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Leaving no one behind
Maximising health care access for key populations affected by HIV

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Declaration of interests relating to this presentation

- **Statement of interests: none**

This presentation

1. **Background:** An overview of HIV services and progress in the European region
2. **Focus:** Who is at risk of being left behind?
3. **Country examples** of HIV service access
4. **Recommendations** for strategy and health care

Background

Overview: HIV in Europe

OVERALL: *The current increasing trends indicate that the Region is **not on track** to meet the WHO and Joint United Nations Programme on HIV/AIDS (UNAIDS) targets relative to attaining the United Nations Sustainable Development Goal (SDG) 3.3.*

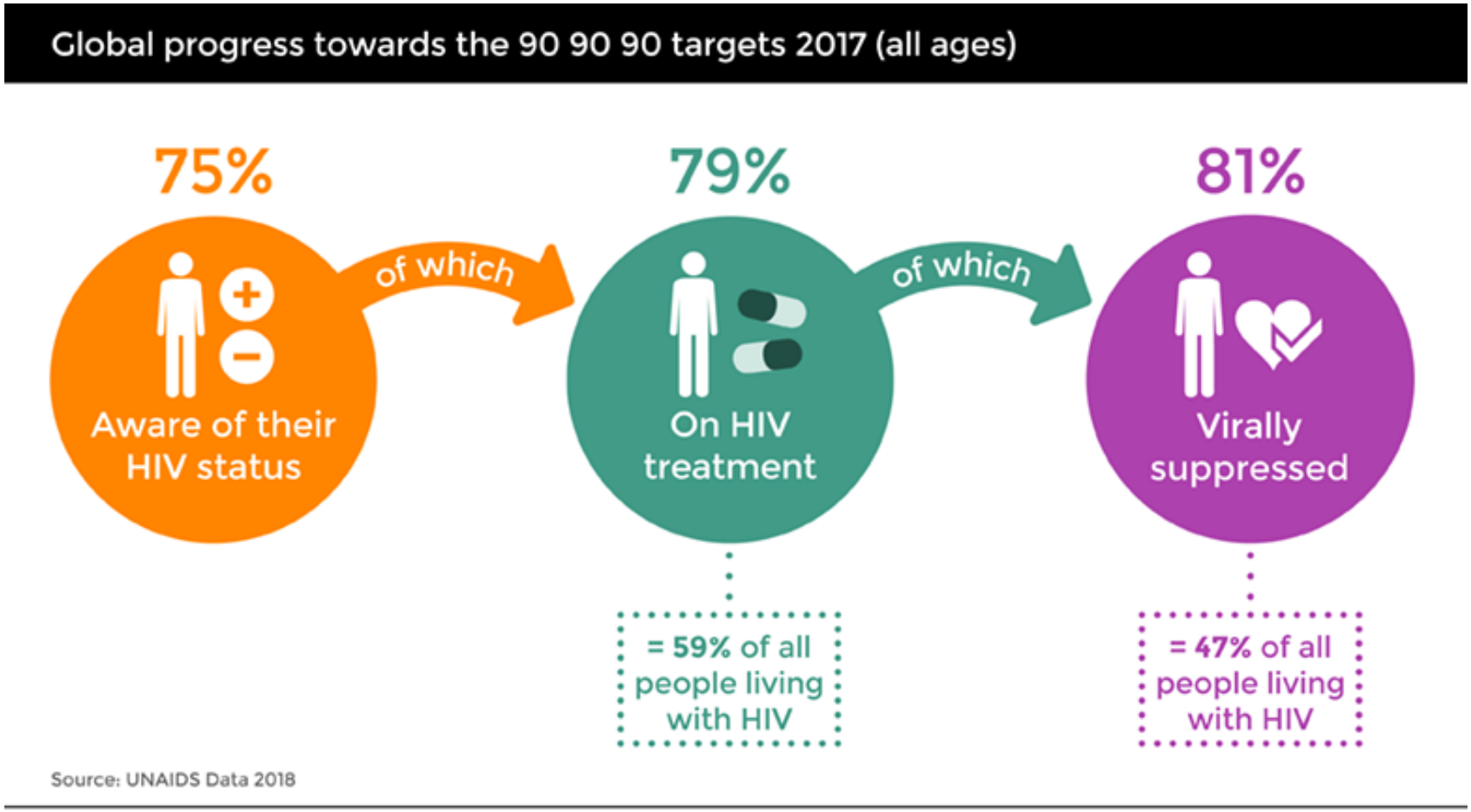
- **Western**: The changing epidemiology of HIV infections over the last decade suggests some progress, particularly on reducing infections attributed to heterosexual transmission and injecting drug use and, more recently, the decline of HIV resulting from sex between men in some EU/EEA countries.
- **Central**: Sexual transmission prevails in all countries, with sex between men being the predominant mode of transmission in 12 of the 15 Centre countries and reported heterosexual transmission prevailing in three. Drug-injection-related transmission remains low but recent outbreaks suggest HIV prevention services for people who inject drugs must be retained with sufficient coverage.
- **Eastern and Central Asia**: The HIV epidemic continues to grow in the East, with many countries not on track to reach key global targets by the end of 2020. HIV transmission among people who inject drugs and their sexual partners account for the majority of HIV infections. Growing HIV epidemics among **transgender people** and **gay men** and other men who have sex with men are understudied and unrecognized by several national HIV responses. Political, legal and technical barriers in many national HIV programmes are delaying the use of new, innovative approaches and tools, such as self-testing and pre-exposure prophylaxis (PrEP).

90-90-90 treatment targets

A useful way of tracking overall progress…though dated

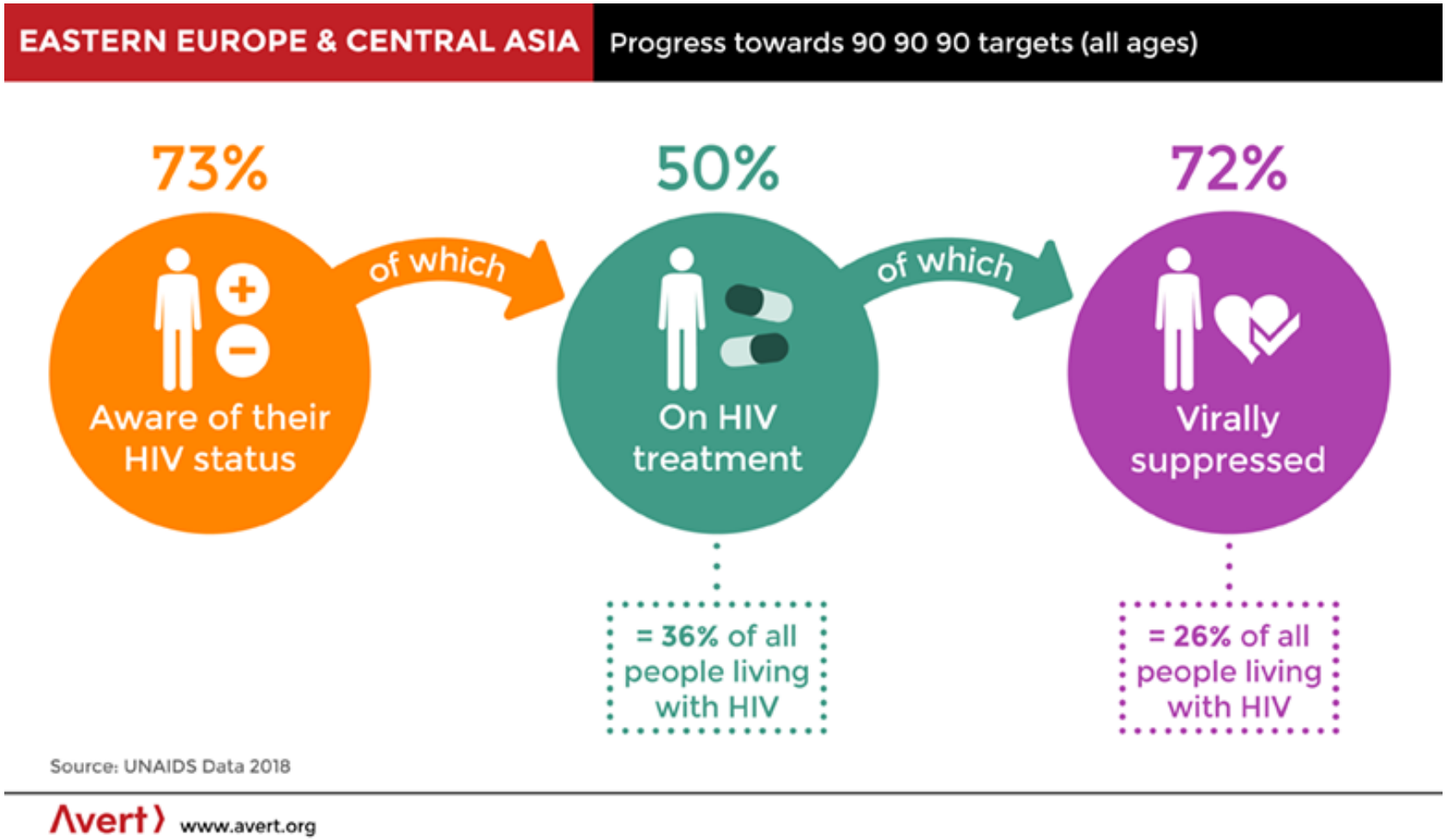
- By 2020, 90% of all people living with HIV will know their HIV status.
- By 2020, 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy.
- By 2020, 90% of all people receiving antiretroviral therapy will have viral suppression.

90 90 90 – progress
Global



90-90-90 – progress

Eastern Europe and Central Asia (EECA)

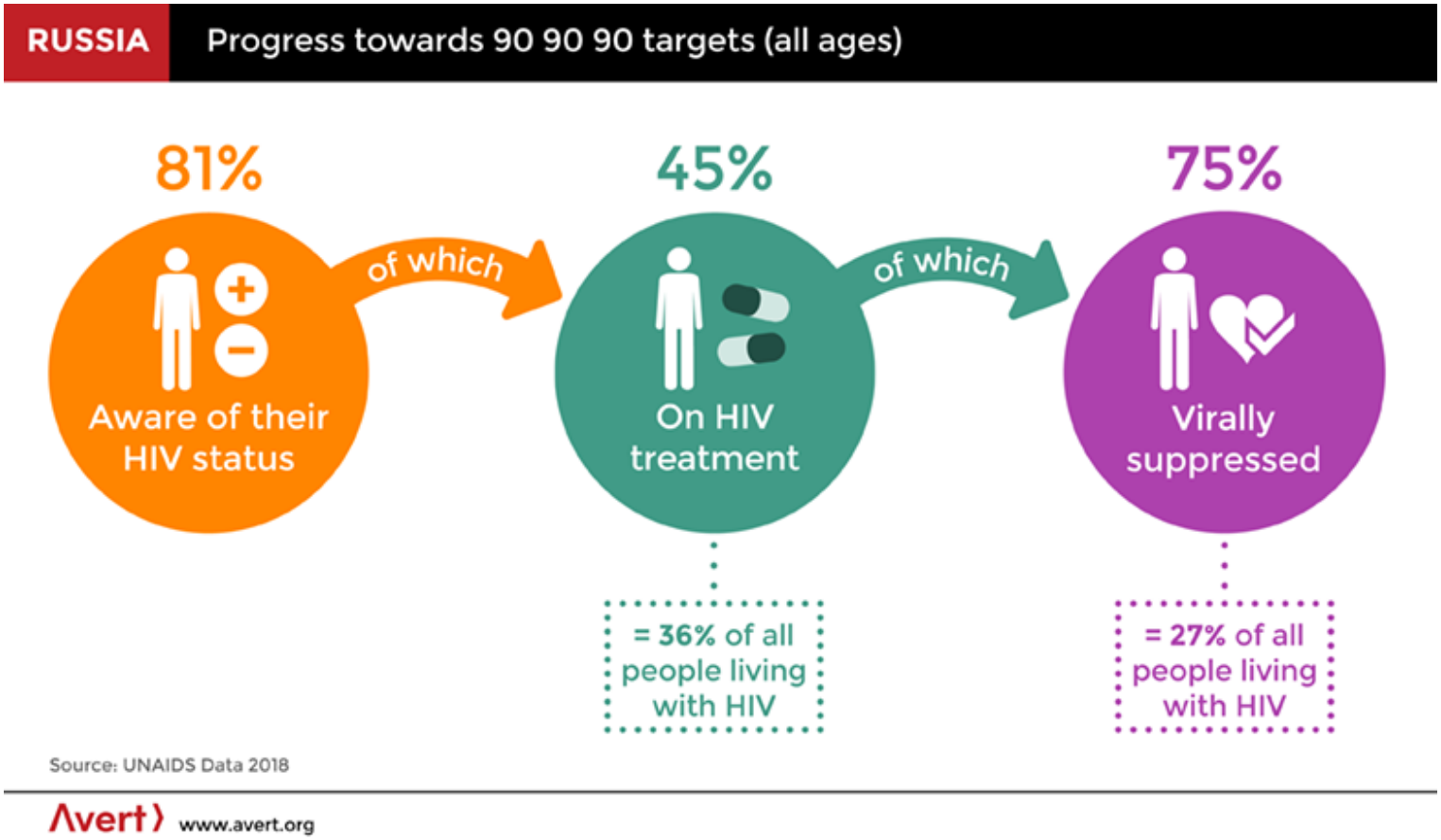


90-90-90 – progress
Challenges in EECA

- **Testing:** The main barriers relate to a lack of community-based testing services and health professionals' knowledge and attitudes. **Limited availability of community-based testing services** a particular barrier for key populations (ECDC, 2017).
- **Prevention:** Political, legal and technical barriers are delaying effective HIV prevention approaches and innovative tools, such PrEP, being implemented (UNAIDS, 2018).
- **Treatment:** The majority of countries in the region have adopted a test-and-treat policy, and although access to ART has expanded significantly in Armenia, Azerbaijan, Belarus, Georgia, Kazakhstan, Kyrgyzstan, Lithuania, Moldova, Russia, Tajikistan, Ukraine and Uzbekistan, **new infections continue to outpace treatment enrolment** (UNAIDS, 2016).

90-90-90 – progress

Focus: Russia

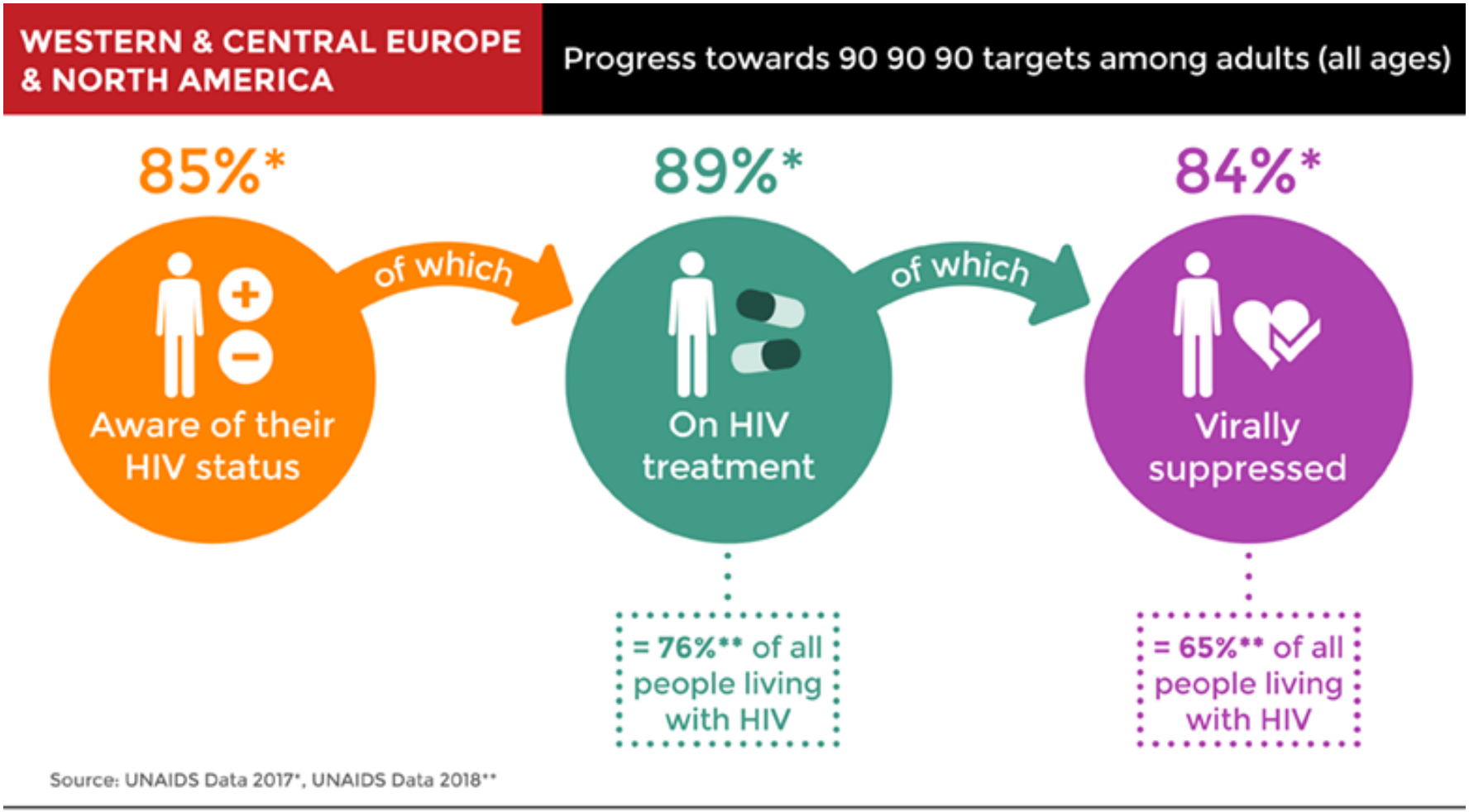


Challenges in the Russian Federation

1. The government promotes a **socially conservative, hands-off, and often church-influenced approach to sexual and reproductive health** and drug policy. *Fueling an epidemic, state policies and inaction have led to more cases than ever of Russians contracting or dying from HIV/AIDS*. (Pulitzer Center, 2018)
2. Aggressive **criminalisation and extreme marginalisation of people who inject drugs:** Many are denied access to information about HIV, and highly unlikely to access testing, prevention, or treatment services [only 10% in one study] (Heimer et al, 2017)
3. **Women living with HIV, especially young women**: Face multiple challenges and barriers to accessing HIV services such as stigma, discrimination, gender stereotyping, violence and barriers to sexual and reproductive health. (UNAIDS, 2016)
4. **Certain laws regulate the availability of information to people under the age of 18:** Preventing comprehensive sexuality education materials. There are no nationally implemented, comprehensive sexuality or lifeskills programmes in school for children and adolescents (Global Giving, 2015)

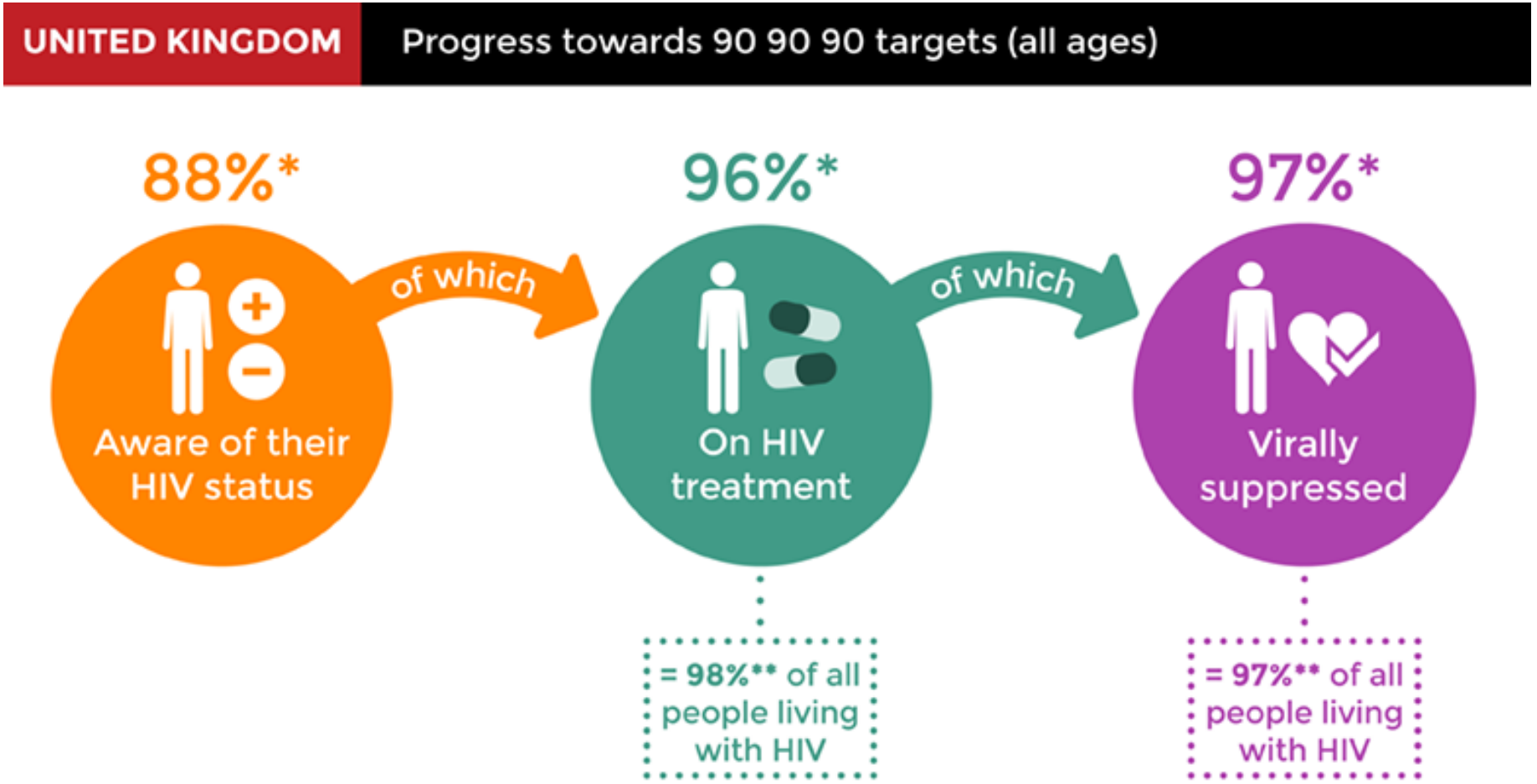
90-90-90 – progress

Western Europe and North America



90-90-90 – progress

United Kingdom

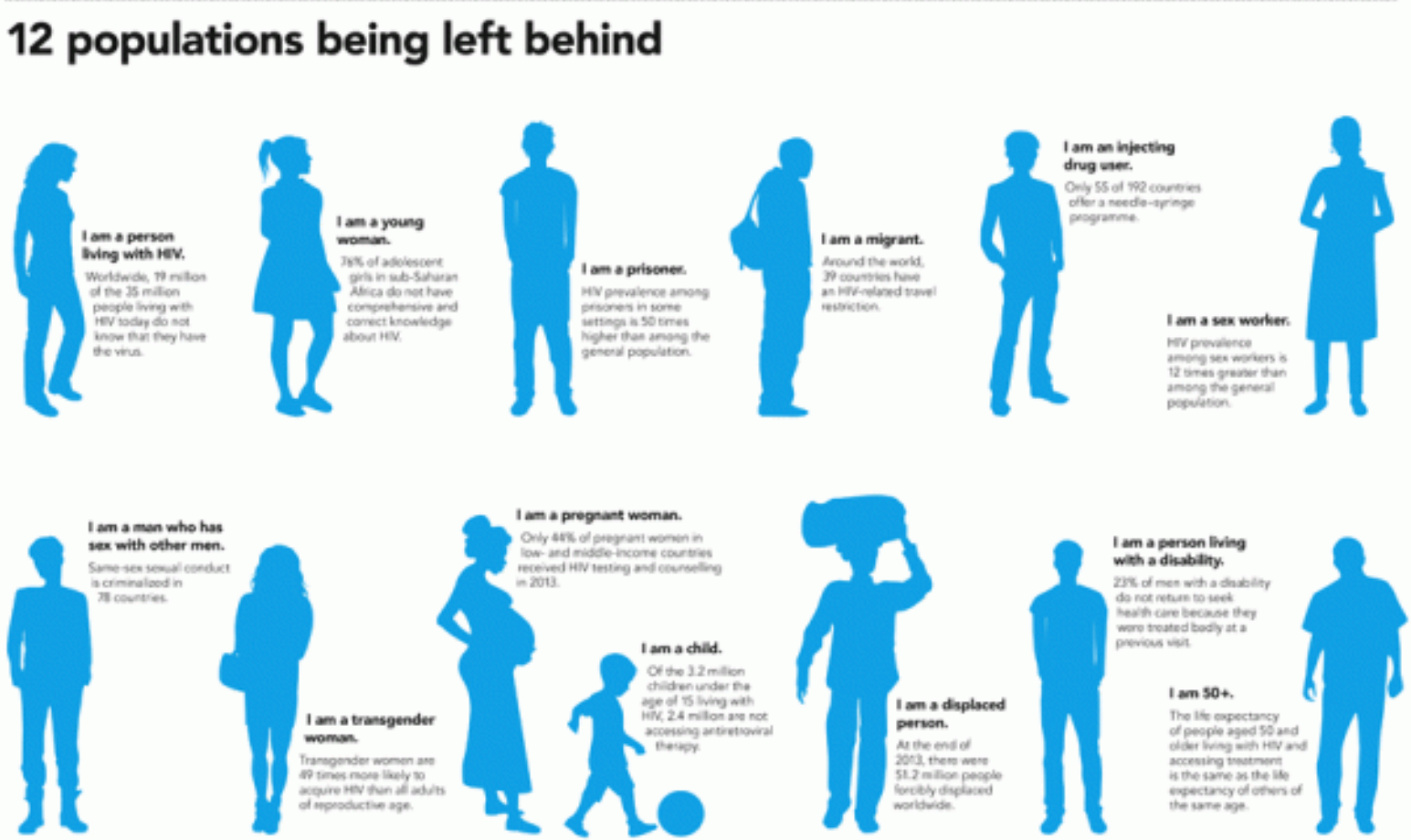


The United Kingdom is 'doing well' but…late diagnoses ☹

- There remains a problem of **late diagnoses**:
  - Rates of late diagnosis are highest in heterosexual men (60%) and heterosexual women (47%).
  - This is a particular issue in black African communities, amongst whom 65% of men and 49% of women were diagnosed at a late stage of infection in 2016.
  - The lowest proportion was among men who have sex with men, where 32% were diagnosed late.
  - 51% of people who inject drugs were diagnosed late in 2017.

Who is at risk of being left behind?

Who are key populations at risk of being left behind?



What are the specific risks?

Key populations are 'key' for a reason

- Example - sex workers
  - **Criminalisation** and discrimination in parts of Europe.
  - In **the Netherlands and Turkey**, sex work is legalised but in Turkey only women can work in brothels – all other groups are criminalized.
  - Many are **discriminated in health settings** and unable to access treatment.
  - Many countries **refuse to adopt laws on prostitution** based on the *Nordic model,* making it illegal to buy sex but not to sell the use of one's own body [this promotes better provision for support and service access].
- Example - people who use drugs
  - By far one of the **most criminalized** and stigmatized communities.
  - Face unnecessary incarceration for victimless non-violent offenses, police brutality and widespread **violations to their right to health**, including failure to provide them with adequate drug dependence treatment.
  - Leads to **marginalisation and social exclusion**, pushing people away from jobs, education, and other health and social services.
- Example - transgender people
  - **Higher risks** of poor physical health, disability, depression and perceived stress compared.
  - Amongst the **most brutalized of all marginalized communities**, with some countries outlawing transgender men and women altogether.

Focus example #1
Women

- The absolute number of women living with HIV is increasing in Europe.
- There are **limited data in Europe on the effect of menopause and HIV**. Yet, women can expect to live 40% of their lives post-menopause and may spend 10% of their lives with menopausal symptoms. [1]
- Of particular concern is the invisibility of **older women in migration**. The almost complete lack of understanding about their experience and their needs increases their isolation and vulnerability. Some women will experience gender-based violence and sexual abuse. [2]
- Drug data are **always male focused**: There is lack of information about specific factors, for example, interactions between the contraceptive pill and ART, the menopause and ART, and data on U=U in women. How can these data gaps, and specific needs, be catered for? [2]
- **HIV treatments may be more difficult to access for women**, for similar reasons to those that make it difficult to recruit women to research. We need to know that not that just the pill works, but that the *whole package* works, including tests. Are these equally accessible? We can't answer this question unless we recruit women. [2]

Sources – European AIDS Treatment Group:

① Ageing with HIV: towards a lifecycle approach (2018)

② Metrodora Report (2018)

Focus example #2
PLHIV +50 years of age

- While AIDS mortality has reduced, deaths from cancer, coronary heart disease, and other co-morbidities are on the rise.
- A shift is needed from a single disease management model into a **multi-dimensional approach to care**. Differing health and social care systems complicate the new issues faced by an ageing population of PLHIV.
- **Ageing can be substantially different among people living with HIV.** There are important issues impacting adherence and quality of life.
- Many long-term survivors of HIV have been through the **traumatic early days** of death, stigma, social exclusion, and discrimination. They are dealing with post-traumatic stress, including self-stigma.
- Some **potential solutions** to address these challenges include:
  - Integrated health and social care systems.
  - Community based peer-support services that inform clinicians, social care and other key actors working on the needs and rights of PLHIV as they age.
  - Arrangements for housing and employment for those who are left without, and mental health support.

Source – European AIDS Treatment Group: Ageing with HIV: towards a lifecycle approach (2018)

Other problems
Political context

- In Europe, **fundamental human rights** have been increasingly under attack, posing significant threat to key populations. “Right wing politicians are looking for ways to close down NGOs” (Jonathan Cohen, 2018)
- For example, **Hungary’s ‘War in Drugs’** led to needle exchange programmes being closed down and harm reduction services attracting government harassment.
- The **far right in Europe** – often aligned with fundamentalist religious movements – promote mechanisms to ban abortion, restrict sexual and reproductive health services, and ‘lock in’ traditional family structures.
- **Example:** ‘Restoring the Natural Order: an Agenda for Europe’:
  - A robust campaign aiming to **ban** same-sex marriage, divorce, gay adoption, the sale of pharmaceutical contraceptives, and IVF.
  - It will **introduce** “anti-sodomy legislation” and bans on “gay propaganda” alongside international bans on abortion, stem cell use, and euthanasia.
  - Seeks the **abolition** of equality legislation.
  - ‘Agenda Europe’ is **active** in Germany, Poland, and elsewhere.

Other problems

*The health context: nurses **do** matter*

- One report from Japan explored the experience of newly diagnosed PLHIV and the role of nurses immediately following diagnosis. The quality of the interaction has **significant impact on acceptance of the diagnosis**, with a lack of HIV knowledge in health care workers affecting service retention (Imazu Y et al, 2017).
- **Europe: stigma and discrimination in health care** (ECDC 2017)**:**
  - **Two out of three countries** in Europe and Central Asia acknowledge that stigma and discrimination within key affected populations is a **barrier to the uptake of HIV prevention and testing services.**
  - **Stigma and discrimination among health professionals**, particularly with respect to sex workers, men who have sex with men and people who inject drugs, reportedly **persists across the region** and plays a role in preventing these key populations from accessing HIV prevention, testing, and treatment.
  - Many countries report that stigma and discrimination is a factor that contributes to **late diagnosis of HIV**.

Focus

Country examples of
HIV service access and best practice

COUNTRY FOCUS

Italy

- No **particular difficulties** for people *generally* to access HIV services. There is free access for all Italians, foreigners, refugees, immigrants, and people who use drugs.
- But, to increase access there is a need to search for 'the submerged', requiring a change in mentality since stigma and discrimination have not disappeared despite considerable progress in treatment.
- **Best practice**: In Italy, for testing, the BLQ Checkpoints (in Bologna and Milan) are run by volunteers offering prevention, information, and education on the HIV transmission. Tests are available and there is access to PrEP (paid via prescription), and condoms.
- Note: in Italy, there is **no advanced level course** available for nurses in HIV care.

Source: *Riccardo Rondini, EHNN*

Country examples

Portugal

- People with difficulty accessing services are **sex workers and mobile populations**, often resulting in late diagnosis. There is stigma and fear within police and immigration services, and for individuals 'deportation anxiety'. Access to national health service only possible after 3 months.
- Ways health care workers can improve access:
  - Community-based, **specialised associations.**
  - **Media channels** are important strategically as community transmitters of current and real HIV information.
  - **Health professional training**: standardise language/practice for better and universal care.
  - **Patient reported outcomes**: Nursing interventions at non-medical aspects of care can translate health gains to users. "If they find a secure anchor in the nurse" it creates the expectation of benefits through "presence, availability, and acceptance."
- Best practices:
  - **Prevention**, especially around harm reduction: 'Say No to a Second Hand Syringe'
  - Focus on **early diagnosis** is a priority – rapid tests are widely available.
  - Focus on **prisoners**, a population at significant risk
  - Emphasis in the national HIV programme on **90-90-90** and **'Fast Track Cities'**

Country examples

Finland

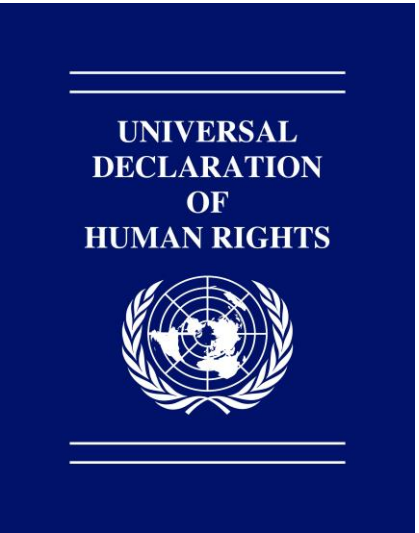
- Access improving **for people who use drugs**, especially in the capital and larger cities – harm reduction services are in place.
- **Refugees** of most concern – they have no status and are anxious. In Finnish law, 'essential care' for mobile populations doesn't stipulate HIV care/treatment – it's defined by health care professional. Anecdotal evidence of social workers with limited empathy for patients (or their translators!). Cultural competence a central priority for health care workers.
- Numbers of **young people affected by HIV is low** – HIV Finland (NGO) arranges groups meetings, events, and information dissemination for those affected.
- Another challenge – **elderly men visiting sex workers across the Russian border** – seven men infected with HIV this way in 2018. Men don't appreciate "the idea that beautiful and healthy-looking women could be HIV positive."
- **Best practice:** Finnish Red Cross and HIVPOINT (NGO) working together to offer information and HIV tests for sex workers/clients in Russian border regions. General improvement in harm reduction and reduction in HIV prevalence among drug users. A significant 'win' for the Finnish national HIV/AIDS programme.

Source: *Riikka Teperi and Helena Mäkinen, EHNN*

Recommendations

2018: 70th anniversary of the Universal Declaration of Human rights (UDHR)

*It is a sad reality of our time that realisation of human rights, especially of [HIV] key populations**, is still denied in law and practice in many parts of the world.** We must acknowledge that much as we have reason to celebrate the 70th anniversary of UDHR, we also need to attend…the continuing violation of rights of key populations.*



Source: The state of human rights in relation to key populations, HIV and sexual and reproductive health (2018)

What can work to improve the rights of key populations generally?

- **Zimbabwe:** Training and sensitisation events around **sex workers** for **health care providers, especially targeting discriminatory practices,** has been linked with improved access to HIV and sexual health services.
- **Indonesia:** Offering **a safe space for people** working alongside key populations in countries where highly conservative views prevail: e.g. the Dutch Embassy in Jakarta hosts 'underground' meetings for civil society organisations working with key populations.
- **Nigeria:** Training on advocacy, focusing on access to sexual and reproductive health, for 30 young people ,had impact on a policy **reducing the age of consent for service access** from 18 to 14 years of age [without parental consent].
- **Ukraine**: Following sensitisation and training with the police, there is evidence of a **reduction in discrimination of people using drugs**, and willingness to gather further information. This is a "significant change."

Source: Aidfonds/Frontline AIDS 2018

- **Hungary**: A response to repression of key populations (and those who work with them) is to **reach out to the community**, share human stories and 'real' facts about [for example] drug users that counteract negative messaging from government.

Source: Peter Sarosi, Rights Activist, 2018

Recommendations: health strategy

- Adopt **a lifecycle** approach:
  - Developing a more **holistic and person-centred approach to care** integrating health and social systems, peer support services, and up-to-date technology for testing etc.
  - Taking into account **the impact** of poverty, homelessness, gender-based discrimination, social exclusion, and isolation.
  - Policy-makers, those designing health professional training, and medical professionals, need to **collaborate with PLHIV**. [1] They often have stronger groups/networks than health care workers ☺
- Target key populations with **tailored services** - for example, for young people:
  - Develop and test **multi-faceted interventions** going beyond health facilities to address broader social barriers to adherence and retention.
  - **Intervention studies** [finding out what works best] should be a priority for retaining young people in treatment and care. [2]

Sources:

① European AIDS Treatment Group: Ageing with HIV: towards a lifecycle approach (2018)

② Casale *et el* (2019): Recent Interventions to Improve Retention in HIV Care and Adherence to Antiretroviral Treatment Among Adolescents and Youth: A Systematic Review.

Universal Health Coverage

One strategic approach to equity

- Universal health coverage (UHC) means **all people and communities** can use health services they need, of sufficient quality to be effective and not exposing the user to financial hardship.
- UHC has three objectives:
  1. **Equity in access** to health services
  2. **The quality of health services** should be good enough to improve the health of those receiving services
  3. People should be **protected against financial-risk**, ensuring that the cost of using services does not put people at risk of financial harm.
- There is **global momentum for UHC**, with advocates making sure HIV is highlighted (rather than subsumed into other categories).

UHC and key populations

Steps for supporting key populations

1. Good governance.
2. Ensure that rights-based and inclusive legislation is in place.
3. **Promote the right to health, including non-discrimination and gender equality.**
4. Include HIV in the health benefit package.
5. Develop short-term and long-term financing plans.
6. **Integrate HIV and other health services to achieve better health outcomes.**
7. **Put equity at the centre by reaching the people being left behind.**
8. **Develop people-centred community delivery models.**
9. **Minimize out-of-pocket payments.**
10. Prioritize accountability for results.

Recommendations: HIV nursing

- **Remember - nurses are at the forefront** to promote a service accessible to key populations.
- Nurse-led services are **proven to be beneficial**, especially in resource-poor areas.
- Nurses will **always play a central role** progressing towards the 90-90-90 and other global health goals – and pooling of knowledge ensures best practice. We need to share and network! So…
- **Training** is vital**,** and initiatives such as the NHIVNA nursing academy, community-based packages (e.g. European AIDS Treatment Group) should be promoted as widely as possible, and…
- We shouldn't underestimate how valuable **our HIV nursing knowledge and experience is** to nurses in other countries: e.g. [PLUG!] the European HIV Nursing conference in September 2019 – includes bringing nurses from Kazakhstan, Kyrgyzstan, and Ukraine.

Final thought…

Efforts towards universal health coverage should include a ***dedicated focus on reaching key populations and marginalised groups.***

People living with HIV and key populations need to be ***acknowledged as people*** *whose care and well-being should be valued equally.*

(UNAIDS, 2019)

It's a matter of human rights.

Thanks to the following

- Riikka Tepere (EHNN), Finland
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Thank you!

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