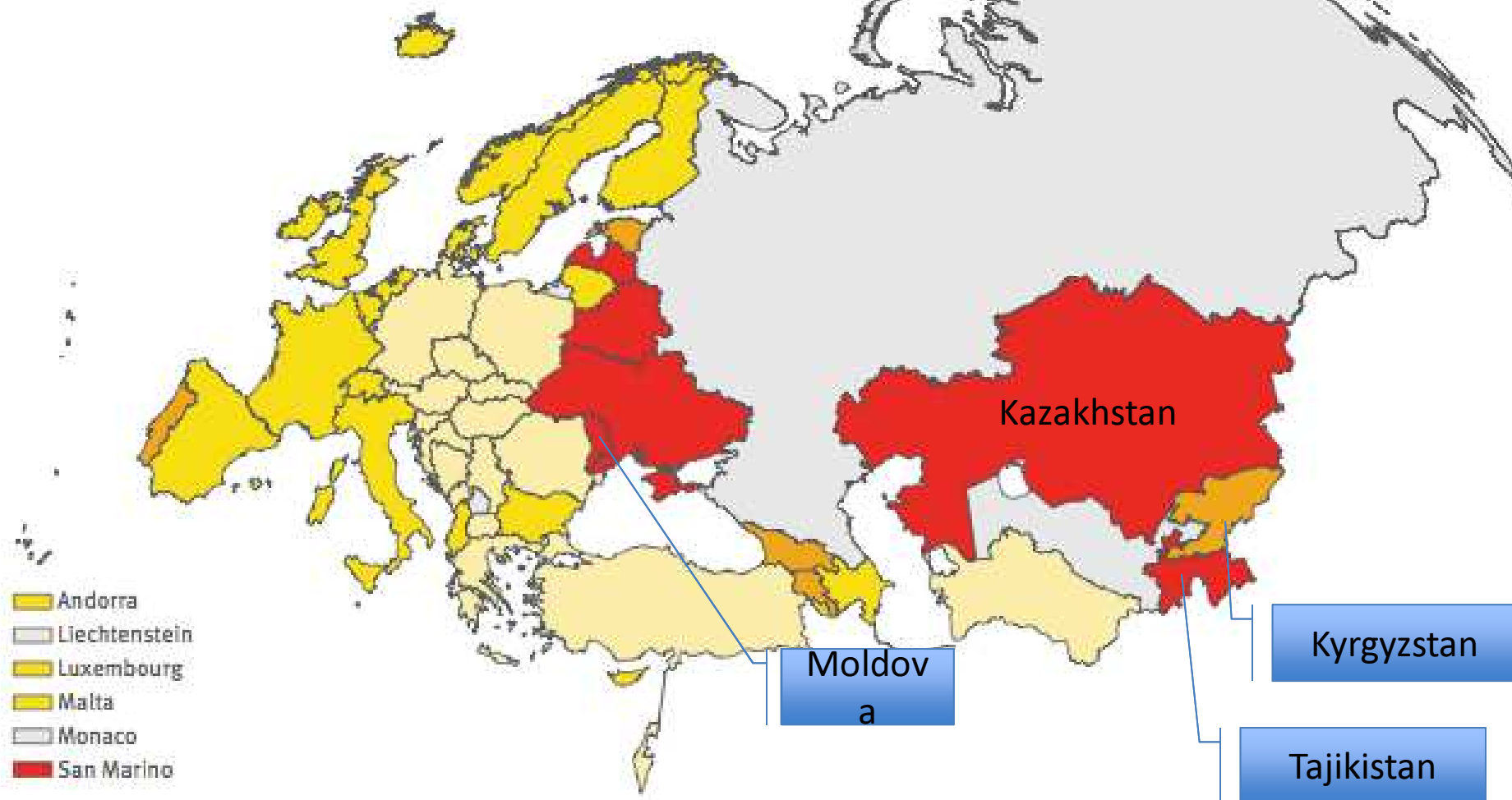
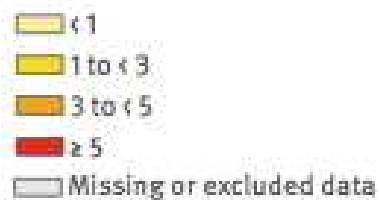
**Map:** HIV infections, per 100 000 male population, reported for 2011: Men who have sex with men cases



Source: WHO, 2011



**Map:** HIV infections, per 100 000 population, reported for 2011: Heterosexual cases



Source: WHO, 2011

# The nature of HIV in Europe

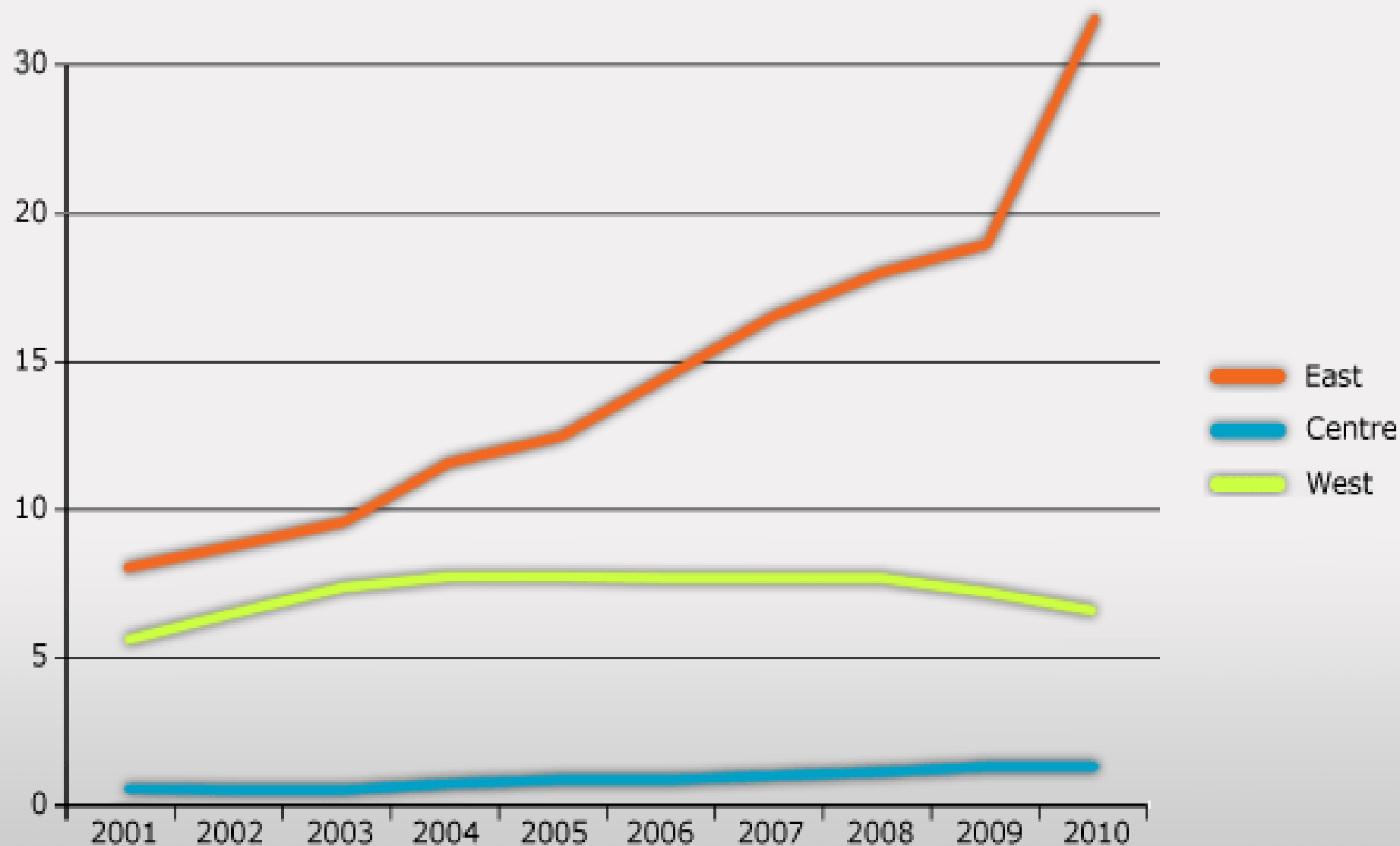
- **Transmission routes vary** according to geographical region
- **Low access to treatment** in Eastern Europe and Central Asia – only 25% of people needing treatment have access
- HIV, in all European countries, “**disproportionally affects** populations that are socially marginalised (such as migrants) and people whose behaviour is socially stigmatised (such as men who have sex with men) or illegal (such as people who inject drugs).” (WHO, 2012)
- Half of the HIV cases reported in Europe in 2011 with information on CD4 cell counts had a low CD4 cell count at time of HIV diagnosis, indicative of **late diagnosis** (WHO, 2012)



Selected countries – HIV and the human development index  
[HIV not *necessarily* related to poverty]

Source: GapMinder

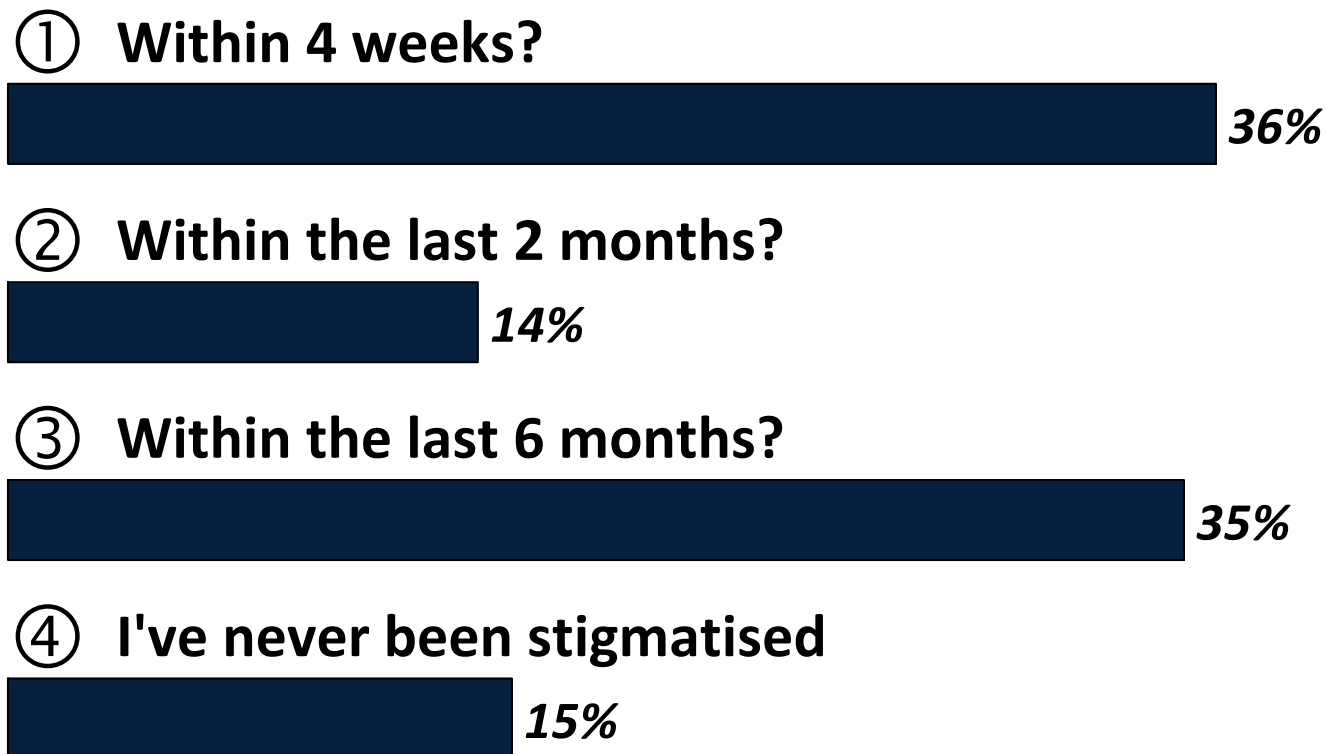
Newly diagnosed HIV cases per 100,000 population reported in the WHO European Region by year of diagnosis (Including Russia, 2010 onwards)



# What is stigma?

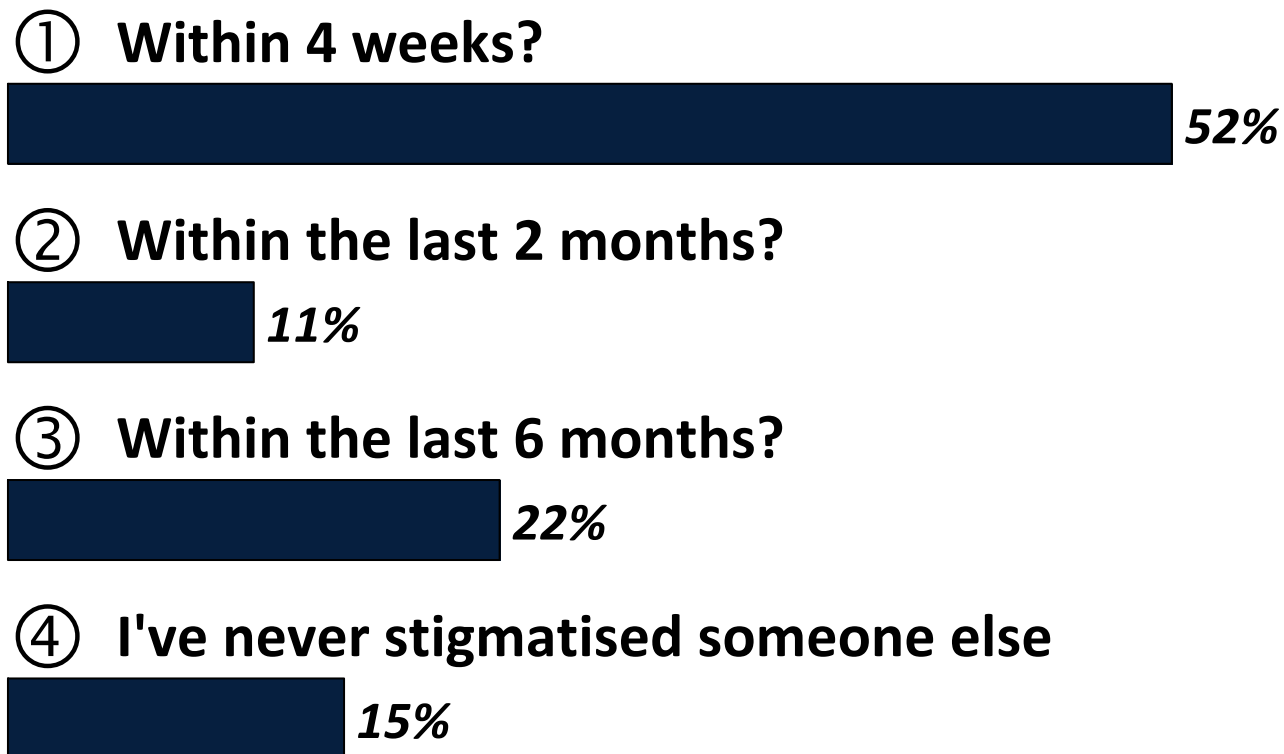
- Stigma is not new....
- Stigma marks an individual as being unacceptably different from 'normal' people with whom s/he interacts, and is...
- ...an attribute that discredits or disqualifies from full social acceptance (Goffman, 1963)
- Stigma is a social process; a feature of social relations reflecting the tension, conflict, silence, subterfuge and hypocrisy found in every human society and culture (Barnett and Whiteside, 2002)
- More than just the way a person is seen. It is social and cultural...

# When was the last time you felt stigmatised?





# When was the last time you stigmatised someone else?



# Points to note...

- Stigmatising illness is not unusual...
- ...leprosy, syphilis, mental illness, certain cancers, and TB are/have been heavily stigmatised
- “TB patients and their families throughout the world continue to face stigma.” (IHAA, 2009)
- Beliefs about danger and pollution are often used as a form of **social control**...
- ...and attaching ‘dirt’ and infection risk to social groups is a common political strategy: e.g. Jews in the 1930s, Tutsis in 1990, immigrants to the UK in the 2000s
- Stigma by association is a potent force

# HIV stigma

- Stigma works at the structural, social, and personal levels
- HIV stigma is complex, and multilayered, rooted in:
  - Fear of infection
  - Disapproval of particular social group – **layered (intersecting) stigma** is when a member of the social group lives with HIV
  - Internalised stigma (self-stigma) – a person infected with HIV feels low self-esteem, self blame, and guilt
- HIV stigma results in poor access to healthcare, poor job prospects, and community ostracism
- Stigma is amplified in countries where legislation criminalises HIV transmission (a specific law exists in **16 European countries**), and certain high-risk groups (in Europe drug users; in some African countries, MSM, sex workers)

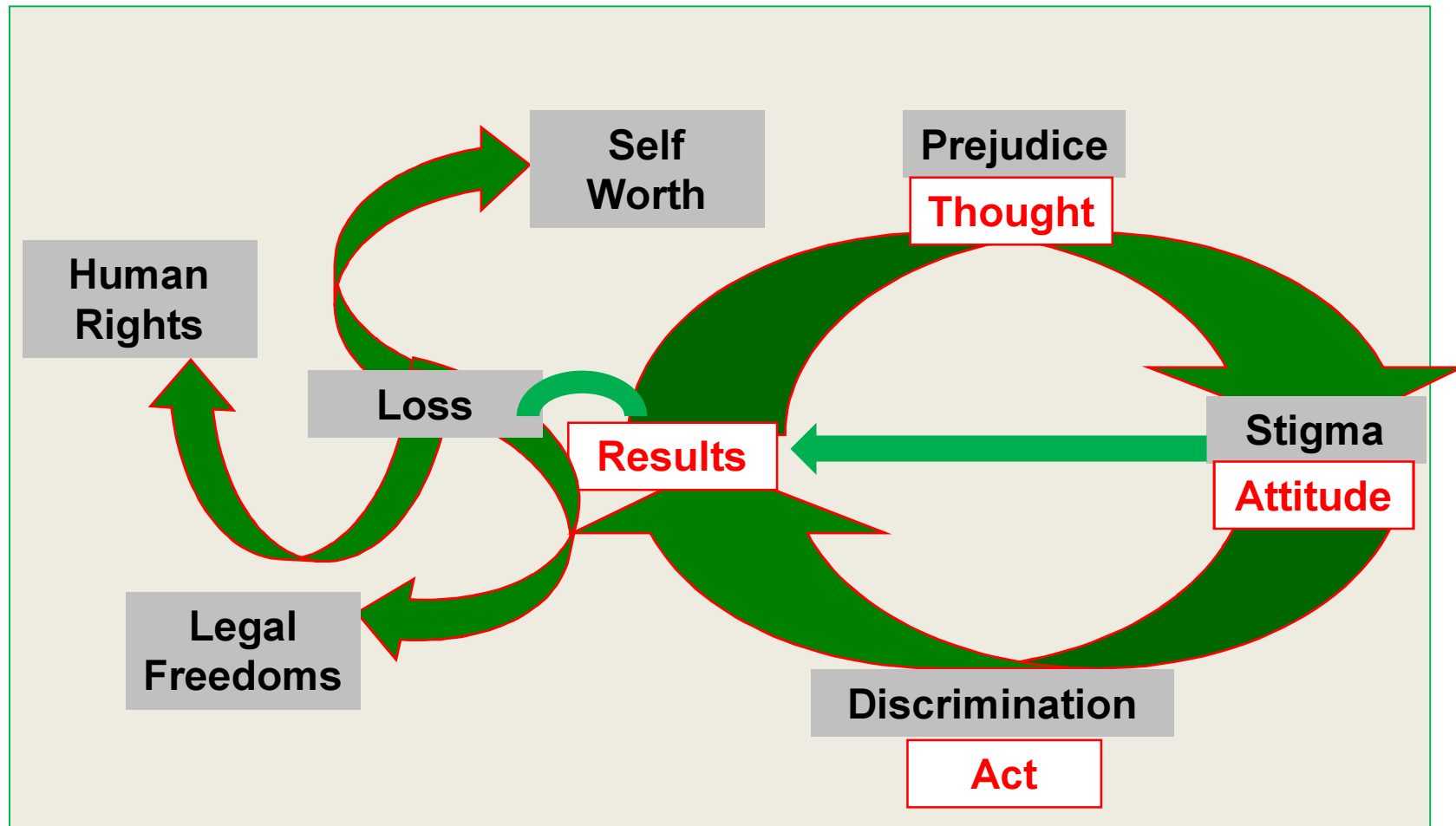
# The experience of being stigmatised

## EXTERNAL stigma

- Avoidance
- Rejection
- Moral judgment
- Stigma by association
- Discrimination (the ACT associated with stigma)
- Abuse of human rights & genocide

## INTERNAL stigma

- Self-exclusion from services or opportunities
- Low self esteem
- Social withdrawal
- Overcompensation: self-blame and guilt
- Fear of disclosure



## Impact of HIV stigma

Source: Julian Hows/GNP+

# HIV stigma across Europe

- Specific issues can include:
  - Fears of **confidentiality breach** in the health system (e.g. Serbia and Montenegro)
  - **Poor treatment** by nurses (e.g. Estonia)
  - **Double jeopardy** of members of minority groups living with HIV (e.g. Roma communities in Hungary and Bulgaria)
  - **Reluctance to be tested** [or even visit a doctor] due to anticipated stigma (e.g. Balkans, Ukraine)

Source: Burholt, 2010



*“According to a study conducted by the All-Ukrainian Network of PLWH in 2009, people living with HIV do not seek help until **2-3 years after they are diagnosed with HIV.***

*From experience we know that much of the reluctance to come forward and seek the necessary help and support is **due to the stigma that people living with HIV/AIDS feel and experience.***”

[Source: HIV in Europe (2011)]



Picture source: International HIV/AIDS Alliance

# Similarities and differences

HIV stigma across the region – just the same?

- Interesting study - HIV stigma in Russia (Balabanova *et al*, 2006) based on:
  - Fear of infection
  - Disapproval of “immoral behaviour”
  - General population was “unforgiving” of HIV acquired through sex or injecting drugs
  - ...ummm – does this sound familiar?
- Generic factors affecting stigma:
  - “Reinforcing the fear of disease was a prejudice against strangers and all their strange ways.” (Stewart, 1949)
  - “Do people in different cultures live in different worlds, or live the same world differently?” (Fay, 1996)
- How can we find out about the CONTEXT for PLHIV?

# The PLHIV Stigma Index

- Launched in **2007**, and includes agencies such as IPPF, GNP+, UNAIDS, ICW
- Aims to **document the (lived) experiences of PLHIV** within a particular community or country regarding HIV-related stigma and discrimination
- **Compares** the situation of PLHIV in one country or across different countries
- **Measures changes over time**, to track improvement or worsening of issues around stigma, discrimination, and rights of PLHIV
- Provides **an evidence base** for policy change and programmatic interventions
- In Europe, **data collected so far** in: Estonia; Germany; Moldova; Russia; Poland; Turkey; Ukraine; and UK

# What issues are tracked by PLHIV Stigma Index?

- Experience of stigma
- Access to work and services
- Internal stigma and fears
- Rights, laws and policies
- Testing and diagnosis
- Disclosure and confidentiality
- Treatment
- Having children



# PLHIV Stigma Index

## Selective Results

- **Moldova (2012):** 13.6% of 403 respondents report denial of health or dental services
- **Estonia (2011):** 17% avoided going to a clinic when they needed to
- **Russia (2010):** 26% experienced sexual rejection due to HIV status; 20% faced psychological pressure from partner with HIV “being used against them”
- **Turkey (2011):** 55% of sample (100) were tested for HIV without their consent
- **UK (2012):** 31% of respondents have not had a “constructive” conversation with a health care provider

Men's Top three reasons for delaying care by country					
	Estonia	Moldova	Poland	Turkey	Ukraine
1	I was not ready to deal with my HIV infection	I was not ready to deal with my HIV infection	I was not ready to deal with my HIV infection	I could not afford health care	I was not ready to deal with my HIV infection
2	I was afraid that someone I knew would see me there	I was afraid that the health care workers would disclose my status without my consent	I did not receive a referral or did not know where to go to get HIV care	I was not ready to deal with my HIV infection	I was incarcerated and not able to access HIV care
3	I was afraid that I would be seen as promiscuous, a sex worker, a drug user, or a man who has sex with men	I did not receive a referral or did not know where to go to get HIV care	I was afraid that I would be seen as promiscuous, a sex worker, a drug user, or a man who has sex with men and I was incarcerated and not able to access HIV care were equally recorded as reasons	I was afraid that the health care workers would disclose my status without my consent and I was afraid that someone I knew would see me there and I was afraid that I would be seen as promiscuous, a sex worker, a drug user, or a man who has sex with men were equally recorded as reasons	I was afraid that someone I knew would see me there

Reasons for delays in accessing care following a positive HIV test

Source: HIV in Europe (2010)

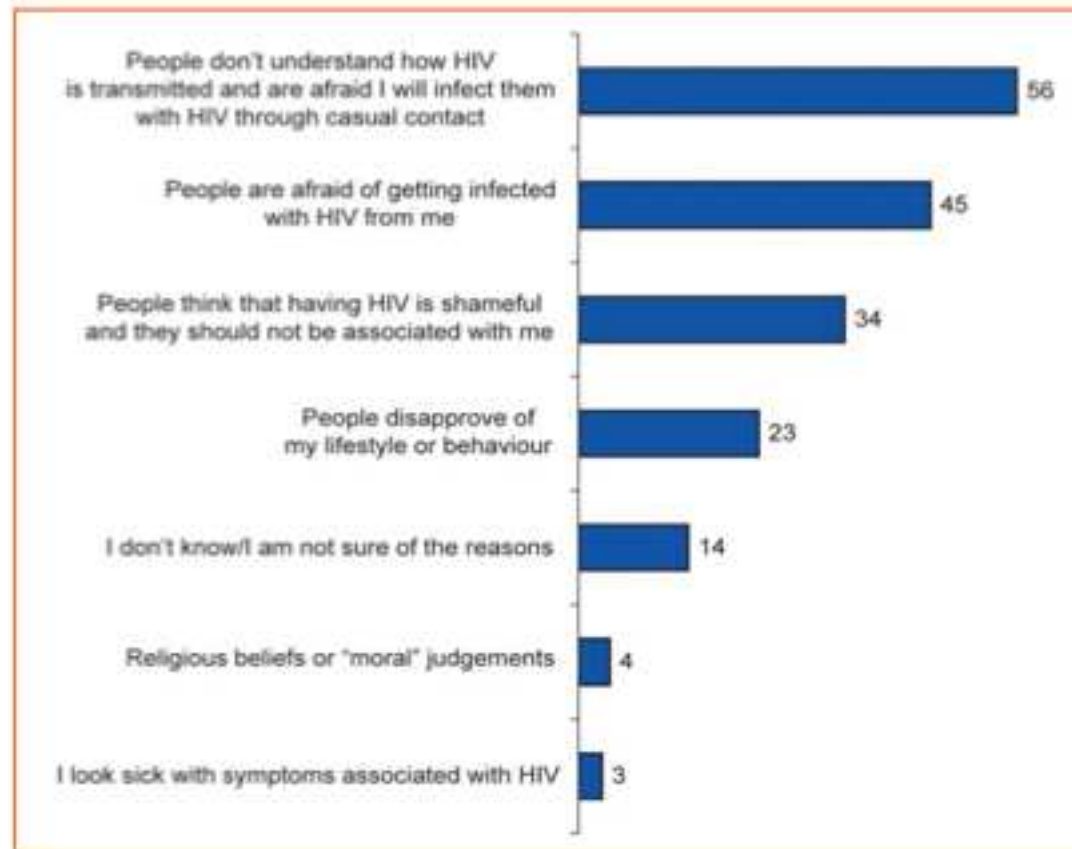


# Personal Story (Ukraine)

*I shared my diagnosis with my mum. She took a drink to ease her grief and told it to her friends and neighbours. Now the neighbours avoid communicating with our family, do not invite us to birthday parties. They do not visit us as well, and when we come across in the street, they turn aside or cast their eyes down.*

*After my baby was born and struck off the registration in the dispensary, I turned to my friend asking to be godmother to my child. She refused, saying bluntly, 'No, you have AIDS!'*

Source: 'Life story, Odessa city'  
[PLHIV Stigma Index report, Ukraine, 2011]



Reasons for stigma and discrimination (% of those who experienced some form of stigma in the past 12 months).

Source: PLHIV Stigma Index Report, Ukraine, 2011

# Personal Story (UK)

*I went to get my bowels investigated...the drip thing was sticking out of my arm.*

*The doctor says [to the nurse]...don't go near that side, there's a live needle there. I says 'What do you mean live?' And he says, 'Are you on medication?', I says 'No' because at the time I wasn't, so he says 'So you're live then.'*

*It weren't that long [ago]...last year, or the year before."*

Source: PLHIV Stigma Index Qualitative Data (UK) 2010 [Glasgow]



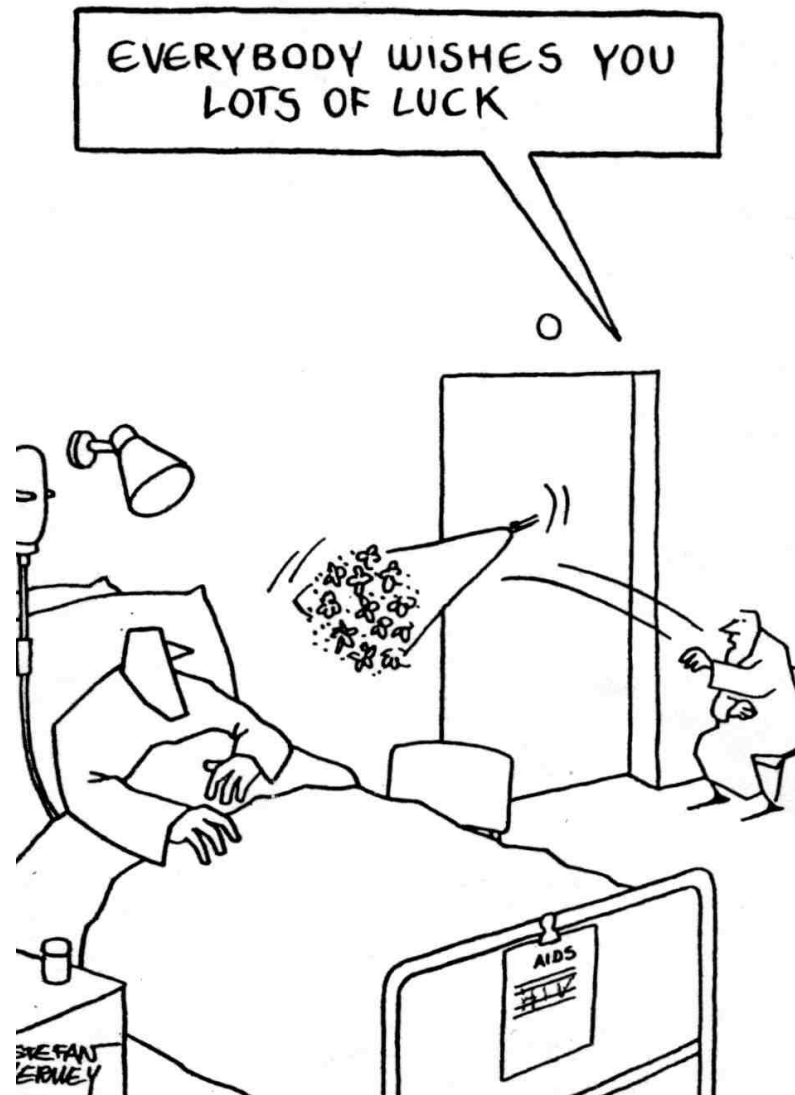
**„WIE WAR'S?"**

**Fazit der Interviewer/innen  
bei positive stimmen**

# Challenges for health and policy

- **Legacy of Soviet health system** in the East - vertical (rather than horizontal) care, with reduced nursing autonomy and limited health system capacity
- **Testing delays** and barriers to testing. especially young people, who report higher levels of hesitancy, and countries where attendance for a test is ONLY because of symptoms
- **Care Delays** – getting people INTO the health system after testing.  
Need:
  - Encouraging **PLHIV-friendly** services
  - Ensuring the health system is **prepared** for PLHIV: what do they know?
  - **Reducing stigma against affected social groups** – for example sex workers, mobile populations, drug users, MSM – this will be CONTEXT SPECIFIC (and has worked in Africa for sex workers)
- **Long term care** – KEEPING people in the health system
  - **Access to treatment** and systems for treatment compliance
  - **Support of PLHIV**; sexuality; legislation; and related issues (sex work, drug use, relationships)

# How does this impact on nursing?



# How does this impact on nursing?

- Many challenges for PLHIV relate to **health services** – how can we remove barriers to care? (including barriers to testing?)
- Though prevalence is HIGH in parts of Europe, levels of **nursing knowledge and expertise (and capacity) should be assumed to be VARIABLE**
- Use of HIV **nursing competencies** are required to protect the rights of patients and ensure quality of care
- A solution? “[PLHIV] are more like friends than patients...they’re no different to me.” [HCW, UK, 2002]
- Services should be **designed and delivered in ways that maximise the opportunities** for PLHIV to consistently attend and remain engaged in care (BHIVA, 2013)

# Active interventions

- **Ensure organisational systems are in place** to protect people against discrimination
- **PROMOTE:** the greater involvement of PLHIV (GIPA), and community mobilisation for better advocacy
- **PROVIDE:** information and education to challenge dominant discourses, and reduce notions of difference
- **ADVOCATE:** for effective human rights-based legislation and constitutions
- **APPRECIATE:** health care is not blind – how adept are we at being non-judgmental?
- **CONSIDER:** are things improving? Africa has much to teach us...



# European HIV Nursing Network

- Promoting an **awareness of the contribution** nurses have to make on all aspects relating to HIV
- Promoting a **high standard of care** for people with HIV
- Facilitating **education, training and research** opportunities for nurses in relation to HIV care
- Liaising with **European organisations** to promote the role of nurses



# Concluding thoughts

- HIV in the European region is (at least) **three related, but distinct epidemics**
- The experience of stigma has **generic, and context-dependent**, features
- Interventions must **be targeted** to local, specific issues relating to the health system, community and NGO support, and the needs of PLHIV, and address not JUST HIV, but also interlocking factors (human rights)
- Nurses in the west of Europe, and Africa, have a **great deal to share** other parts of Europe, though sensitivity to local systems is needed...



**I AM  
NOT**  
DIRTY  
HELPLESS  
BEING PUNISHED  
A VICTIM  
**SICK**  
AN ADDICT  
A WHORE  
DYING  
A STEREOTYPE  
GUILTY

**I AM  
HIV**  
POSITIVE

IT'S TIME TO CHANGE THE WAY WE SEE, THINK, & SPEAK HIV.  
IT'S NOT WHAT IT USED TO BE. YOU CAN HELP END THE STIGMA.

THE  
**S+IGMA**  
PROJECT

# THANK YOU

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**Thanks to:** Julian Hows and Liz Tremlett (GNP+)

