HIVOutcomes

BEYOND VIRAL SUPPRESSION

GOOD PRACTICES IN THE LONG-TERM CARE OF PEOPLE LIVING WITH HIV: LEARNING FROM COUNTRY EXPERIENCES
GERMANY AND ROMANIA

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EXECUTIVE SUMMARY

As life expectancy for people with HIV has increased, additional unmet requirements for achieving good long-term health and well-being have emerged. Although people with HIV can now anticipate near-normal life expectancy, there are unique needs that must be met if their quality of life is to match that of the rest of the population.

HIV Outcomes is a multi-stakeholder initiative focused on advancing the health and well-being of people living with HIV. It aims to promote an integrated, outcomes-focused and patient-centred approach to long-term care. By engaging experts, healthcare professionals and policymakers, HIV Outcomes seeks to ensure that the overall HIV response meets the needs of people with HIV.

In 2017, the initiative published five recommendations designed to enable people living with HIV to remain in good health as they grow older and lead successful, productive and rewarding lives.[1] These were road-tested in 2018 in Italy and Sweden to establish their value in a real-world setting. Building on this work, and addressing a number of barriers identified through that process, action was taken in 2019 to support the implementation of policy and clinical changes. In addition, the recommendations were also road-tested in Germany, Romania and Spain in 2019. This report focuses on the lessons learned to date in Germany and Romania, providing two distinct settings in which to explore the impact of the HIV Outcomes recommendations. A report highlighting lessons learned in Spain will be published in early 2020.

An estimated 86,000 people in Germany are living with HIV – around 20% live in Berlin. Germany is on the verge of reaching the UNAIDS '90-90-90' goals[2] and has developed, amongst other measures, an innovative approach to community-based testing known as 'Checkpoints'. However, there is still work to do to improve long-term health outcomes and quality of life. Adding a fourth goal – quality of life – could help to focus policy and service delivery on long-term outcomes.

This report highlights some good practices in Germany including the introduction of quality-assured specialist services which provide excellent care to people with HIV.

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[1] HIV Outcomes: Recommendations launched at the European Parliament (November 2017), http://hivoutcomes.eu/recommendations/

[2] The UNAIDS 90-90-90 targets aim to achieve the following by 2020: 90% of all people living with HIV will know their HIV status, 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy, and 90% of all people receiving antiretroviral therapy will have viral suppression

Qualitätssicherungsvereinbarungen ensure a high standard of care and coordinate the patient journey. A more comprehensive evaluation of the services' structure, how they influence patient outcomes, and the integration of digital tools, could build on this foundation. The report also recommends expanding data collection to include information on comorbidities and long-term well-being. Concrete measures to address discrimination in the health system, and the adoption of a clear target for improving quality of life, are advised.

Romania offers a distinct opportunity to apply the HIV Outcomes approach in a unique context. Half of Romania's 16,000 people living with HIV were infected while in state-run orphanages and hospitals between 1985 and 1995. Universal access to medication has been available since 2001, making Romania one of the first countries to reduce barriers to care for people with HIV. Current legislation ensures a wide range of rights to social and health benefits for people affected.

However, the concept of quality of life for adults living with HIV is not well established. Research is required to deepen understanding of what quality of life means to various subgroups of people with HIV in Romania. Efforts to improve medical education – at undergraduate and postgraduate level – are essential to address patient needs. Public advocacy campaigns are also required to address stigma and discrimination. Policymakers can enhance service delivery by establishing regional centres as independent entities and linking them to medical schools. This would also help to attract younger health professionals and promote multidisciplinary care.

The findings and good practices identified in Germany and Romania were presented in the European Parliament in November 2019. This enabled stakeholders to share important learnings that will prove to be valuable in countries across Europe – as well as for other disease areas – and further strengthen efforts to improve long-term health outcomes and quality of life of people living with HIV. Further progress is anticipated in both countries in 2020 and beyond, as the national HIV Outcomes steering groups will be established (in the case of Germany) or expanded (in the case of Romania).

Initial talks with some potential members of the German HIV Outcomes steering group have taken place. Some have contributed to this report which should be considered a first assessment of the situation. Future work will focus on bringing together leading experts to discuss in detail how the recommendations can be applied. In Romania, the steering group will expand and prioritise research on quality of life. It will also support advocacy projects designed to update and secure the approval of the National Strategy Plan (PNS) for HIV which overlaps strongly with the HIV Outcomes recommendations.

INTRODUCTION

HIV is a chronic and manageable long-term condition, if diagnosed early and managed appropriately. Life expectancy for people living with HIV is now broadly in line with the wider population. Improved longevity does not always mean living in good health. People with HIV have higher rates of cancer, kidney failure, bone disease and cardiovascular disease. They are also at greater risk of mental health issues. This represents a significant shift from the 1980s when the condition was seen as a fatal illness. Progress on viral suppression[3] and life expectancy is welcome but new policies are required to improve health outcomes and quality of life for people living with HIV.

The HIV Outcomes initiative was created in response to the increasingly widespread recognition that important aspects of the health and well-being of people living with HIV receive too little attention from policymakers and healthcare providers. The initiative aims to ensure that these aspects of HIV care become a central pillar of the HIV response. In November 2017, HIV Outcomes launched multi-stakeholder recommendations on the long-term health, well-being and chronic care of people living with HIV. These recommendations have been road-tested in real-world settings in several countries to provide vital insights into how to ensure they are taken up more widely. In 2018, HIV Outcomes published an Online Compendium of Good Practices[4] for securing the long-term health and well-being of people with HIV. The present report focuses on progress made in 2019 in road-testing the HIV Outcomes recommendations in additional countries.

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[3] Viral suppression refers to the reduction of a person's viral load (HIV RNA) to an undetectable level. When the virus is undetectable, it cannot be transmitted to HIV negative partners

[4] http://hivoutcomes.eu/compendium-of-good-practices/

RECOMMENDATIONS

The recommendations published by HIV Outcomes are the result of a year-long collaborative process to capture and distil the perspectives and expertise of people living with HIV, clinicians, public health professionals, and the wider HIV community. Two expert roundtables identified priorities for the long-term health and well-being of those living with HIV. Using these insights, discussions at an expert workshop, and written input from leading experts, draft recommendations were developed. The contributors to this collaborative process are listed in Annex I.

The final recommendations were launched in the European Parliament in November 2017, with cross-party support from Members of the European Parliament. They aim to inform and inspire decision-makers to develop and implement new approaches and policies that recognise HIV to be a long-term condition that poses significant challenges to health and well-being.

Recommendations

1. Adopt an integrated, outcomes-focused, and patient-centred approach to long-term care;
2. Expand national monitoring of long-term HIV care and outcomes;
3. Fund cohort studies to provide information on the long-term health of people living with HIV;
4. Combat stigma and discrimination within health systems;
5. Upscale involvement of the HIV community in priority setting at country level.

Road-testing the recommendations for national implementation

With the aim of focusing European thought-leadership on delivering the greatest potential impact at national level, the HIV Outcomes Steering Group (see Annex II) chose to road-test the recommendations in 2018. Italy and Sweden were selected as the first countries in which the recommendations would be tested. Both countries had already demonstrated commitment to good health outcomes for people with HIV. Italy has published a 'White Book' setting out a model for long-term chronic care for HIV, and Sweden is the first country to achieve the UNAIDs '90-90-90' targets.

The results of the 2018 road-testing in Italy and Sweden are available here[5]. HIV Outcomes used the recommendations as a basis for discussions on ongoing measures to improve long-term care for people with HIV and to identify existing obstacles to implementing the necessary changes as well as the best way to overcome these. In 2018, HIV Outcomes published an Online Compendium of Good Practices for securing the long-term health and well-being of people with HIV. It was agreed that the road-testing had validated the recommendations in countries where the issue of living with HIV 'beyond viral suppression' was already being considered (i.e. Italy and Sweden). The Group decided in 2019 to support the implementation of changes in Italy and Sweden, based on their experience as the first countries to test the recommendations, to continue progress in those countries.

Extending to three new countries: Germany, Romania and Spain

It was also decided to extend the initiative to Germany, Romania and Spain. Findings from these national initiatives in Germany and Romania are shared for the first time in this report, with further insights from Spain to be published separately. The rationale for selecting these countries was to achieve a broader geographical balance and to include countries where health systems were less well resourced. In the latter case, this would require tailoring the recommendations to settings where the environment, infrastructure and stakeholders are not focused on quality of life issues for people living with HIV. In Germany, key HIV Outcomes stakeholders were already working to shift the health system to view HIV as a long-term condition. In Spain, stakeholders had laid the foundation for embracing the recommendations by studying the need for new policies to address HIV beyond viral suppression.

Romania offered an opportunity to road-test the HIV Outcomes approach in a unique context as it has a large group of people who were infected with HIV as children in hospitals in the late 1980s and early 1990s. Many of these citizens have lived with the condition for approximately 30 years. Road-testing the HIV Outcomes recommendations in Romania was viewed as a way to make an impact in a country where there is considerable unmet need, and where the policy and budgetary environment is seen as challenging.

Fostering reform, advocacy and alignment with European initiative

Several actions are required to support the road-testing of the HIV Outcomes recommendations. The first step is to build national advocacy platforms – with input from

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[5] http://hivoutcomes.eu/wp-content/uploads/2018/11/Good-Practices-in-the-Long-Term-Care-of-People-Living-with-HIV-Learning-from-Country-Experiences.pdf

patient/community groups, civil society, healthcare professionals, academia and political champions – to tailor the recommendations to meet local needs. This helps to localise the initiative and make it more relevant to the real-world environment in both countries. It also enables future engagement with policymakers and clinicians on the changes needed to address long-term health outcomes and quality of life of people living with HIV. The European secretariat provides support to national HIV Outcomes groups to ensure alignment of the initiative across Europe.

In all countries, road-testing the recommendations entails:

- Creating an expert core group
- Tailoring the HIV Outcomes recommendations for local implementation
- Identifying country-specific barriers to be overcome
- Showcasing national good practices and case studies
- Determining the policy and changes needed to improve long-term health outcomes and quality of life of people living with HIV and how to inform relevant policy and clinical debates.

Examples of good practice in both countries have been identified for inclusion in HIV Outcome's Compendium of Good Practices for the long-term health and well-being of people with HIV. This online 'good practice clinic' is a resource that can inspire and support key stakeholders across Europe to ensure that the specific long-term care needs of people living with HIV are met.

This report summarises the outputs of the work carried out by Germany and Romania to date. It expands the range of countries in which the HIV Outcomes recommendations have been road-tested and offers other countries opportunities to learn and adapt this approach in their own health systems.

Spotlight on Germany

An estimated 86,000 people in Germany are living with HIV – around 20% live in Berlin. Quality-assured specialist practices provide excellent care to people with HIV. Known as *Qualitätssicherungsvereinbarungen*, these services ensure a high quality of care and coordinate the patient journey. Specialists liaise with GPs and other physicians, working closely with the patient, to ensure their needs are met. While this is seen as an efficient and patient-centred approach, a more comprehensive evaluation of the structure and patient outcomes is required. Adoption of digital medicine and modern communication tools could further strengthen these services.

The Robert Koch-Institute provides reliable monitoring of data on age, sex, region and infection risk of people with HIV/AIDS. This could be expanded to collect data on comorbidities and therapy outcomes to provide valuable information on long-term HIV care, particularly for an ageing population. Discrimination and stigma remain a challenge in German society and in the health system. The German government has made addressing discrimination a priority of its 2030 strategy, but more concrete measures are required to ensure impact.

Germany is on the verge of reaching the UNAIDS 90-90-90 goals and has developed an innovative approach to community-based testing known as 'Checkpoints'. However, there is still work to do to improve long-term health outcomes and quality of life. Expanding these goals to include a fourth target – better quality of life – would represent a step forward. This fourth goal would address a range of factors including stigma, access to healthcare, and long-term well-being. This report also identifies room for improvement in the area of HIV care and research, which would accelerate efforts to meet the needs of people living with HIV.

Romania in focus

Romania's population of people living with HIV is unique. Of the 16,000 estimated cases, around half is made up by the so-called Romanian Cohort. These adults were infected as children in the state system of orphanages and hospitals in the period from late 1980s to early 1990's. Reliable official records from that time are not available but it is estimated that around 13,000 children (most of them born between 1988 and 1990) were infected while in state care (20-25% of them out of orphanages). People living with HIV in Romania are registered in a national register, and are treated by infectious disease specialists in regional centres or in county hospitals.

The approach to long-term care in Romania is very complex and is covered by multiple pieces of primary and secondary legislation. Since 2002, the law ensures that every person with HIV is entitled to benefit from social assistance including financial allowances for medicines, food and personal assistance, if required. The law also provides for various rights including to education, work and medical treatment, and obligations including undergoing testing and regular visits to regional health centres. However, even before the law came into force, people with HIV had access to basic care, including medication. In 2001, Romania was among the first countries in the world to provide free universal access to antiretroviral medication.

HIV Outcomes identified several areas where services could be improved. Central to this is establishing the concept of quality of life for the population of people living with HIV. A research study is needed to enhance understanding of what quality of life means to various groups of people with HIV in Romania. This work could engage with patients to define quality of life, identify barriers to achieving it, and propose solutions that would enhance well-being.

An education programme for all doctors would also deepen knowledge within the health system. This initiative should engage medical students at universities as well as established doctors through continuous education programmes.

Advocacy efforts must be stepped up to convince the Ministry of Health to rethink how the health system serves people with HIV. Specifically, establishing regional centres as independent entities and linking them to medical schools would make these services more attractive to a new generation of doctors and promote multidisciplinary care. Improving public awareness of the needs of the HIV community is also advised. A media campaign could play a role in combatting stigma and discrimination, improving understanding and empathy towards people living with HIV.

The continued work of HIV Outcomes in Romania has significant potential to improve care. Expanding the steering group to include younger doctors and patient representatives would offer a more holistic and sustainable approach. Investment in building research capacity and support for a study to explore quality of life among people with HIV in Romania would accelerate uptake of the HIV Outcomes recommendations.

Conclusion

The findings and good practices identified in Germany and Romania were presented in the European Parliament in November 2019. This enabled stakeholders to share important learnings that will prove to be valuable in countries across Europe – as well as for other disease areas – and further strengthen efforts to improve long-term health outcomes and quality of life of people living with HIV.

HIV OUTCOMES GERMANY – ROAD-TESTING THE RECOMMENDATIONS

Germany is on the verge of reaching the UNAIDS 90-90-90 goals: As of 2017, 87% of all people living with HIV are diagnosed, 92% of those diagnosed receive treatment and, of these, 95% achieve viral suppression. In Germany, since 1982, information on HIV/AIDS cases has been collected at the AIDS Centre of the Robert Koch Institute (RKI), a German federal government agency and research institute responsible for disease control and prevention. Since 1987, all laboratories performing HIV confirmatory testing have been required to report positive results anonymously. Although the case register of RKI only registers about 50% of HIV cases occurring in Germany, it is the most accurate and holistic HIV surveillance system for Germany.

The RKI's latest comprehensive HIV report dates to 2018 and paints an ambiguous picture: there are an estimated 87,900 people in Germany infected with HIV. About one in five of all people with HIV lives in Berlin, making it a key city in Germany for prevention and services delivery. Officially, 77,300 people have been diagnosed with the disease in Germany, implying that the number of unreported cases remains high. Of those 77,300 diagnosed cases, 61,800 are men and 15,500 women. As in most other European countries, men who have sex with men (MSM) are the population group most at risk of HIV infection, accounting for three quarters of people living with HIV in Germany. RKI data suggests that the number of undiagnosed people with HIV has not been reduced significantly in recent years. In 2011, there were an estimated 10,800 undiagnosed cases whereas the number slightly fell to 10,600 in 2018.

The number of new infections, however, has seen a recent drop from 2,500 new infections in 2017 to 2,400 in 2018. Since antiretroviral treatment (ART) is covered by statutory health insurance, the number of people diagnosed with HIV who receive ART and achieve viral suppression is continuously increasing. This trend is supported by the German/Austrian HIV treatment guidelines that suggest ART initiation irrespective of CD4 cell counts. In contrast to other countries, these guidelines are not binding, but leave physicians freedom to provide individualised and tailored treatment. Nevertheless, a high number of people presenting late with HIV remains a concern for healthcare professionals and policymakers. Both in Germany and in Europe as a whole, the proportion of late presenters at the initial diagnosis of HIV infection is still close to 50%, according to international figures from the COHERE cohort study as well as data from the German PROPHET study conducted by the *German working group of outpatient/office-based physicians treating HIV patients* (DAGNÄ). Late presentation is associated with higher morbidity and mortality, comorbidities, reduced quality of life and higher costs.

The structure of German HIV care

Deutsche AIDS Hilfe (DAH), a patient organisation, recommends that people diagnosed with HIV immediately seek the care of a physician specialised in HIV care. The National Association of SHI Accredited Physicians (KBV) has, in close cooperation with the German Medical Aids Association (DAIG), DAGNÄ and the DAH developed and implemented a concept for the quality-assured care of HIV/AIDS patients through specialist practices (*Qualitätssicherungsmaßnahme*). The aim is to delay the onset and progression of immunodeficiency disease for as long as possible through high-quality standards and coordinated cooperation between HIV specialists and other general practitioners (GP) and specialists.

Physicians specialised in HIV care can be found in specialised outpatient practices or ambulatory care units and provides experienced medical, psychological and social counselling and care, as well as access to innovative drugs. Many of these out-patient HIV specialists work as general practitioners and internists, which allows them to coordinate treatment and to refer people with HIV with serious comorbidities to hospital specialists. In Germany, about 20% of people with HIV are treated in hospitals/ambulatory settings whereas 80% are treated in outpatient practices. The so-called Berlin Model (Schöneberger Model) is considered an international role model. Central to this approach is the personal relationship of the person with HIV and their HIV physician, good networking with other specialist areas and the inpatient sector, well-equipped practices, cooperating pharmacies as well as consistent health insurance financing.

The generally high quality of HIV care in Germany is not only defined by the treatment guidelines mentioned above but stems from the fact that many HIV specialists are experienced and have been active in HIV medicine for 20 to 30 years. To further ensure the nationwide quality of treatment and a stable patient relationship, HIV specialists sign quality agreements with the Regional Association of SHI-Accredited Physicians (*KVen*). These agreements assign HIV specialists the task of coordinating the treatment of people with HIV with other medical specialists and assuring the quality and success of the treatment.

Addressing care gaps

Patient organisations such as DAH, and medical associations including DAGNÄ, support people with HIV in finding a specialised physician. In large urban areas, people with HIV have good access to specialised HIV physicians. In smaller cities and regions, however, people with HIV often have to travel long distances to find such specialists. This results in a care gap between those in the big cities and people in other regions.

There is also a significant East-West care gap, according to the RKI. While the Institute assumed in 2018 that about 75% of people with HIV in former eastern Germany are diagnosed, the rate in former western Germany is almost 90%. On top of that, patient and physician organisations point to an ageing physician population and a lack of young physicians which exacerbates the shortage of HIV specialists.

Despite this, over the last couple of years, the structure of German HIV care has improved notably. The introduction of quality agreements described above in 2009 was a major step forward towards an integrated, patient-oriented approach to HIV care. After a lengthy process, statutory health insurers began covering Pre-Exposure Prophylaxis (PrEP) in September 2019 – an important measure to lower infection rates. This was achieved with sustained support from certain policymakers. Physicians will also have corresponding reimbursement for risk groups (e.g. MSM), making the further successful roll-out of PrEP very likely.

The availability of CE-marked HIV self-tests since September 2018 was another milestone to improve diagnosis rates. Experiences from other countries such as Australia, France, Italy, the United Kingdom and the US suggests that HIV self-tests are generally well accepted by the public. ‘To go and get a HIV test done was a big hurdle for me before I was diagnosed with HIV 13 years ago. I would have preferred to have access to a self-test or home-test at that time,’ said one patient when speaking with Prof. Georg Behrens (a member of HIV Outcomes’ European Steering Group). The recently passed Digital Healthcare Act (‘Digitale Versorgung Gesetz’) is an effective step towards digital health. Patients with chronic diseases will have more opportunities to use digital apps, as they can be prescribed by physicians and reimbursed by health insurers according to the new law. On the one hand, this facilitates therapy control for physicians. On the other, telemedicine enables patients with chronic diseases to reduce their regular visits to their doctor's practice while still following their therapy. In addition, there is hope that the planned provision of pseudonymized care data can permanently improve the quality of care overall in Germany.

Germany’s HIV Strategy

With the 2005 German HIV/AIDS strategy, the Federal government laid the foundations for battling HIV/AIDS in Germany. In 2016, the government replaced the previous HIV strategy with a more holistic umbrella strategy. Rather than viewing HIV in isolation, the new approach connects HIV care with other sexually transmitted infections (STIs) and blood-borne diseases, including hepatitis B and C. The so-called BIS2030 Strategy aims to sustainably contain STIs, especially amongst risk groups, and to combat stigma and discrimination. The strategy outlines several areas of action including education, information campaigns, establishing best practices in German regions, support for research, promoting cross-sectoral networking and collaboration, and further expanding monitoring and surveillance.

To incorporate advice from the expert community, a supporting committee was established featuring members from others medical and patient organisations. It is too early to evaluate the success of the BIS2030 strategy as only a few concrete measures have been implemented to date. There is currently no concrete plan nor binding milestones to achieve until 2030. Members of the Green parliamentary group of the federal parliament have criticised the strategy and asked for a concrete timeline, financial commitments and a timely evaluation.

Quality of life and long-term health

Viral suppression is only one element of the well-being of people living with HIV – although it is a very important one. In the expert community, there is increasing emphasis on the broader quality of life for people living with HIV (e.g. side effects, emotional and mental health, stigma, deprivation, comorbidities) which are not represented in the UNAIDS 90-90-90 goals. In its 2018 monitoring report on HIV care, the European Centre for Disease Prevention and Control (ECDC) collected, for the first time, data about the quality of life of people living with HIV in Europe. Of all the participating Member States, only seven reported back and Germany was not amongst them. Thus far, quality of life is also not captured by the RKI HIV Surveillance system and the overall data available on the quality of life of people living with HIV in Germany needs to be improved.

It is also striking that the German government’s HIV strategy does not address the issues of quality of life nor the fast-growing number of older people living with HIV who face higher cardiovascular morbidity, an increased cancer risk and other challenges. In order to adapt the German healthcare system to the evolving needs of people with HIV, further efforts by policymakers and the expert community are necessary – HIV Outcomes is an opportunity to point towards solutions and provide valuable expert recommendations.

Findings

The HIV Outcomes Initiative has developed a set of recommendations to improve quality of life and long-term health outcomes for people living with HIV. The European Steering Group decided to road test the HIV Outcomes recommendations in Germany in 2019. A local steering group is being created to engage with selected medical and patient experts. While these discussions will continue, stakeholders have provisionally identified a series of recommendations on how Germany can achieve the goals of HIV Outcomes.

Recommendation 1: Adopt an integrated, outcomes-focused, and patient-centred approach to long-term care

Cooperation between state authorities, medical and patient organisations and other NGOs is vital to delivering patient-centred HIV care. Various regional HIV support organisations receive public funding to run 60 Checkpoints[6] for HIV and STD testing in Germany. In some cases, these organisations offer on-site tests, for example in gay venues. Such checkpoints should become important contact points for immigrants as well, but it remains to be seen whether this concept works in practice. Germany's Federal Centre for Health Education, the RKI, and DAH have created a programme to provide testing in selected drug treatment facilities – a promising approach that needs to be expanded and extended.

The quality-assured care of people with HIV through specialist practices (*Qualitätssicherungsvereinbarungen*) can be considered best practice in HIV care in Europe. Minimum requirements for care providers, such as experience in the care of people with HIV, participation in training courses or a minimum number of HIV cases, ensure a high quality of care. In the role as care coordinator, specialised HIV physician can work together closely with the patient and coordinate his/her patient journey. Cooperating GPs and other physicians commit themselves to send people with HIV to a HIV specialist on a regular basis and to be in constant communication with the specialist. Experts consider this patient-centred approach as an efficient and effective structure for outpatient HIV care. However, a more comprehensive evaluation of the care structure and patient outcomes is advised, especially regarding lifelong therapy and care. On a separate note, an increased use of digital medicine and modern communication technologies would offer the opportunity to strengthen an integrated and patient-centred approach to HIV care.

Recommendation 2: Expand national monitoring of long-term HIV care and outcomes

Currently, national HIV monitoring by the RKI provides reliable information on age, sex, region of residence and the possible infection risk of people with HIV/AIDS. In addition, reliable information on the medical circumstances leading to the diagnosis of HIV/AIDS, information on medical care and therapy, and other data are collected. More systematic gathering of data on comorbidities and therapy outcomes could provide valuable information on long-term HIV care, especially for an ageing population of people living with HIV.

Given the existing HIV surveillance structures at the RKI, the implementation of this recommendation could be a quick win if policymakers and RKI representatives value collecting data on long-term health outcomes. The RKI should also continue to monitor important sub-populations, such as women.

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[6] See Case Study on Checkpoints for more details

Recommendation 3: Fund cohort studies to provide information on the long-term health of people living with HIV

The results of studies on the long-term health (including quality of life) of people living with HIV in Germany show that the most common psychological burdens affecting quality of life were fatigue and lack of energy, sadness/depression, sleep disorders, sexual problems and weight gain. This is in line with the results of international studies. Surprisingly, in one study, older people with HIV over 61 years of age reported better physical quality of life than the norm. This is presumed to be an effect of survival bias.

Unfortunately, efforts to establish nationwide HIV cohort studies have failed several times in the past. To conclusively assess the feasibility and research goal of more comprehensive cohort studies in Germany, further expert discussions within the German HIV Outcomes steering group, once it is formally established, will be required. One opportunity to fund such studies could be through the innovations fund of the Federal Joint Committee (G-BA). To be granted funding from the innovations fund, cooperation between several institutions is required.

Recommendation 4: Combat stigma and discrimination within health systems

Discrimination against people with HIV is still a problem within the German health system. One person in five has been refused medical treatment, 10% did not consult a doctor when they should have, and 13% do not regard their medical records as confidential. The German government has highlighted discrimination within the health system as a priority in its 2030 strategy, but at this point concrete measures are not universally applied.

The engagement of non-government organisations in combating stigma within the health system is to be noted. DAH, for instance, has introduced a certificate for doctors' offices that are free of discrimination. Furthermore, the patient organisation offers training courses for physicians on how to communicate with patients about sexual relations, HIV and other STIs, and there is cooperation with the German Dentist Association (KZBV) to train dentists on how to engage with people living with HIV without discrimination. To reach the goal of zero discrimination, sustainable cooperation between government organisations, medical and patient organisations seems like a very promising approach. Existing efforts should be built upon, and there remains room to expand cooperation more widely.

Recommendation 5: Scale up involvement of the HIV community in priority-setting at country level

As mentioned above, patient organisations already play an important role within the German health system. Powered by partial government funding, they are very active in running campaigns against discrimination and for the improvement of the HIV care structure.

From a general political perspective, the German healthcare system is characterised by the self-government of physicians, dentists, hospitals and health insurance funds. The G-BA is the highest decision-making body of the joint self-government. It issues directives regarding the benefits to be offered by statutory health insurance funds (GKV) for more than 73 million insured persons and thus specifies which services in medical care are reimbursed and how the care system is defined. Patient organisations have consultation rights within the G-BA, but unlike representatives of medical, hospital and health insurance associations, they do not have voting rights.

However, there are other measures that can be pursued to scale up the involvement of the HIV community. For example, patient organisations are very active in running public campaigns and also in engaging with policymakers. Their actual influence on the national health agenda, however, is difficult to quantify.

Next steps

As stated in this report, Germany is on the verge of reaching the UNAIDS 90-90-90 goals, but there is still a lot do in terms of improving long-term health and well-being of people living with HIV. The time to set new goals and to broaden the perspective is now. To expand the 90-90-90 goals, a fourth goal should be addressed, which is quality of life, that consists of several factors such as zero stigma, convenience of healthcare and the long-term health of people living with HIV.

Initial talks with some potential members of the German HIV steering group have taken place. Although some clinicians and patients have already contributed to this report, the findings above should be considered an initial assessment. Now, the next step for HIV Outcomes Germany is to bring together leading experts from different disciplines to discuss the status quo and the applicability of the recommendations in further detail.

Nevertheless, this initial assessment shows that there is room to strengthen the focus of HIV care and research in Germany on quality of life and long-term health. For this purpose, the HIV Outcomes steering group provides a great opportunity to foster cooperation between patient and clinician representatives as well as other experts, and to reinforce various aspects of HIV care on the national health agenda. Additionally, according to the assessment, country-specific challenges in Germany such as regional differences in healthcare provision must also be considered. The priorities of the initiative, including engagement with external stakeholders, will be set by the future German HIV Outcomes steering group.

CASE STUDY

CHECKPOINTS: COMMUNITY-BASED TESTING

In Germany, community-based facilities that offer advice and testing for HIV and other STDs have existed in several cities for a number of years. These so-called Checkpoints mark the beginning of a new generation of HIV and STD prevention, treatment and psychological care. Diagnosis, psychosocial counselling and medical care for have been brought together under one roof. The approach is anonymous and safe. Some of the facilities also offer a Pre-Exposure Prophylaxis (PrEP) check. The importance of anonymity can inform the choice of location: some checkpoints are, for example, integrated in vaccination practices. Therefore, it is not obvious whether people are coming to the facility for an HIV test or vaccination. During the appointment, people are then tested for whatever diseases (HIV, syphilis, chlamydia, gonorrhoea etc.) they wish. Most of the available rapid tests already offer results on the same day.

Checkpoints tackle the challenge of enhancing timely diagnosis of HIV and thus support Germany in reaching the 90-90-90 goals. They also offer an opportunity for people at risk of HIV to overcome their reservations about going to the doctor, and can overcome fear of discrimination and stigmatisation within the healthcare system. Checkpoints take a patient-centred approach and are implemented in cooperation with national and regional state authorities, medical and patient organisations, individual physicians and other NGOs.

60 checkpoints in 20 cities

Community-based testing facilities now exist in over 20 major German cities. Various regional HIV/AIDS support organisations receive public funding to run a total of 60 checkpoints in Germany. They are distributed across the country, for example, in Berlin – where one fifth of all people with HIV live – and in Frankfurt, Freiburg Karlsruhe, Munich, Nuremberg and Regensburg. The checkpoints predominantly target men who have sex with men (MSM). This group makes up a large proportion of those infected with HIV. In addition, some checkpoints treat people who are not covered by health insurance. Therefore, checkpoints are also aimed at the group of uninsured sex workers with a particularly high risk of STD infections, as well as at people living in other precarious situations, who are unable to access more conventional medical services.

If a person receives a positive diagnosis, they are given additional testing as well as treatments. If long-term treatments (e.g. for HIV or hepatitis C) are necessary, the person will be referred to an appropriate specialist practice. Checkpoints also offer counselling if the person wishes to talk about sexual health, substance abuse or other topics. As some doctors in Germany do not talk openly about sexual health, checkpoints offer an opportunity for open exchange on sensitive issues.

Results

Checkpoints offer a number of benefits. First, they are a simple and anonymous way of increasing the number of diagnoses of new HIV infections and other STDs. Second, they guarantee that those diagnosed will be treated. Third, they provide psychological counselling under the same roof as medical care. This patient-centred service has been very successful at various checkpoints all over Germany. The main target group, MSM, but also other groups and minorities, such as women, use these checkpoints. At some key locations, including Berlin, the demand is so high that people sometimes have to be referred to a later date and time. Stakeholders, including Ute Hiller from the patient advocacy group Berlin AIDS Aid (BAH), are full of praise for the concept. She expects the success of this approach to be reflected in the statistics of the RKI in the coming years.

The Checkpoint Study is a collaboration between RKI, the patient advocacy group DAH, and a larger number of testing facilities. It compiles data from the years 2015 to 2016. The study collected and evaluated anonymous data from various checkpoints. Results clearly show that checkpoints reach people with significant risks of HIV and other STDs. The study found that 1.2% of all tests at the checkpoints showed a reactive or positive HIV test result. In the MSM group, 1.62% of the tests were reactive or positive. This number was significantly lower for women (0.48%) and heterosexual men (0.40%). In the group of ‘others’, which was the smallest group with a total of 409 persons tested, the proportion of positive/reactive tests was around 2%. These numbers demonstrate that checkpoints have so far contributed to diagnosing HIV in Germany and that they actually reached the main target group of MSM during the investigated period. Other results indicate that the checkpoints also reach the target group of non-insured patients. A study with current data is currently under development.

Future action

As the checkpoints are very well received by the target groups, their reach should be extended. This means that the existing centres should be further promoted and expanded, and new ones should be built. When choosing the location of new checkpoints, special consideration should be given to regional differences in healthcare provision. A majority of late-presenters stem from rather rural parts of Germany, which results in a the ‘non-metropolis-and-other-regions’ care gap outlined above. This gap could be addressed by establishing checkpoints in these areas. In rural regions, the offer of an anonymous point of contact could be particularly beneficial and increase the likelihood that patients will attend the facility.

The Checkpoint Study by RKI and DAH, and a large number of testing facilities, also gives recommendations for politicians and donors. It emphasises that the checkpoints need to be staffed and funded so that examinations can be carried out free of charge. As checkpoints are an important contact point for people without valid health insurance, they should also expand to provide vaccinations and treatment for infections detected in this patient group.

From a public health point of view, examinations for epidemiologically relevant infections should be as easily accessible as possible. Therefore, accessibility, opening hours, acceptance and confidentiality are important factors. In addition, the consultation and all examinations should cost as little as possible and, ideally, be free of charge. The comparison between a checkpoint in Hamburg, where the state pays for the examination costs for MSM, and other institutions, where the tests have to be paid for by people themselves, suggests that those who forego testing for financial reasons are at the same risk of receiving a positive diagnosis. Thus, access to free or, at least affordable, testing should be offered at all facilities.

HIV OUTCOMES ROMANIA – ROAD-TESTING THE RECOMMENDATIONS

Context

Approximately 16,000 people in Romania are living with HIV/AIDS and 315 new cases were detected in the first six months of 2019 (179 new HIV cases and 136 new AIDS cases). The number of HIV/AIDS deaths recorded in first six months of 2019 was 74. There is a slight downward trend in the number of new infections, beginning in 2013 when the total number of HIV/AIDS cases was 1,012 (529 new HIV cases and 483 new AIDS cases). Since then, the numbers have fallen to 924 in 2014, 869 in 2015, 810 in 2016, 780 in 2017 and 750 in 2018.

Most of the people living with HIV are adults. Of these, about a half is made up of people that were infected in state hospitals and orphanages between late 1980s and early 1990s. For the period of 1985 to 1989 there are no reliable official records. However, research shows that around 13,000 children (most of them born between 1988 and 1990) were infected with HIV in the state system (20-25% of them out of orphanages). This population is referred to as the Romanian Cohort.

A National HIV/AIDS Surveillance Programme is in place, coordinated by the National Institute for Infectious Diseases Prof. Dr. Matei Bals in Romania. The primary data is collected from nine Regional Centres for the Evaluation and Monitoring of HIV/AIDS Data and by County Public Health Authorities.

Prevalence of HIV/AIDS

People with HIV face a number of health issues associated with their disease, arising from comorbidities and ageing-related conditions. As life expectancy for people with HIV has increased, the number of people living with the disease has risen. The cumulative number of HIV/AIDS cases for 1985-2019 is 24,333. Of these, 16,355 is the total number of AIDS cases while 7,979 is the total cumulative HIV cases for the same period. The number of people living with HIV/AIDS is 15,999. A total of 15,665 are aged 20 years or older, according to the National Institute for Infectious Diseases.

In its annual report published in November 2017, the European Centre for Disease Prevention and Control (ECDC) stated that during in the decade from 2006 to 2016, there was a stable trend of HIV/AIDS diagnoses in Romania. It was 6.8 per 100,000 people in the earlier part of the 10-year period of surveillance and had fallen to 5.9 in 100,000 in 2016. Romania has also adapted and implemented the ECDC's Cascade of Care monitoring tool. This assessment tool has helped Romanian healthcare professionals to identify inconsistencies between the numbers of diagnosed and undiagnosed persons, access to public medical services, and successes and gaps in specific national interventions.

For people with HIV in Romania, the two most frequent comorbidities are tuberculosis (TB) and hepatitis, as well as mental health problems. A national guide is in place for the management of TB/HIV cases. There are also provisions for HIV patients in the National Plan for Mental Health, as well as numerous studies and guidelines on the management of hepatitis and HIV. Romania has a population of 20 million people. HIV prevelance is 0.07% and annual incidence is 0.002%. Prevalance of hepatitis B is now 5.6% and incidence is 0.001%. There has been a 21-fold decrease in annual incidence compared to 1995 thanks to the introduction of vaccination. The prevelance of hepatitis C is 1.9% while the incidence is 0.0003%.

Long-term HIV care

The approach to long-term HIV care in Romania is very complex. It comprises multiple pieces of primary and secondary legislation, notably Law 584/2002 which contains measures to prevent the spread of HIV in Romania and the protection of people living with HIV. In addition, the care of people with HIV is also addressed in several Government Decisions, Ministry Orders, technical regulations, guidelines, plans and strategies. Since 2001, even before the introduction of Law 584/2002, Romania was among the first countries in the world to provide free universal access to medication. Law 584/2002 provides a unique mechanism whereby all people with HIV benefit from social assistance with financial allowances for drugs, food and personal assistance, if deemed necessary. People living with HIV in Romania are registered in a national register, and are treated by infectious disease specialists in regional centres or in county hospitals. The law also provides for various rights including to education, work and medical treatment, and obligations including undergoing testing and regular visits to regional health centres.

Other pieces of legislation with provisions for long-term HIV care include:

- National Health Strategy 2014-2020 – approved by Government Decision no. 1028/2014
- National Strategy for Tuberculosis Control in Romania 2015-2020 – approved by Government Decision no. 121/2015
- Inclusion Strategy for Romanian citizens belonging to the Roma minority for the period 2014-2020
- National Strategy for the protection and promotion of the rights of the child 2014-2020 – approved by Government Decision no. 1113/2014
- National Strategy on Social Inclusion and Poverty Reduction 2015-2020 – approved by Government Decision no. 383/2015

A key piece of legislation, the National Strategic Plan (PNS) for the surveillance, control and prevention of HIV/AIDS cases in the period 2018-2020, proposes an integrated approach to care. The PNS aims to prioritise prevention interventions and use HIV testing as a gateway to treatment. It also provides measures to ensure universal access to antiretroviral treatment for people diagnosed with HIV/AIDS and to provide social benefits and services. The draft document proposes the reconstitution of the National Commission for the Surveillance, Control and Prevention of HIV/AIDS cases. This Commission would coordinate implementation of the strategy.

The Romanian HIV Outcomes secretariat conducted a comparative analysis between the proposed provisions of the PNS and the HIV Outcomes recommendations and found strong synergy between the two. Unfortunately, due to budget constraints and lack of political will, the PNS has not yet been approved. It is still viewed positively, and one of the goals of HIV Outcomes in 2020 is to support advocacy projects aimed at the updating and approving the PNS.

HIV Outcomes: National Engagement

HIV Outcomes began work in Romania in January 2019, holding several meetings in Bucharest with members of the European Streeting Group and Romanian stakeholders. Building on this kick-off meeting, the secretariat conducted a stakeholder mapping analysis and subsequently engaged the following:

- Ministry of Health – a representative of which is also part of the Steering Committee
- National Institute for Public Health – not represented in the Steering Committee but offering access to data and support in future programmes
- National Institute for Infectious Diseases Prof. Dr. Matei Bals
- Victor Babes, Clinical Hospital for Infectious Diseases
- National Union of Organisations of People Affected by HIV/AIDS (UNOPA) – the only federation in Romania encompassing 22 organisations, focusing on advocacy for promoting and protecting the rights of people affected by HIV in Romania
- The Romanian Anti-SIDA Association (ARAS) – a member of *Coalition PLUS, Civil Society on HIV/AIDS Forum, Civil Society Forum on Drugs, Eurasian Harm Reduction Network (EHRN). Its objectives include the prevention of HIV, hepatitis B and C, and other sexually transmitted infections (STIs); and promoting non-discrimination against people living with HIV and against populations at risk of infection*

- Carusel – an NGO aiming to improve the quality of life for drug and alcohol users, sex workers or individuals who have multiple sex partners, persons who live on the streets, people who are socially and economically disadvantaged, and those at risk of illness or facing social exclusion

- Romanian Angel Appeal – an NGO running programmes for children and young people in need, including those with chronic diseases, HIV/AIDS, etc. by offering medical, psychological, social and material support. The organisation works through network development, training courses, research, campaigns and advocacy programmes, in partnership with public authorities, private companies, non-governmental organisations and individuals

In addition, a list of potential members for the Romanian Steering Group were identified:

- Silvia Asandi – President, Romanian Angel Appeal (NGO focused on HIV and TB)
- Roxana Cernat – Regional HIV centre, Constanta county
- Silvia Chirtoc – GSK/ViiV Healthcare
- Adrian Streinu Cercel, professor and leading expert in HIV, member of Romanian Academy for Medical Sciences
- Tudor Ciubotaru – Gilead Sciences
- Nicoleta Dascalu – ARAS (longest established HIV/AIDS association)
- Mariana Mardarescu – Regional HIV centre Bucharest
- Ioan Petre – Carusel (patient care NGO)
- Iulian Petre – UNOPA (Union of Patient Associations)
- Paula Rusu – independent journalist
- Amalia Serban – Director, Ministry of Health

Findings

HIV Outcomes explored the extent to which HIV care and long-term health are addressed at national level in Romania. While there is extensive regulation in place, there is no recent national strategy for the management of HIV/AIDS. The last national strategy was approved by the Government in 2004 and was valid until 2007. Since then, the system has operated based mostly on inertia. In 2018, the Government proposed a new plan, that was supposed to apply from 2018 to 2020. Due to budgetary constraints, the Plan was never approved although it is a good document, drafted by the Ministry of Health together with experts supported by the World Bank. There is a high degree of similarity between the provisions of the Plan and the HIV Outcomes recommendations.

The treatment guidelines are also outdated – the last guidelines were published in 2014. The Ministry has postponed updates of the guidelines on several occasions, pending the approval of the National Plan. Since 2016, doctors in Romania have consulted the European AIDS Clinical Society (EACS) and World Health Organization (WHO) guidelines as well as guidelines developed by the Paediatric European Network for Treatment of AIDS (PENTA).

HIV Outcomes Recommendations

Recommendation 1: Adopt an integrated, outcomes-focused, and patient-centred approach to long-term care

The regional centres were initially set up with a view to providing interdisciplinary HIV care. However, following a series of reforms of the national health system, combined with budgetary constraints and the decreasing number of doctors, the regional centres have lost some of their capacity. The Romanian HIV Outcomes group highlighted the need to re-establish the centres as independent entities, separate from county hospitals, with multidisciplinary teams of doctors and stronger links with social services.

Recommendation 2: Expand national monitoring of long-term HIV care and outcomes

The National Institute for Infectious Diseases Prof. Dr. Matei Bals provides high quality monitoring of HIV. Nonetheless, until 2019, long-term care was not among the indicators routinely tracked. There are several technical issues to be addressed, especially with monitoring people living with HIV in vulnerable social groups and those outside the system. Social assistance authorities do not have a clear reporting system regarding people with HIV and this will be addressed by HIV Outcomes in 2020.

Recommendation 3: Fund cohort studies to provide information on the long-term health of people living with HIV

This recommendation was one of the most frequently discussed issues among members of the HIV Outcomes group in Romania. There are currently no cohort studies in Romania focused on long-term care and quality of life. The group concluded that a study of this kind should be among the first action items for the HIV Outcomes initiative in Romania.

Recommendation 4: Combat stigma and discrimination within health systems

HIV-associated stigma remains an issue among society at large but also among healthcare professionals. This is caused both by lack of specific knowledge about HIV but is also the legacy of past media campaigns that created unwarranted concerns. The HIV Outcomes group's discussions on this issue focused on both the education of healthcare professionals (with family doctors needing particular attention) and a public campaign on the recent facts regarding HIV and the related effects of long-term treatment.

Recommendation 5: Upscale involvement of the HIV community in priority setting at country level

The Romanian HIV Outcomes group also highlighted the need to complete national legal reforms dedicated to preventing and fighting HIV. The current legislation is obsolete and the publication at the end of 2018 of a National Strategic Plan was considered an important step. Notwithstanding the failure of the Government to approve and publish the Plan, it saw significant participation of the HIV community in the discussion around the document.

Improving long-term care at national level

The concept of long-term care is not new in Romania, particularly due to the large number of people in the so-called Romanian Cohort. However, progress on multidisciplinary and person-centred care faces a number of challenges:

- The organisation of regional centres as part of the county hospitals creates problems regarding access to treatment, availability of doctors and other budgetary issues.
- The concept of quality of life is relatively new and is not a goal of the care system – treatment being the main priority. The concept has not been supported by a formal definition, and doctors are not aware of all the factors that influence quality of life for people with HIV in Romania.
- Lack of specific HIV education for doctors in other specialties remains a problem, and people with HIV in Romania still face discrimination and are denied treatment (especially, but not limited to, surgical and dental specialties) when they disclose their condition.
- There is a generation gap in the medical system: doctors that are very much aware of the HIV/AIDS problem are getting older and young doctors show less interest in the infectious diseases specialty (and even less interest in HIV).
- Stigma is present in wider society but also in the medical sector. Much of it comes from the many negative media campaigns in the late 1990s and lack of any general media

campaign regarding the evolution of treatment, positive outcomes, and key messages about viral suppression, i.e. ‘undetectable = untransmittable’.

Conclusions and next steps

As a result of the multiple interactions with key stakeholders, both at the level of the Steering Committee but also others not involved in the Steering Committee, the following potential future actions are being considered:

1. A study on quality of life among people with HIV in Romania. This research would explore the quality of life of various groups of people with HIV in Romania and the factors that influence well-being.
2. An education programme for doctors – both in medical schools but also in continuous education programmes.
3. An advocacy campaign to encourage the Ministry of Health to establish regional centres as independent entities. Rather than being part of county hospital structures, as is currently the case, regional centres should be linked more closely with medical schools (especially for doctoral studies), in order to attract younger doctors into the system and promote a multi-disciplinary approach.
4. Support other advocacy projects aimed at updating and approving the National Strategic Plan for HIV.
5. A media campaign organised with the help of the National Institute for Public Health aimed at combating stigma and discrimination

Steering Committee members are in favour of launching the proposed study on quality of life soon, as a starting point for any other future actions to be initiated by HIV Outcomes in Romania. A large majority of members is in favour of expanding the group to include younger doctors (particularly from regional centres) and additional patients (as recommended by UNOPA/Carusel). The Committee welcomed news that the National Institute for Public Health has pledged support for a HIV media campaign in 2020 which will feature public information messages on radio and television.

CASE STUDY

‘CEAUSESCU’S CHILDREN’

The first case of HIV/AIDS was diagnosed in Romania in 1985. It was reported to the European Centre for the Epidemiological Monitoring of AIDS in Paris. Romania was still part of the communist bloc at that time. Healthcare and social assistance services were underdeveloped, and communication with the western bloc was limited. Local and central authorities tended not to report information that may have reflected negatively on the regime. After the Revolution of December 1989, communication channels and borders opened, authorities gradually changed their perspective, and information began to flow.

1990 was the year when an open conversation about the HIV/AIDS epidemic began in Romana. In March 1990, an HIV/AIDS surveillance and reporting system was put in place with support from WHO experts and the Romanian Ministry of Health. This set the course for the evolution of Romania’s HIV/AIDS systems. It soon emerged that thousands of children had been infected with HIV/AIDS in state-run hospitals and orphanages. In fact, as authorities began reporting accurate data to the WHO for the first time, it became clear that over half of Europe’s children with HIV were in Romania.

A unique cohort

The existence of the so-called Romanian Cohort was first identified, somewhat inadvertently, by Dr Victor Patrascu, a virologist with a veterinary background. He was convinced that HIV was present in Romania, despite official policy statements at the time claiming that the disease did not exist in the country. Dr Patrascu convinced a group of hospital doctors to test some patients for HIV. The results were overwhelming: 10% of children in hospitals were HIV positive and over half of the children in orphanages were infected. Around 13,000 children, according to official data, were infected with HIV in the state system between the late 1980s and early 1990s. More than half of them survived.

Turbulent times

From 1990 to 1995, Romania was in chaos. The country endured radical political changes, riots, serious underfunding of healthcare and social assistance systems, and a deep economic downturn couples with triple-digit inflation. International support, exchange of information and knowledge transfer, genuine cooperation, and personal involvement helped an embattled nation – and thousands of people with HIV – to survive.

Milestones

- **March 1990:** Experts from WHO, CDC and Romania agreed a first case definition in the Romanian context; a HIV/AIDS surveillance and reporting system was implemented; an urgent short-term action plan was put in place
- **1992:** Ministry of Health implemented a new, robust HIV surveillance system for children (aged 0-13) and adults (aged >13)
- **1995:** First special budget for HIV infection
- **1997-1998:** Establishment of HIV Regional Centres for Monitoring and Evaluation of HIV/AIDS Data in Romania
- **1998:** The National Prevention of Mother to Child Transmission Programme. A new electronic recording system was introduced. It categorised children and adults separately, in line with international standards.
- **2001:** Ministry of Health declared HIV/AIDS as a public health priority and developed the Plan for Universal Access to Treatment and Care, designed to increase access to antiretroviral therapies (ART)
- **2001**: Establishment of the Compartment for Monitoring and Evaluation of HIV/AIDS Data in Romania, where the national database was reorganised and established as a National Registry
- **Since 2001:** All data on HIV/AIDS collected since 1985 were put into the national database: the database constitutes a unique monitoring system in European HIV/AIDS (i.e. the cases are not duplicated)
- **2002:** Adoption of a new law on HIV prevention and care for people living with HIV
- **2004:** National strategy approved by the Government (valid until 2007)
- **Since 2013:** Treatment made available regardless of CD4 count

Key dates for Romanian Cohort

- **1990:** Creation of the first clinic at the National Institute for Infectious Diseases dedicated to the care of children with HIV. Support from Health Aid UK introduced new methods and holistic ways of working, offering children not just medical care but also hygiene, nutrition, education, play and psychological support

- **1991-1992:** Opening of first houses that follow the 'familial model' for infected children
- **1996:** Opening of first day-care clinic, following the English model, with medical, diagnostic, psychological, oral medicine and other services
- **1996:** Establishment of alternative care services for children in state institutions, including maternal assistance, adoption, re-integration; provision of ART monitoring, school orientation and integration, health and sexual education

Results

More than half of the children from the Romanian Cohort are alive today. Doctors such as Mariana Mardarescu, who cared for the Romanian Cohort as children, are now taking care of their children. This was made possible by the efforts of doctors, nurses and others who were committed to addressing problems generated by the failure of an abnormal system which negatively impacted many children's lives. Policy changes and a shift in mindset were possible thanks to their personal dedication, willingness to embrace best practices, and acceptance of support from private entities and the international community.

Recommendations

The result of the incredible efforts of those who fought this epidemic has helped Romania to build strong infrastructure and a good system to support people living with HIV. The greatest challenges facing the system arise from policy changes and healthcare system restructuring, declining attention given to this subject, inertia in the system, decreases in funding, and the complex issues associated with living longer with HIV. Notwithstanding this positive outcome from a very challenging situation, it is essential that the system learns from the past so that it can ensure continuous increases in survival rates and in quality of life.

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With support from the HIV Outcomes Secretariat

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