

European AIDS Clinical Society Standard of Care for HIV and Co-infections in Europe



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EACS European
AIDS Clinical Society



**EACS STANDARD
OF CARE**
for HIV and COINFECTIONS in Europe

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Introduction

This meeting was the fifth in a series of biennial Standard of Care meetings that alternate with the European AIDS Clinical Society (EACS) conferences. Reports on the previous meetings can be seen on the relevant EACS pages as well as on aidsmap.com, which has filed the most prominent news stories from the meetings as well as compiling the main report on each one – see the 2019 and 2020 conference pages.

To quote the EACS Standard of Care page, “Information on the current European situation shared during the meeting[s] will constitute the basis to elaborate a common platform for a European standard of care, which is currently lacking.”

The 2022 meeting reported on a significant advance in the development of this common platform – a funded agreement between EACS and the European Centre for Disease Prevention and Control (ECDC) to develop a number of different activities – audits, educational webinars and publications – over the next four years, that will work towards the harmonisation and improvement of standards of care.



EACS already produces its influential **clinical guidelines**. To distinguish these from standards of care, guidelines summarise the 'gold standard' of care for patients, as indicated by the latest scientific data. They may suggest alternatives to first-choice treatments, especially if availability is an issue, but do not delve into local practicality or what is achieved in clinics' individual practice.

Standards of care are all about care in practice, rather than about ideal care. Given the inevitable constraints under which healthcare services run, which range from poor financial and personnel resources, obstructive or absent government policy, technical errors, and difficulty in linking patients to care and retaining them, what guidelines recommend is not usually achieved perfectly in practice. Standards of care formulate benchmarks and desirable targets, measure actual care delivery against them, and provide tools to help health services improve.

The key technique in formulating guidelines is the scientific study; the key tool in advancing standards of care is the audit.

Audits are not pieces of research so much as tools that enable individual practitioners, clinics, and regional or even national healthcare systems to measure their performance both against agreed targets and against each other (and therefore against an average). A vital part of auditing is the re-audit, which evaluates whether conducting an audit has resulted in an improvement in services.

In 2019, EACS took a key step forward in its Standard of Care initiative by conducting its **first-ever pilot audit**, on hepatitis services, in five countries. However, progress towards expanding EACS' audit capability then stalled as the COVID pandemic intervened; staff were redeployed into COVID care, in-person patient appointments were minimised and laboratory time was reallocated. In the last year, however, as in-person HIV and related services have resumed, EACS did conduct a re-audit of hepatitis care in four of the five original countries, with promising results, as we report below.

The EACS/ECDC Standard of Care collaboration

Perhaps of greater significance, however, is the collaboration announced at the meeting between EACS and ECDC which, for the first time, offers a significant degree of funding to EACS' Standard of Care initiative. This should enable a considerable expansion of its auditing and related activities.

Teymur Noori and Dr Ann Sullivan, representing ECDC and EACS respectively, introduced the new agreement at the 2022 meeting. A panel discussion then sought meeting attendees' opinions on which 'modules' should be the focus of the four years of the partnership's planned existence.

Modules are broad areas of care. In the case of the pilot audit, the module was the care of viral hepatitis co-infection in people with HIV. Within one module, audits could cover different kinds of care such as laboratory, clinical and psychosocial, and could assess different kinds of services, such as primary care services, hospital outpatient departments or non-governmental organisations (NGOs).

Noori said that in 2018 a project was initiated between EACS, ECDC and the [Centre of Excellence for Health, Immunity and Infections](#) (CHIP) in Denmark in order to define the scope of a set of auditable standards of care.

The overall objectives of the contract are to define standards of HIV and related care, and measurable and auditable outcomes for them, in EU/EEA countries, and to develop a tool which can be used to audit the implementation of standards at national, clinical and community levels. Auditable standards will be succinct, with a few standards for each module. The auditing of standards of care is outside ECDC's remit as a surveillance and epidemiological organisation, but EACS and ECDC together will decide on the modules to be audited. EACS will then devise the auditable standards and conduct the audits.

It was clear from the 2020 meeting that any expansion in the EACS audit programme would need funding and ECDC put out a tender for a European audit of HIV services. EACS' bid was accepted and the two bodies signed an agreement just the week before the Standard of Care meeting.

The tender is for four years and this should allow time for four modules, each covering a theme, in the same way that the pilot was of hepatitis testing and treatment.

As well as conducting audits and having an annual Standard of Care meeting (co-located with the EACS conference in alternate years), the Standard of Care initiative will disseminate its audit method to be used as a tool by other bodies. It will conduct webinars and other educational events based on audit inputs and audit findings. Additionally, though audit findings have no control or comparator group, they can still be published and can shed light on differences in care performance for different populations or in different locations. Noori commented that this might be particularly useful for issues where there is a dearth of scientific data, such as migrant health.

Noori gave examples of areas suitable for auditing, including uptake of PrEP and PEP; late diagnosis; linkage to care and loss to follow-up; viral load monitoring and suppression; co-morbidity monitoring and treatment; care for ageing patients; measuring stigma within and outside healthcare settings and how it affected provision and adherence (e.g. of PrEP); and patient-reported quality of life. But he welcomed other suggestions.

Noori commented that ECDC's involvement brings in the possibility of including Standard of Care and audit findings within ECDC's remit to annually report Europe's progress with reference to the United Nations' Sustainable Development Goals (SDGs), in line with the Dublin Declaration.

"Being able to measure countries' performances against each other relative to the SDGs is when countries get nervous and really sit up and act," he commented.

Sullivan outlined what each standard-of-care module might look like. There would be a very brief outline and rationale for the defining and auditing of care standards in the module area; a number of 'quality statements', or suggested benchmarks or targets, adjusted regularly against future developments; and a set of more specific auditable outcomes.

Auditable outcomes could be set low within suggested care levels (i.e. as the bare minimum that is acceptable), or high (i.e. as aspirational targets).

Giving initial assessment of people diagnosed with HIV as an example module area, the outline would consist of one sentence saying something like "all patients should have full assessment and appropriate management of their HIV delivered in a timely fashion", with the rationale being what the EACS guidelines define as optimal or near-optimal clinical care. (Modules such as those concerning co-infections or quality of life might refer to other guidelines/recommendations.)

"Europe's wide spectrum of services makes it important to be flexible when choosing auditable outcomes."

Auditable outcomes should include laboratory testing, clinical assessment and psychosocial support as far as possible within each module area. For a new patient, an example of the first might be viral load testing performed within a specific time; for the second, which tests and checks were performed; an example of the last might be proportion referred to peer support and within what time.

Europe's wide spectrum of services makes it important to be flexible when choosing auditable outcomes. Differences are due not only to resource levels but to health service structures and cultural differences, as well as to recording and coding practices. Some standards needed to be specific to countries or regions, or to populations served, if they are to be relevant and achievable. Others were more usefully pan-European.

Whenever possible, audits should use data that is already there, but sometimes missing data is recorded differently. For instance: if you have a high target for something readily achievable such as viral load testing within a certain time frame, how would viral load testing of a patient 'lost to follow-up' be interpreted? Simply as missing data or as 'missing = failure'? This may make a big difference to reported outcomes.

Targets need to vary according to an outcome's relative ease of achievement. For instance, in the case of something like CD4 testing within 30 days, there are few reasons why it should not happen. But other outcomes will be more dependent on process issues such as the availability of appointments and of other specialists.

Lastly: what is the most useful way for results to be reported, so that clinics can make the best use of them? The outcome measure does not have to be a percentage of procedures performed. It could be an inter-quartile range (i.e. whether the clinic's performance on each indicator is within the top or bottom 25% of clinics, or somewhere in the middle). Or it could be, especially in re-audits, stated in terms of which centres had managed to improve each outcome, or their overall outcomes, by (for example) 10%.

Emerging themes and suggestions for the collaboration

Meeting attendees were asked for reactions and suggestions. Themes or questions that emerged included:

- Attendees felt generally hopeful and excited about the project. One senior doctor remarked: "Audits are especially good at highlighting what you didn't know you don't do. For instance, when we did the pilot audit, I realised that my own clinic did not do hepatitis delta testing."
- To what extent are improvements dependent on technology or the quality of services? For instance, better rates of viral suppression have been due at least as much to better drugs as to better guidelines and testing practice.
- Suggestions for auditable targets that were not listed included harm reduction for injecting drug users, STIs, migrant health and practice. Regarding the latter, a central European doctor said: "The Ukraine war made us realise there is no consensus on which services to offer migrants, and which not."
- Prior to auditing, it might be a good idea to ask clinics for their own perceptions as to what gaps they perceive in their services. This might reduce the perception that the object of an audit is to 'shame' clinics into better performance.
- Is shaming a clinic or country for lack of provision an incentive to improve, or an incentive to cover up lack of improvement? And should targets be relatively easy to achieve or hard? The consensus seemed to be that a mixture of very achievable and very aspirational targets might work best.
- In some cases, lack of provision is due to national policy, not local performance. An example was of the countries' health services that still do not fund PrEP at all. In these cases, could improved access to PrEP be achieved by an audit comparing provision against other countries, or a campaign for a change in policy?
- On the other hand, **90-90-90** was essentially an inter-country auditable target that had, to some degree, worked by 'shaming' countries that performed worse than their neighbours, and had itself forced changes in policy and funding.
- Widely different auditable areas may be interlinked, though difficult to audit together. One example was that of a country whose health services essentially do not refer patients to peer support due to high levels of stigma. It was pointed out that a new group within the European Commission had been set up to investigate the link between public health and stigma in communicable diseases.
- Similarly, auditing implies the existence of a multidisciplinary, one-stop-shop model of care, but this is often not the reality. For instance, in a number of centres in the hepatitis re-audit, it became clear that clinics did not know how many of their non-immune patients had received hepatitis A and B vaccines because the practice was to refer elsewhere.
- A Ukrainian attendee highlighted the way that HIV services had largely been preserved during wartime by devolving many services to NGOs and practitioners within NGOs, so maybe for some standards NGOs should be included as well as healthcare centres.
- The auditable outcomes most likely to lead to change may be the ones where the results matter equally to individual patients and to public health/politicians (an example being viral load suppression).
- A Greek attendee said that government inertia had been such an important factor in delaying care improvements in Greece and south-east Europe generally that the Greek HIV and infectious diseases society had in essence already set up its own standards of care project, Hestia, to monitor gaps in service delivery
- It was agreed that it was important to ensure that the Standard of Care project was not just the concern of, or developed by, doctors. From the start, it needed to be standard practice to involve people using healthcare services, funders and policy makers in advising on and devising modules.

This discussion was probably the most important forward-looking session at the meeting. It provided attendees with a palpable sense of progress, though many practical questions still needed to be solved.

The pilot re-audit

Allied to it was the presentation of the pilot re-audit of viral hepatitis services. Because of the legacy of service restraints during COVID, this could only be conducted in 16 clinics in four countries instead of the original 23 clinics in five countries.

The findings were generally promising. Notable improvements included a change from annual to six-monthly screening for liver cancer in people with cirrhosis; an increase to virtually 100% in the proportion of people who had either had hepatitis C antiviral treatment or had it planned; and a large increase in the proportion of clinics who assessed and advised gay and bisexual men about chemsex.

On the other hand, there had been no improvement in screening for hepatitis delta virus and a puzzling decrease in the proportion of patients with antibodies to hepatitis C who were tested for viral RNA, which indicates active infection. This might be due to testing resources still being diverted to COVID.

As already mentioned, the re-audit also highlighted how some audit findings may be hard to interpret if the questions do not take note of local practice. The rate of uptake of hepatitis A and B vaccinations among those who needed them, in this case, was difficult to gauge in settings where patients were referred to other centres for vaccination – for instance, to primary care. Nonetheless, the proportion of patients eligible for vaccination (especially against hepatitis A) who refused it was high, even after correcting for onward referral, and needs further investigation.

The full report on the pilot re-audit of hepatitis services can be read on aidsmap.com.



Dr Ann Sullivan at the EACS Standard of Care meeting. Photo by Bernard de Keyzer.

Georgia's unique hepatitis elimination programme

The meeting's opening lecture was given by Professor Tengiz Tsertsvadze, Director General of the Infectious Diseases, AIDS and Clinical Immunology Research Centre, in Tbilisi, Georgia.

Georgia offers an example of how a national drive to standardise care has led to a situation where it may become one of the first countries in the world effectively to eliminate hepatitis C as a significant public health issue.

For HIV, Georgia has yet to reach the 90-90-90 standard, which would mean that just under 73% of all people with HIV would be virally suppressed. In fact, 66% of Georgia's HIV-positive population is virally suppressed, but the target has been exceeded in women with 74% suppressed. In both sexes, it is HIV testing, at 83% of people with HIV diagnosed, that has been the drag on reaching the target.

“Prevalence of hepatitis C has been slashed, among people with and without HIV. The target is to reach 90-95-95 by 2025.”

There are an estimated 8100 people with HIV in Georgia. This is a per-capita prevalence about 50% higher than that represented by the almost 100,000 people with HIV in the UK, which has 18 times Georgia's population. New diagnoses reached a peak in 2016 at 719 but declined to 530 last year (a 21% decline).

However, the number of late diagnoses has not declined, and these undiagnosed people, many of whom may have had HIV for years, may drive continued incidence. Georgia started a PrEP programme in 2017 with 17 people, and in 2021 expanded to 792 people, but clearly this needs to expand further.

In addition, during COVID, HIV diagnoses declined, possibly due to testing declining by 12%. More worryingly, the number starting antiretroviral therapy declined by 24%.

The number of people with HIV who have ever tested positive for hepatitis B surface antigen is 5.4% but previously, only 2.06% of these had active infection (slightly lower than the general-population prevalence, estimated as 2.7%). Now, with tenofovir treatment having been universally available since 2011, the proportion with active infection has been cut to 0.24%. Ninety-two per cent of all people with HIV mono-infection who are not already immune to hepatitis B have been vaccinated.

Prevalence of hepatitis C has been slashed, among people with and without HIV. The target is to reach 90-95-95 (90% of people with active hepatitis C diagnosed, 95% of them started on treatment, and 95% cured – in other words, just over 81% of all people with active hepatitis C cured) by 2025.

For hepatitis C, as well as HIV and TB, Georgia decided to initiate an intensive national, door-to-door screening programme – Tsertsvadze said that to his knowledge, this was a unique initiative. In addition, there is active case-finding and contact tracing of people who do test positive. Hepatitis C treatment has been delegated to a national network of 96 local primary care clinics – for comparison, if Georgia had the population of the UK, that would be 1250 clinics.

So far, two-thirds of the country's population (2.5 million out of 3.7 million) has been screened for hepatitis C antibodies. Of these 152,302 were antibody-positive but only 98,725 were RNA-positive, i.e. had active chronic hepatitis C. Of those, 75,045 (76%) have initiated at least one round of antiviral treatment and 99% of them are considered to be cured. However, only 55,803 have received post-treatment testing for sustained viral response, meaning that 56% have a proven cure.

The percentage of screening tests that were positive for hepatitis C RNA declined from 5.4% in 2015 to

1.8% last year. The one step in the hepatitis C treatment cascade that has prevented an even greater reduction in hepatitis C is that not everyone eligible for treatment has started it.

With regard to people with HIV and hepatitis C co-infection, the estimated number who are hepatitis C RNA positive and therefore have chronic hepatitis C has gone down from 1811 ever testing as RNA positive to an estimated 274 who are still RNA positive now. At 85%, this is a greater reduction than the 76% seen in the general population.

Tsertsvadze commented that Georgia's Ministry of Health had received several awards – notably from the European Association for the Study of the Liver (EASL), the hepatitis equivalent of EACS – for its successful hepatitis C elimination drive.

The next step was to start a similar national screening and vaccination project for hepatitis B that would reduce cases by as much in HIV-negative people as had already been achieved in people with HIV.

PrEP provision in central Europe

The way in which stigma and the provision of PrEP are related was illustrated by a presentation by Dr Bartosz Szetela of Wroclaw Medical University in Poland.

The number of people able to access HIV PrEP in most countries of central Europe – a region that saw large increases in HIV cases among gay and bisexual men in the 2010s – still numbers in the tens to hundreds of people rather than thousands, and there are no signs of immediate improvements, he said.

Szetela said that inconsistent guidelines, access restrictions and lack of training were all preventing PrEP programmes from being properly developed in the region.

Szetela's team has been conducting a survey among STI physicians and community activists in central Europe. So far it has information (in more or less detail) from Lithuania, Poland, Czechia, Slovakia, Hungary, Slovenia, Romania and Bulgaria and is looking to include other countries.

It is thought that Poland has the highest level of PrEP provision in central Europe with about 5000 PrEP users. This also represents the highest usage per head of population (one in 7560 people). Hungary may have 1000 users and Czechia about 800. Bulgarian informants counted 410 users, nearly all accessing PrEP through one clinic in Sofia. Slovenia has about 200 and Slovakia 60. Lithuanian and Romanian informants could not even make an educated guess.

PrEP access is influenced by many factors. Health Ministry guidelines for PrEP exist in Czechia, Poland, Slovenia and Slovakia. Bulgaria intends to issue some soon and Romania in the next few years, but so far Hungary and Lithuania have announced no intention to do so.



Dr Bartosz Szetela at the meeting. Photo by Bernard de Keyzer.

In the case of Poland, PrEP provision started to increase when cheap generic tenofovir disoproxil/emtricitabine became available in 2017. Since then, a network of PrEP clinics – which have also effectively become Poland’s STI centres – have appeared, offering free testing and monitoring.

“Survey respondents in almost all countries referred to stigma among medical professionals, especially older doctors.”

Making PrEP cheap or even free does not guarantee access, however. In the survey, in all but three countries (Bulgaria, Czechia and Romania) PrEP pills should now be obtainable, in theory, free of charge through the countries’ universal healthcare system, through HIV or STI clinics (Romania, Slovenia, Poland) or via specialist physicians (Lithuania).

But in practice, a combination of restricted access to free medication or the associated testing and equally difficult access to sympathetic physicians means that except in Slovenia, few people get PrEP for free and most people pay something.

The biggest barrier to PrEP, however, is stigma within the medical profession, Szetela said. Survey respondents in almost all countries referred to stigma among medical professionals, especially older doctors. It means that most people seeking PrEP outside the big cities will probably still receive a refusal and a lecture on behaviour rather than a course of PrEP pills.

Szetela urged medical associations to make firm plans for PrEP provision and to conduct cost-effectiveness modelling to prove that providing PrEP is not unaffordable in their country. Comparing HIV incidence in PrEP users with HIV incidence in all Polish gay and bisexual men allowed Szetela’s team to estimate that 285 infections were prevented by PrEP. This implies that HIV incidence would be 20% higher in Poland without the current level of PrEP.

This is not enough, though: at current background incidence levels, it is estimated that 27,000 people at risk of HIV would need to be on PrEP in order to bring Poland’s HIV incidence down to the UN Sustainable Development Goal by 2030.

Szetela emphasised to aidsmap that the difficulties are not restricted to central Europe.

“In the Netherlands, the number of people who can access PrEP is still capped,” he said, “and in Portugal, there is no cap as such, but lack of staff means there is a year-long waiting list for it, which makes nonsense of the idea that PrEP should be there during ‘seasons of risk’.

“I’m afraid that European politicians are using the economic situation to reduce PrEP access still further,” he said. “We need a stronger, pan-European policy to ensure access throughout Europe.”

[The full report on the survey of PrEP provision in central Europe can be read on aidsmap.com.](https://aidsmap.com)

The ECDC stigma survey

The topic of stigma is being tackled directly by ECDC. Preliminary results presented to the meeting from a survey on stigma devised by ECDC in collaboration with the European AIDS Treatment Group, AIDS Action Europe, and the UK's National AIDS Trust show that people living with HIV in Europe are as likely to have experienced stigma in recent years as they were a decade ago.

This is particularly the case with some types of stigma experienced in healthcare settings, where the fear of stigma, and to some extent, the reality, are if anything stronger than ever.

It also uncovered a strong link between state of health and the experience of stigma and discrimination. People who rated their health as 'bad' or 'very bad' were more than twice as likely as those with good health to have been threatened or verbally or physically abused by family or friends, or to have been excluded from family activities.

“A third of survey respondents had experienced healthcare staff being discriminatory to others with HIV.”

Teymur Noori told the meeting: “We can't combat stigma and discrimination till we get a better idea of how prevalent they are and how they operate.”

Between November 2021 and January 2022, it received responses from 3272 people with HIV from 54 countries.

Asked whether they were ashamed of their HIV status, and secondly if they had low self-esteem because of it, 27-28% agreed or strongly agreed with both questions, and 45-49% disagreed or strongly disagreed with them.

But when asked if it was difficult to tell other people about their HIV status, the proportions were reversed, with 57% agreeing that this was difficult or very difficult and 24% saying it was not.

The isolation of having HIV was underlined by 17% of respondents saying they had not told even one friend about their HIV status. Nineteen per cent had told no sexual partners (current or previous) and 26% no family member.

The respondents were then asked about whether they had experienced six kinds of negative reactions to their status: rejection by friends (24% said yes, they had); threats, or verbal or physical abuse, from a sexual partner (17%); discriminatory remarks or gossip by their family (16%); being blackmailed by people they knew (15%); threats or abuse from their family (11%); and being excluded from family activities (10%).

One of the most revealing findings was that respondents were as likely to say they had last experienced negative reactions in the previous year as they had more than ten years ago.

There was a strong association between stigma and physical health. People who rated their health as 'poor' or 'very poor' were 50-70% more likely than those with 'fair' health to report rejection by friends, negative gossip by family, or threats or abuse from a partner. They were 3-4 times more likely to experience these than people rating their health as good or very good.

The survey also asked about experiences of stigma in healthcare settings. It found that what has been called anticipated stigma in health care was as powerful in people with HIV as it always had been. For instance, 56% had worried they might be treated differently by healthcare staff because of their status, 45% were afraid to go to some services, and 36% had actively avoided them. Experiences of overt discrimination were less common but a third had experienced healthcare staff being discriminatory to others with HIV (11% in the last year), 29% had heard staff making discriminatory remarks or gossiping (9% in the last year) and 23% had experienced reduced or delayed services due to their HIV (7% in the last year).

ECDC will follow up this survey with one among healthcare workers, concentrating on training or lack

of it, fears of HIV infection and avoidance of people with HIV, attitudes towards people with HIV and to key populations, and the policy and guidelines environments in which healthcare workers operate.

In the meantime, a smaller survey conducted recently in Ireland, largely answered by healthcare workers who were not HIV specialists, found that although 83% claimed knowledge of 'Undetectable = Untransmittable' (U=U) and treatment as prevention, 40% said they would still be nervous about drawing blood from a person with HIV. Many took unnecessary precautions such as wearing gloves or even two pairs of gloves at all times when treating people with HIV.

[The full report on the stigma and discrimination survey can be read on aidsmap.com.](https://aidsmap.com)



Teymur Noori at the meeting. Photo by Bernard de Keyzer.

Other presentations

This report does not include all presentations made at the Standard of Care meeting. Dr Miłosz Parczewski from Szczecin University Hospital in Poland presented on HIV among Ukrainian war refugees in the country. He also presented at the HIV Glasgow conference, which [aidsmap reported on](#).

Poland is the country that has received by far the largest number of Ukrainian refugees. So far, given that HIV prevalence in Ukraine is ten times that in Poland, one might have expected that about 8000 of them would use HIV services. So far, only 2500 have accessed them. While this has still raised the total number of people in HIV care in Poland by 16%, it is far lower than expected. Parczewski commented that many refugees appeared to be afraid to come forward for care because they were staying with hosts and were afraid to reveal their status. It was also possible to cross back into Ukraine periodically to go to clinics there.

This situation may change as the war lasts longer, or if more refugees go to countries further away from Ukraine.

The first day also included some interesting background presentations on guidelines and current provision of services, as well as an update on monkeypox.

Further details of the 2022 EACS Standard of Care meeting can be seen [on the EACS website](#) and in the [scientific programme](#).



Dr Miłosz Parczewski at the meeting. Photo by Bernard de Keyzer.

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