HIVOutcomes
BEYOND VIRAL SUPPRESSION

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

NOVEMBER 2018

AIDS ACTION EUROPE
AFEW
ECUO East Europe & Central Asia Union of PLWH
EATG European AIDS Treatment Group
GILEAD
ViiV Healthcare

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INTRODUCTION

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 policy makers and healthcare providers. The initiative's aims are 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 PLHIV.

RECOMMENDATIONS

The recommendations 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 – in December 2016 and June 2017 – identified priorities for the long-term health and well-being of those living with HIV. In September 2017, an expert workshop discussed and developed draft recommendations. The outcomes of that workshop, and subsequent written contributions from participating experts, are reflected in these recommendations. The contributors to the development of the recommendations 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.

These recommendations aim to inform and inspire policy- and 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 focussing 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. HIV Outcomes used the recommendations as a basis for discussions on what is already ongoing 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.

The Steering Group undertook to road-test the recommendations in Italy and Sweden. Both countries have 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[1].

In both countries, road-testing the recommendations entailed:

- Creating an expert core group consisting of patient organisations, healthcare professionals and academics to engage with national and regional stakeholders on changes needed to properly address long-term health outcomes and quality of life for people with HIV;
- Tailoring the HIV Outcomes recommendations for local implementation and identifying country-specific barriers to be overcome;
- Identifying and showcasing national good practices (case studies) for long-term HIV care;
- Determining the policy and changes needed to improve long-term health outcomes and quality of life for PLHIV and how to inform relevant policy and clinical debates.

Collecting examples of good practice allowed HIV Outcomes to create an online Compendium of Good Practices for the long-term health and well-being of people with HIV. This 'good practice clinic' will be a resource that can inspire and support key stakeholders

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[1] The UNAIDS 90-90-90 target 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.

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 Italy and Sweden.

Findings

In the following two national reports, approaches and challenges are described, which are frequently similar in both countries.

Both Italy and Sweden have identified the requirement for an interdisciplinary, cross-functional approach to HIV care (in line with HIV Outcome Recommendation 1: ‘*Adopt an integrated, outcomes-focused, and patient-centred approach to long-term care*’). The Italian HIV Outcomes group highlighted the need to improve the model of care through the development of multi-disciplinary networks of specialist centres. They also underlined the importance of care pathways that combine traditional healthcare services with social assistance, as people increasingly live with HIV for the long-term. In Sweden, the example of cross-functional care in a clinic that integrates a psychiatrist, venerologist, general practitioner and conversational therapist is showcased.

The HIV Outcomes groups in Italy and Sweden both identified Recommendation 4: ‘*Combat stigma and discrimination within health systems*’ as needing particular attention to improve the lives of people living with HIV. In Italy, HIV associated stigma remains an issue among healthcare professionals, where a lack of knowledge about HIV is reported to create unwarranted concerns. Further efforts are needed to raise awareness in this group (and more widely) that people with HIV who are using effective treatment and have a viral load that is undetectable are uninfectious to other people (U=U, undetectable = untransmittable).

Similar concerns were identified in Sweden; the local HIV Outcomes group considers that a strong, long-term programme of education and certification would reduce the HIV associated stigma among healthcare professionals. This is a particularly pressing requirement for primary care, dentistry, geriatric care and home care.

Both groups identified as a key priority the need for adequate resources to develop a fourth ‘90’ target with its focus on measuring and attaining the best quality of life for people with HIV.

Italy also highlighted the need to complete national legal reforms dedicated to preventing and fighting HIV. The current legislation, which entered into force in the early 1990s, was primarily designed to address HIV and AIDS as a fatal disease. In today’s world, where effective therapy means that HIV has evolved into a long-term manageable condition, this legislative framework needs to be adapted accordingly. The Swedish group stressed the need to implement the recently-published (November 2017) national strategy on HIV and other infectious diseases.

Conclusion

Looking at ways to apply the HIV Outcomes recommendations in real-world situations in Italy and Sweden has given vital insights into the best ways of ensuring their wider uptake. The 2018 workstreams confirmed that the HIV Outcomes recommendations are fit for implementation and have demonstrated ways to overcome barriers to their adoption. The HIV Outcomes initiative aims to implement the recommendations in Italy and Sweden. At the same time, the initiative will seek to disseminate the recommendations further afield and tailor them for implementation in additional countries during 2019.

The findings and good practices identified in Italy and Sweden were presented in the European Parliament in November 2018. 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 ITALY – ROAD-TESTING THE RECOMMENDATIONS

Context

Approximately **130,000 people in Italy are living with HIV**. The national Ministry of Health systematically collects data on newly-diagnosed people living with HIV on an annual basis and updates a comprehensive map of the HIV positive population. This includes breakdown by age, gender and area of residence, via its HIV Surveillance System, which has been in place since 2012[2].

In 2016, 3,451 people were diagnosed with HIV (5.7 in every 100,000), marking a decrease in the aggregate number of newly-diagnosed people living with HIV on previous years. At the same time, data show an increase in the average age of both people with HIV generally and of those infected with HIV through sexual intercourse. Of newly-diagnosed people living with HIV, 76.9 percent were men with an average age of 39, while the average age of newly-diagnosed women was 36. Around 25 percent of newly-diagnosed people living with HIV were between 40 and 49 years old, while 38.5 percent were foreign. The Regions with the highest incidence of people living with HIV in 2016 were Lazio, Marche, Tuscany and Lombardy.

The data collected by the national HIV Surveillance System are published at the start of every year and therefore cover the previous year: they are not updated on a continuous basis. At a regional level, data are collected regularly but they are only shared with healthcare professionals and stakeholders; moreover, the 21 Regions/Autonomous Provinces do not share criteria for updating the data, as each Region has a wide degree of autonomy in managing both its own Surveillance System as well as its own healthcare service. As a consequence, some of the Regions update and publish their data more frequently than others.

The latest available data are shared with the scientific community by the ICONA Foundation, a private organisation that provides data on newly-treated people living with HIV, classified according to epidemiological, clinical, biological and behavioural criteria.

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[2] As foreseen by the Ministry of Health Decree of 31 March 2008 "Institution of the Surveillance System on the new HIV & AIDS diagnoses"

The ICONA cohort can be regarded as representative of the epidemiology of HIV across the country. Since 1997, ICONA has involved 16,654 patients (318 of which were in the first six months of 2018). In 2015-2018, 81 percent of the 3,944 people living with HIV in the ICONA cohort were men; among Italian citizens alone, the share of men was 87 percent, dropping to 63 percent among resident foreigners. The way HIV is transmitted has changed significantly over the years, with sexual intercourse now being the principal source of transmission.

As regards age-related comorbidities, dyslipidaemias are the most frequent across all age groups (<50; 51-60; >60), particularly among women (89.4 percent in the 51-60 age group). High blood pressure, diabetes, heart attacks, hepatic impairment and chronic kidney diseases are less common but still widespread among elderly patients.

The Italian HIV Outcomes working group, based on the expertise of its members and on their perception, believes that it is important to stress the rising proportion of foreign citizens among naïve patients. In fact, the data collected by ICONA show that foreigners, mainly from Africa, account for 27.2 percent of new diagnoses over the last three years. Based on the expertise of its members, the working group believes that, in many cases, these people living with HIV have been infected in Italy, probably due to the conditions of social deprivation in which they live.

In Italy, anti-retroviral therapies are offered to patients by the State-run National Healthcare Service, which relies on the principle of free and universal access to care. Clinicians are free to prescribe the therapy they regard as most appropriate for each patient, while in some other countries this freedom is restricted.

Access to therapy for HIV+ patients is managed by the NHS hospitals' Infectiology Centres. It is therefore the infectiologist that takes charge of people living with HIV, including when they develop serious comorbidities, in which case they will consult other specialists. The pivotal role played by the infectiologists as care coordinators and the cooperation with other specialists has resulted in a satisfactory overall retention in care.

However, the improvement of the HIV care model towards this holistic approach, according to which Infectiology Centres are in charge of managing comorbidities and polytherapy, is a relatively recent achievement. This has been developed in a number of Infectiology Centres as a result of the cooperation between clinicians and patients' associations. This approach has developed as a response to the increasing proportion of ageing people as a fraction of the people living with HIV. However, this holistic approach is not evenly spread and those Infectiology Centres that follow it are insufficient to manage all people living with HIV in the country. With the exception of a few centres of excellence, an integrated approach to long-term HIV care is still lacking in the national landscape. Pathways that combine therapy with social assistance are also increasingly needed, as people living with HIV rely on the support of their families to a lesser extent than in the past, due to their greater life expectancy.

The lack of a harmonised approach arises from the fact that each Region/Autonomous Province enjoys a large degree of autonomy in organising its healthcare system. One of the consequences is that people living with HIV often move from their own Region to another, or even from their existing Infectiology Centre to another within the same Region, to have better access to innovative therapies and superior care from better-trained healthcare professionals. In fact, in some Regions stigma and discrimination among healthcare professionals is still a barrier to adequate treatment (dentists are particularly reluctant to provide people living with HIV with adequate care because they are afraid of infection). Patient migration raises challenges that are not always tackled effectively; for example, there is no methodology or infrastructure in place for systematic information exchange among Regions. This means that in many cases, effective information flow is only ensured by informal relations between clinicians and patients. This has a clear negative impact on the quality of HIV care and patients' health.

Personalising the therapeutic approach according to the peculiarities of each people living with HIV (e.g. age, general health conditions) is another priority. The ambition is to achieve a long-term, outcomes-focused care model and prevent the proliferation of numerous comorbidities.

Above all, the ageing of people living with HIV is a key challenge; those diagnosed with HIV now have a life expectancy approaching that of the general population, but nevertheless will need continuous care. This is why the need to provide elderly people living with HIV and geriatric patients with anti-retroviral therapies must be considered when identifying the best approach to HIV care. A key issue raised by patients is coordination between Infectiology Centres and other specialist ambulatories. People living with HIV often contact clinicians upon their own initiative and then revert to the infectiologist to make sure that the therapies prescribed are compatible with their anti-retroviral therapy. A limited number of centres of excellence aside, knowledge and expertise in geriatric care is sorely limited among clinicians and healthcare professionals. Instead, elderly patients and geriatric patients living with HIV are de facto restricted from accessing the therapeutic pathways for non-HIV patients due to the cultural stigma. For example, simply being admitted to nursing homes or receiving domiciled nursing care can prove a challenge for elderly people living with HIV.

From a broader perspective, HIV - like any other chronic condition - can be managed at the regional level through two alternative approaches:

- Centralising care in a dedicated hospital (and Infectiology Centre). In this approach, the hospital defines personalised care plans and offers all relevant services and treatments internally via its own healthcare professionals;

- Decentralising care. In this approach, dedicated primary care structures (s.c. "Case della Salute") that offer both primary and ambulatory specialist care as well as social assistance.

In their increasing tendency towards decentralised care, Regional Healthcare Services have not taken certain important elements into account. For example, many people living with HIV have been treated by the same infectiologist in the same centre for decades; they may not want to see another infectiologist simply because "they are closer to home". Moreover, decentralised care should not underestimate the needs of patients requiring multi-specialist care and therefore should receive their care in specialist Centres, while other people living with HIV may be followed by a general practitioner. The HIV care model should therefore evolve towards one that combines proximity and specialisation of care.

Another recent development is the adoption by Regions of Diagnostic-Therapeutic Pathways dedicated to HIV care. Most of these are focused on pharmacologic therapies with a view to rationalising the use of financial resources allocated to HIV care. It is not by chance that diagnostic-therapeutic pathways are more frequently adopted by those Regions struggling to reduce their healthcare deficits. Generally, the adoption of diagnostic-therapeutic pathways often is to the detriment of a holistic, patient-centred approach to HIV care.

Recently, patient associations have focused their requests on the need to pursue the so called *4th 90 percent target*, i.e. ensuring that 90 percent of people living with HIV enjoy a good health-related quality of life. This issue has been addressed in the AIDS Plan adopted by the Italian Government, but dedicated actions have not yet been adequately planned.

Another important initiative in line with the need for a holistic approach is to set up ambulatory clinics to provide vaccines (particularly those for pneumococcal and varicella-zoster) and for screening of the elderly population within Infectiology Centres. This represents a significant improvement for people living with HIV that has considerably spread in recent years.

In future, one of the most important challenges is to organise a network of specialists to conduct screening programmes on stabilised people living with HIV (with a negative viral load) for early diagnosis of chronic-degenerative diseases, especially those affecting kidney, heart, liver and bones (particularly in the case of women). It would also be advisable to offer neurocognitive tests, as cognitive impairment is one of the most frequent conditions in elderly people living with HIV.

Only a limited number of studies on ageing with HIV have been conducted in Italy to date. The most important, as it has a European relevance, is GEPPO – Geriatric Patients Living with HIV/AIDS. This is a prospective cohort study on people living with HIV over 65 years of age, conducted in ten different infectiology centres aimed at assessing the role of pharmacologic therapies in managing HIV patients with comorbidities[3]. The study has collected and compared data on the state of health of more than 1,200 people living with HIV with those in the general geriatric Italian population.

However, the interaction between the anti-retroviral therapies and other pharmacologic therapies has not yet been adequately studied. This is particularly important given that the metabolism changes with age and the liver is less able to deal with drugs-induced toxicity. Therefore, it is important for infectiologists to choose the most suitable anti-retroviral therapy for each patient, the one that minimises toxicity and interaction with other therapies that the patient takes for the treatment of other conditions, including age-related ones.

The GEPPO cohort consists in part of patients that have survived AIDS when it was still a fatal disease, and in part people that were infected more recently and at a more advanced age. People living with HIV develop other diseases more frequently than the general population, therefore they are more likely to take drugs with the potential to interact with their anti-retroviral therapy. As a consequence, they need a personalised care model. The GEPPO study has collected data on the clinical characteristics of ageing people living with HIV, including on anti-retroviral therapies, comorbidities and patient-reported outcomes. The study has shown, for example, that the most frequent comorbidities among people living with HIV are cardiovascular diseases, kidney diseases and bone diseases.

Another study was conducted by the ‘Lazzaro Spallanzani’ National Institute for Infectious Diseases on a cohort of people living with HIV of more than 50 years of age, to assess their neurocognitive functions. Data have shown that approximately 20 percent of people living with HIV have some kind of neurocognitive deficit and in more than 50 percent of cases, this deficit is asymptomatic, affecting functions such as memory, motor skills and certain operational skills without obviously compromising the everyday life of people living with HIV, their work and their social life.

Another study conducted by the Infectious Diseases Unit in the Medicine Department of the University of Turin, on a cohort of 107 patients of more than 65 years of age. This analysed the correlation between HIV and the risk of developing comorbidities in the cardiovascular, neurocognitive and bone areas respectively. This study has shown a strongly-elevated risk of developing a cardiovascular disease (between 68.5 percent and 88.5 percent of patients

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[3] For further information see https://www.ncbi.nlm.nih.gov/pubmed/28605493

according to the risk score), and a lower risk of developing either neurocognitive impairment and bone diseases[4].

It is not easy to assess to what extent the HIV Outcomes recommendations are being implemented in Italy, given the great variety in how healthcare services between different Regions are organised and occasionally between different healthcare units/hospitals within the same Region. Often, even those Regions that have adopted a dedicated diagnostic-therapeutic pathway for HIV care cannot ensure that the same protocol is being applied in all hospitals of their Regional healthcare service. Therefore, every member of the HIV Outcomes working group for Italy is knowledgeable about the situation in their own healthcare unit and may only have an indirect knowledge of how HIV care is organised elsewhere in Italy.

Despite this, Italy is characterised by a high level of involvement of the HIV community in priority-setting at the national level (Recommendation No. 5). Here, the experience of HIV community activism has set a standard for other EU Member States. Patients associations have been involved in working groups set up in institutional settings from the outset, both at national regional/local levels, and are still an essential interlocutor in any discussion on policy actions for fighting HIV/AIDS. There remains room for improvement, on many occasions the involvement of the HIV community has not led to any shared policy action and relevant decisions have been taken in different settings. From another perspective, there is capacity for patient associations represent the HIV community better, by including certain social and economic categories that are currently underrepresented.

The HIV Outcomes working group for Italy believes that while there have been significant steps in adopting an integrated, outcomes-focused and patient-centred approach to long-term HIV care (Recommendation No. 1), successful examples are unevenly spread throughout the country. This is particularly the case for those people living with HIV who have been treated by the same specialist or by the same medical team for a long time. Their systematic participation in decision making on their care (sub-recommendation No. 5) is simply part of the trusted relationship between doctors and their patients.

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[4] For further information see “La geriatria nell’infezione da HIV”, https://www.researchgate.net/publication/315599459_La_geriatria_nell%27infezione_da_HIV

National engagement as HIV Outcomes

Based on the HIV Outcomes recommendations, the Italian members of the European Steering Group - **Prof. Antonella D'Arminio Monforte**, Full Professor of Infectious Diseases - University of Milan, and **Mario Cascio**, Vice-Chair of the Board of Directors of the European Aids Treatment Group (EATG), have involved selected clinicians and representatives of those patients associations most actively engaged on the topic of ageing with HIV in Italy, thus setting up the HIV Outcomes working group for Italy. The full list of working group members is:

- **Massimo ANDREONI**, Department Medicine of Systems - Infectious Diseases University Tor Vergata in Rome;
- **Valeria CALVINO**, ANLAIDS (Italian Association for Fighting AIDS);
- **Margherita ERRICO**, NPS (Network HIV-Positive People) Italia Onlus;
- **Giuseppe IPPOLITO**, National Institute for Infectious Diseases "Lazzaro Spallanzani" (INMI) in Rome;
- **Massimo GALLI**, University of Milan;
- **Giovanni GUARALDI**, University of Modena and Reggio Emilia;
- **Sandro MATTIOLI**, Plus (HIV-Positive LGBT People) Onlus;
- **Cristina MUSSINI**, University of Modena and Reggio Emilia;
- **Giustino PARRUTI**, Hospital of Pescara;
- **Giuliano RIZZARDINI**, "Luigi Sacco" Hospital in Milan;
- **Domenico SAVARINO**, LILA Onlus (Italian League for Fighting AIDS).

In 2018, the working group conducted a thorough exchange of views (meetings, tele-conferences, email exchanges) on how HIV as a chronic condition and the ageing of people living with HIV have been managed by the National Healthcare Service and by the various Regions. The dialogue within the working group has focused on identifying potential guidelines that could serve as basis for a strategy to improve long-term HIV care while ensuring good quality of life. The observations and comments shared by the group members are summarised in this document.

In addition, the group has discussed a number of case studies that show success in improving both the provision of HIV care and the involvement of the HIV community in priority-setting and decision-making processes at the national level. Three case studies, selected by the working group, were presented by the Italian members of the HIV Outcomes steering group at the HIV Outcomes Workshop: *Developing a best practice compendium on long-term chronic HIV care*, held in Amsterdam on 24 July 2018:

- Council of the Associations for the fight against AIDS (Now Group “M” of the technical Healthcare Committee) and other initiatives for the involvement of the HIV Community;
- Ageing Clinics;
- Dedicated Vaccination Programmes for people living with HIV.

Before the start of the working group activities, the HIV Outcomes initiative was presented to a senior official at the Ministry of Health. They welcomed it and encouraged the working group to ask to be heard by the relevant technical body within the Ministry on the fight against AIDS, once their activities are concluded. The engagement with the relevant national institutions will continue on a larger scale in the coming months.

Findings

Currently, there are a number of hurdles and flaws in managing HIV as a chronic condition that prevent the approach to long-term care of people living with HIV in Italy from evolving according to the principles outlined in the HIV Outcomes recommendations. These factors are in part related to the organisation of healthcare and social assistance and in part due to the (lack of) availability of financial resources.

To overcome these flaws, it is paramount to:

- Increase the public resources allocated to research, with a view to rebalancing the current situation, where scientific studies are almost entirely funded by private entities;
- Train more infectiologists, as the number of new medical doctors that choose to specialise in this area is gradually dropping;
- Improve the legislative framework, by completing the reform of the national law dedicated to the prevention and fight against AIDS (Law n. 135/1990[5]). The legislation that came into force in the early nineties was primarily designed to tackle AIDS as a fatal

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[5] Law No. 135 of 5 June 1990 establishing a programme of urgent interventions for the prevention and control of AIDS.

disease; as a consequence, a reform is now necessary. HIV has evolved into a chronic condition and the legislative framework setting the general principles concerning HIV care should be updated accordingly;

- Improve the organisation of HIV care by creating personalised care pathways adapted to the characteristics and needs of each person living with HIV. To achieve this, therapies should be differentiated according to a set of clearly-defined criteria that can distinguish between patients requiring low intensity of care (who may be followed by a general practitioner) and those with polymorbidity and disabilities. More generally, the notion of HIV care should be expanded to include social assistance as well as healthcare; in fact, the fragility of people living with HIV includes their loneliness and the difficulties they encounter in their social life. Therefore, there should be a holistic approach to HIV care, which could provide a model for managing other chronic diseases;

- Implement the measures laid down by the 2017-2019 National HIV/AIDS Plan[6], which was adopted by the Ministry of Health in 2017 but is still largely not realised. That plan was drafted in cooperation with the relevant scientific societies, the HIV community, academia and other stakeholders. The plan underlines the importance of improving quality of life of people living with HIV and combatting stigma. The latter is an issue among the general population for cultural reasons, as well as among healthcare professionals (including clinicians, nurses, etc.) that have reservations in treating people living with HIV due to their lack of knowledge and training. The actions to implement to combat stigma and discrimination include: spreading the concept that *undetectable=untransmittable* (i.e. people with a negative viral load cannot transmit the virus) and combatting self-stigma among people living with HIV, who may marginalise themselves because they do not want to disclose their HIV+ status.

The HIV Outcomes working group for Italy believes that the top priority for policy actions at the national level is to promote an integrated approach to HIV care that tackles the needs generated by the ageing of people living with HIV. These actions should identify long-term HIV care models that are targeted according to the age and health status of sub-groups of patients. This requires building a consensus on HIV chronic care among experts in health

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[6] The National AIDS Plan 2017-2019 was drafted by the Ministry of Health and approved by the State-Regions Conference in October 2017. The document is aimed at ensuring access to care and retention in treatment for all people living with HIV, especially for disadvantaged populations.

economics and infectious diseases as well as other specialists, patients, healthcare unit managers, healthcare professionals, etc.

At the same time, the Italian healthcare system offers several examples of good practice beyond the three success stories described in this document. Italy is characterised by excellent quality of training of NHS specialists, although this is not evenly spread across the country and across infectiology centres. Also, Italy already has effective screening programmes in place, not only for the detection of HIV but also for the direction of HIV-related and age-related diseases.

Conclusions and next steps

The HIV Outcomes working group for Italy believes that policy actions should also be taken at the EU level, including allocating financial resources for research into ageing with HIV. Also, the EU could take the lead in encouraging Member States to implement screening programmes to detect undiagnosed people living with HIV, thus helping to prevent further infection. NHS units should be included among the bodies eligible for funding, so as to allow Infectiology Centres to benefit.

At all levels of government, it is paramount to include HIV among the priorities of the healthcare policy agenda, both because HIV still poses a significant burden and because HIV care management has traditionally set a benchmark for other therapeutic areas. Improving the HIV care model by building multi-disciplinary networks of specialist centres would therefore greatly benefit other areas, including oncology and rheumatology.

HIV OUTCOMES ITALY – CASE STUDIES

CASE STUDY 1

AGEING CLINICS

Context

The most recent therapeutic solutions, particularly the introduction of anti-retroviral therapies (ART), have transformed HIV/AIDS from a fatal viral disease to a manageable chronic condition. Life expectancy in people living with HIV now has the potential to match that of the general population. Moreover, diagnosis of HIV infection in adults has increased over the years.

However, HIV can accelerate the ageing process, due to HIV-related chronic inflammations and the cumulative effects of pharmacological treatments.

Healthcare professionals involved in HIV care should adopt an approach that takes account of the associated frailty and disability as well as the increased risk of developing comorbidities. This approach should focus on the quality of life of Older Adults Living with HIV (OALWH); patients over the age of 50 with non-infectious comorbidity.

Introduction

In Italy, as in other European countries, Ageing Clinics have been established in a number of healthcare facilities to target the specific needs of OALWH. These clinics provide a multi-disciplinary health service with a mission of addressing comorbidities and complications associated with HIV/AIDS and/or antireviral therapy (ART) use in OALWH.

Aims

From an HIV/AIDS perspective, the aim of Ageing Clinics is to ensure that OALWH receive integrated and holistic treatment. A multidisciplinary staff of infectious disease specialists, cardiologists, diabetologists, nephrologists, orthopaedists, oncologists, neuropsychologists, nutritionists and occupational therapists evaluate patients' anthropometric, immune-metabolic and physical functions as well as any cognitive impairment.

Method

Access to Ageing Clinics is free for all people living with HIV; patients do not need a NHS prescription from their general practitioner. This service is organised by infectious disease units, with each patient managed by a multi-disciplinary team of clinicians focusing on the health status of OALWH.

In addition to the routine blood test, OALWH attending Ageing Clinics undergo a number of additional tests (e.g. DXA, abdominal and thoracic CT, IMT). This information is then used by the infectious disease specialists to help personalise lifestyle interventions, optimise treatment for non-infectious comorbidities, manage polypharmacy and, perhaps most importantly, optimise anti-retroviral treatment.

Results

Experience with OALWH has shown that access to Ageing Clinics improves quality of life and makes an important contribution in mitigating the harm and side effects of both HIV and/or ageing.

In particular:

- Screening programmes have allowed serious diseases (particularly cancers) in people living with HIV to be detected earlier
- Where a patient is the subject of multiple treatment regimes for different diseases, comprehensive information on the patient’s current state of health allows healthcare professionals to evaluate potential changes to medicines to avoid the risk of any drug/drug interaction and manage potential inappropriate prescriptions
- Ageing Clinics have improved the relationship between patients and their healthcare professionals, particularly where OALWH had not previously visited infectious disease units on a regular basis.

Recommendations

Ageing Clinics are not uniformly spread across the country. An important short term goal should be to replicate this practice by establishing new metabolic care networks in those infectious diseases units that do not currently offer them. The work of Ageing Clinics should be undertaken in close coordination with the clinics where patients receive their ART.

CASE STUDY 2

COUNCIL OF THE ASSOCIATIONS FOR THE FIGHT AGAINST AIDS AND OTHER INITIATIVES TO INVOLVE THE HIV COMMUNITY

Context

Italy is at the forefront of involving the HIV Community in policymaking on managing this therapeutic area. In 1990, legislation was created which was dedicated to preventing and battling AIDS. This has seen a National Committee for the fight against AIDS established within the national Ministry of Health that includes members of HIV Associations. This has allowed national and regional decision-makers to adopt a multi-stakeholder approach to their policy choices, drawing on the knowledge and expertise within the Associations.

Introduction

The Ministry of Health established a consultative body, the Council of the Associations for the fight against AIDS. This initiative was the first and most important in allowing HIV Associations to participate directly in policymaking concerning the management of this disease. Since then, direct involvement of the HIV community in policymaking has become widespread practice in Italy.

Aims

The Council's mission is to collect and share "contributions and opinions concerning the design, implementation and assessment of information/prevention programmes in the fight against HIV."

The expertise of the associations represented on the Council make a vital contribution to the institutions. This places the institutions in a stronger position to identify unmet health needs and social issues encountered by people living with HIV and to formulate adequate responses.

Method

The Council, which consists of representatives from the main associations focused (exclusively or partially) on HIV-related topics, meets at least three times per year. It works in closely with the national Committee for the fight against AIDS, a multi-disciplinary body of clinicians and scientists.

The Council and the Committee coordinate via a continuous flow of information and working documents; in addition a number of members, such as Ministry of Health representatives, belong to both bodies.

Following an internal reorganisation of the Ministry of Health, the Council and the Committee are both now sections of the Technical Healthcare Committee, namely section 'M' (the former Council of the Associations for the fight against HIV) and section 'L' (the former National Committee for the fight against AIDS).

Results

Section M is active in all major HIV initiatives, notably in drafting important dedicated plans, such as the National HIV/AIDS Plan, which is approved jointly by Sections M and L and then submitted to the Ministry. In addition, Section M is working on the revision to Law n.135/1990, providing further evidence of the role played by the HIV community in all major decision-making processes that impact the management of people living with HIV. Within this process, the associations are providing contributions on aspects including the training of healthcare professionals (dentists, dermatologists, etc.) and the fight against stigma both inside the NHS and in the broader society.

The HIV Council is allowing the HIV community to take a proactive role within the Institutions. Recent initiatives involving the HIV community include:

- 1st Geriatric HIV Medicine Summit (Rome, February 2018). This initiative was promoted by Policlinico Gemelli of Rome and involved a number of clinicians and academics as members of the Scientific Committee and keynote speakers, particularly infectious disease specialists and geriatricians. They exchanged views on topics relating to the ageing of people living with HIV receiving ART and on those fragilities specifically related to ageing. One of the goals of this workshop was to improve the training of infectious disease specialists and geriatricians with a view to encourage creating multi-disciplinary teams for managing ageing HIV+ patients.

- Let's Stop HIV! Più qualità alla durata della vita (Greater quality for a longer life). This conference encourages the exchange of views between charities, patient associations and clinicians from different specialties on various aspects of the daily life of people living with HIV.

- Involvement of Associations in the Retention in Care of people living with HIV in Italy. This research project is part of the activities of Section M of the Technical Healthcare Committee. It is publicly funded, with the National Institute for Infectious Diseases 'Lazzaro Spallanzani IRCCS' playing the role of lead institution. The goal was to contribute to implementing and harmonising the activities of HIV Associations in improving the retention in care of vulnerable people living with HIV. The project conducted a national survey to assess all activities currently in place from HIV associations aimed at improving patients' retention in care. The survey also measured both patient acceptability of the different initiatives in place and the attitude of healthcare professionals on the active role played by HIV associations. The findings provided the basis of a better understanding of patients' needs, ultimately helping achieve an optimal retention in care.

Recommendations

Cooperation between institutions, clinicians and associations in policymaking for the management of HIV is an example of best practice. It should be retained and promoted further in future, potentially by allowing other associations representing people living with HIV to add their contribution.

This approach to cooperation between a proactive HIV community and policymakers has the potential to be replicated across Europe, particularly in those countries where such cooperation it is currently less well developed, as is the case in some Eastern European countries.

CASE STUDY 3

DEDICATED VACCINATION PROGRAMMES FOR PEOPLE LIVING WITH HIV

Context

Due to their compromised immune system, people living with HIV face a higher risk of developing infections. In addition, this means that certain infections pose a greater risk to people living with HIV than they would to the general population. This makes vaccination a fundamental tool for preventing a number of communicable diseases. However, because of their immunodeficiency, some vaccines risk infections in people living with HIV. For this reason, vaccinations to be administered to people living with HIV need to be selected carefully. For example, the Herpes Zoster vaccine should not administer to seriously immunocompromised people - including people with HIV - because it increases their risk of developing the infection.

It is vital that vaccinations for people living with HIV should comply with the treatment guidelines for people with HIV already adopted both at the European and at the national level.

Introduction

In Italy, vaccination programmes targeted at people living with HIV are regulated by two plans:

1. National Vaccine Prevention Plan (Piano Nazionale di Prevenzione Vaccinale - PNPV)

2. National HIV/AIDS Plan (Piano Nazionale di Interventi contro HIV e AIDS – PNAIDS)

Both plans were drafted by the Ministry of Health and agreed upon in the State-Regions Conference. This means that they are shared by the two levels of Government responsible for managing the NHS. Both plans have a section dedicated to vaccinations for people living with HIV.

Aims

The goal of the National Vaccine Prevention Plan is to harmonise vaccination programmes across the country. This should ensure that everyone has access to the benefits of vaccination, thus improving individual and collective health. In addition, the plan aims to provide target sub-populations - including people living with HIV - and actively offer them vaccines.

Those vaccines listed in the plan are classified as the basic levels of assistance and thus are offered free to those belonging to the relevant target sub-populations.

In the HIV/AIDS plan, vaccines are viewed as a method of preventing infections in people living with HIV. It includes specific actions designed to address the needs of people with HIV relating to immunodeficiency. The plan sets the following objectives:

- Implement the National Vaccine Prevention Plan and the guidelines adopted by the scientific community (in particular by the Italian Society of Infectious and Tropical Diseases – SIMIT)
- Conduct a survey in a number of infectious disease units to determine the genuine vaccination rate in people living with HIV and any flaws or shortcomings in the provision of vaccines
- Promote personalised vaccination programmes targeted at people living with HIV
- Harmonise vaccines on offer of across the country.

Method

Both plans have set the goal of increasing immunisation coverage for people living with HIV. However, achieving this goal has been frequently hampered by the limited funding available.

A more sustainable way of promoting immunisation is to put in place dedicated programmes for providing specific sub-populations of people living with HIV (e.g. ageing people) with access to vaccines.

A number of infectious disease units across the country have already implemented dedicated vaccination programmes targeting the needs of specific categories of people living with HIV. More specifically, the units offer the following vaccines:

- Meningococcal
- Pneumococcal
- Herpes Zoster
- Hepatitis A and B
- Human Papillomavirus Infection (HPV).

A number of the units have a dedicated vaccination schedule in place.

In addition, in units where patient registries have been digitalised, selected vaccines are actively offered to specific sub-groups of people at risk.

Where digitalised and integrated systems are available, the personalised vaccination programmes also include serologic follow-up after vaccine administration as well as automatic alerts (e.g. for recalls) to minimise the risks potentially harming the retention in care.

Results

Data on the outcomes of vaccination programmes in people living with HIV is not yet available, as both plans are still in the course of being implemented. However, the HIV/AIDS Plan has established performance indicators, giving a clear sign that policymakers aim to assess the outcome and performance of the people living with HIV vaccination programmes with a view to updating the Plan.

Yet even before any outcome assessment, it is clear that adopting dedicated vaccination programmes for people living with HIV in infectious disease units has been a major success. It marks a major advance, from planning vaccination strategies at the national level to actually implementing them locally. Although the vaccines offered to people living with HIV vary considerably between regions and even within individual regions, vaccines are now successfully actively offered to people living with HIV in a number of units across the country.

Recommendations

- Set HIV vaccination programmes for all infectious disease units across the country
- Digitalise all vaccination registries
- Wherever dedicated vaccine programmes are in place, systematically collect data on number and types of vaccines offered to people living with HIV to help estimate the number of infections avoided
- Create a dedicated registry for adverse events following vaccinations in people living with HIV.

HIV OUTCOMES SWEDEN – ROAD-TESTING THE RECOMMENDATIONS

Context

HIV Outcomes - a European initiative - was established in 2016 to shed light on the important health and psychosocial concerns of people living with HIV.

Led by eminent European experts within the field, the initiative operates under the banner "Beyond Viral Suppression". This aptly describes the challenges that remain in the treatment and care of people living with HIV post viral suppression.

The initiative came into being to address the general lack of up-to-date knowledge on HIV, in society as a whole but also specifically, among decision makers and healthcare professionals. Medical advances within antiretroviral therapy ensure that nowadays people diagnosed with HIV can have a normal life expectancy without fear of infecting others. This changes their needs - society now needs to ensure that as the virally-suppressed age, they can sustain their health and enjoy a good quality of life. The landscape for, and challenges facing, people living with HIV have changed; this requires new measures and policy.

Research suggests that over 80 percent of people currently living with HIV are likely to have at least one comorbidity by 2030. In comparison to those that do not have HIV, they are more likely to be affected by kidney disease, heart disease, cancer, diabetes, osteoporosis and/or depression. For example, a person living with HIV is one-and-a-half to two times more likely to suffer heart disease and four times more likely to suffer from lung cancer. As a result, in coming years broader parts of the healthcare system will increasingly come into contact with people living with HIV - situations where HIV is no longer the primary basis for treatment. This will place completely new demands on the functions and professionals in the healthcare system.

HIV Outcomes recommendations

HIV Outcomes has developed five policy recommendations for improving long-term health and quality of life for people living with HIV. These recommendations, developed with leading clinicians and patient organisations, were launched at a well-attended seminar at the European Parliament in November 2017.

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.

During 2018, HIV Outcomes has sought to clearly understand the HIV care landscape in the EU and the progress that Member States have made on implementing the recommendations. Sweden and Italy were chosen to pilot a more in-depth evaluation of the recommendations and how well they apply in a national context.

The status of HIV in Sweden

In many respects, care for people living with HIV in Sweden already functions well. Sweden was the first country in the world to meet the UNAIDS/WHO global '90-90-90' target for 2020. This target requires a minimum of 90 percent of people living with HIV to know of their HIV status, of which 90 percent should be receiving antiretroviral therapy, of which 90 percent should achieve viral suppression.

Currently, there are approximately 7,700 people living with HIV in Sweden. The Swedish quality registry InfCareHIV estimates that 95 percent of those are virally suppressed. The number of new cases per year remains at a consistent - and low - level, approximately 450 per year, 75 percent of which are among migrants. In 2017, as in previous years, the greatest number of HIV cases were reported from Sweden's metropolitan areas, with men outnumbering women by 273 to 161 respectively.

While many aspects of the healthcare system function well and the spread of HIV remains under control, a number of challenges remain. In particular, that of stigmatisation of people living with HIV. In 2016, a study by the Public Health Agency of Sweden showed that 25 percent of respondents had experienced negative attitudes in the previous six months. In addition, many of them worry about growing older, with 38 percent of respondents expressing concerns about not receiving adequate care and treatment as they age. 45 percent of people in Sweden currently living with HIV are over 50, and these people are generally considered to be among the first generation to age with HIV.

That stigmatisation remains a challenge is further supported by the government's national strategy against HIV/AIDS and other infectious diseases, published in November 2017. Sub-goal 3 of the strategy states: "Stigma and discrimination related to HIV is to be minimised, enabling people living with HIV to share their HIV status without fearing discrimination." Explaining the goal further, the government states: "Knowledge of, and an understanding for, the implications of living with a chronic infection, and its suppression when treated, needs to reach more people - particularly professionals within healthcare, geriatric care, home care and education."

Today, there is a lack of national research both on the evolving needs of people living with HIV as they age and also the implications, responsibilities and challenges for our healthcare system and society.

National engagement as HIV Outcomes

In spring 2018, HIV Outcomes Sweden was established to assess the recommendations from a national perspective. It formed a working group with representation from healthcare professionals, patient organisations and academia.

On 8 June, the group came together for a one-day workshop. Reflections from this workshop were further developed in smaller working groups throughout the summer and were presented at the 22nd International AIDS Conference in Amsterdam on 24 July and then a seminar during the 5th HIV and Hepatitis Nordic Conference in Stockholm on 27 September.

- **Pernilla Albinsson**, Nurse at the Infectious Disease Clinic, Karolinska University Hospital. Pernilla is a member of the InfCareHIV National Quality Registry Steering Group and engaged in quality of life studies.
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- **Bo Hejdeman**, Senior Physician at Venhälsan, a part of the Infectious Disease Clinic at Stockholm South General Hospital. Bo is affiliated to the Institution for Clinical Research and Education at the Karolinska Institutet and is a member of the Board at the Centre for HIV Research in the Karolinska Institutet.
- **Peter Månehall**, Public Advocate at the patient organisation HIV-Sweden.
- **Åsa Mellgren**, Senior Physician at the Infectious Disease Clinic, South Älvsborg Hospital. Åsa is a member of the InfCareHIV National Quality Registry Steering Group.
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Findings

HIV Outcomes Sweden has analysed the five European recommendations from a Swedish perspective. Although the recommendations are - to a varying degree - largely already in practice today in Sweden, they do highlight areas where more work is required. Following are comments on how the European recommendations align with the Swedish context. The perspectives presented below are not definitive, but rather initial reflections based on discussions within the HIV Outcomes Sweden Working Group. HIV Outcomes Sweden plans to analyse these recommendations and their local implications more extensively during 2019.

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

Data from the quality registry InfCare HIV suggests that people living with HIV in Sweden are generally satisfied with their care. However, as people living with HIV age and face an increasing risk of comorbidities, HIV Outcomes Sweden feels that cross-functional cooperation - such as between primary care and geriatric care - needs to be strengthened.

In Sweden, primary care serves as the entry point for all care. In the longer term, primary care should also preferably provide this function for people living with HIV. At present, primary care in Sweden faces several challenges of organisation, resourcing and staffing; these could negatively impact the continuity of care for patients. Similarly, other areas of the healthcare system - such as psychiatry - also see challenges with continuity. As a consequence, many people living with HIV feel greater security staying with their infectious disease clinics, also opting to seek care for their non-HIV related needs there. Therefore, it becomes second nature for people living with HIV to view their infectious disease clinics as their primary point for care.

In the interest of improving the quality of care provided, HIV Outcomes Sweden believes it is important that Sweden focuses on new, more wide-reaching ways of working within HIV care. Some such initiatives have already been taken - the infectious disease clinic at Stockholm South General Hospital has reinforced their staff with a psychiatrist, general practitioner, venereologist and a conversational therapist (See Best Practices, Case 2). At the

Karolinska University Hospital, there are patient-centred discussions with relevant specialists and contact has been initiated with health centres expressing greater interest in developing HIV expertise.

Sweden has made considerable advances in working with a patient-centred approach. For example, all larger infectious disease clinics maintain a patient-specific clinician and nurse, improving continuity of care.

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

Sweden already has well-established quality registries and has made significant progress in following up and monitoring people living with HIV. The quality registry InfCareHIV maintains the highest quality standards and has one of the best-developed registries. There is scope to improve monitoring of comorbidities, medicine consumption and other aspects by connecting the various quality registries with each other. Swedish HIV researchers are already involved in a number of such projects.

Data from InfCareHIV also plays an important part of the Public Health Agency's national reporting to, among others, the European Centre for Disease Control (ECDC). There are ongoing discussions as to how to use InfCareHIV's data more effectively, further improving the quality of national reporting.

InfCareHIV recently decided to work towards fulfilling a fourth '90' target, focusing on improved quality of life for P HIV. To meet this target, relevant data is essential. The first step therefore is ensuring that 90 percent of those virally supressed regularly complete the quality registry's health survey, which assesses areas such as physical and mental health, sexuality and the side-effects of treatment. Several Swedish infectious disease clinics are making good progress towards this.

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

The Swedish HIV-cohort has been monitored by InfCareHIV since 2004. The initiative to form InfCareHIV was taken by healthcare professionals, with their involvement a key factor in its success. The registry is part-financed by the Swedish Association of Local Authorities and Regions and part by infectious disease clinics around the country.

There is significant interest in conducting cohort studies in Sweden; the promise this offers is substantial - vast amounts of high-quality data are available through InfCareHIV and the other national quality registries. However, interest exceeds available funding. The new financing and governance system for quality registries in Sweden is putting the possibilities for healthcare professionals and patient organisations to steer future development of InfCareHIV at risk.

Simultaneously, national financing of efforts to combat HIV and other infectious diseases has been reduced in Sweden over the past years. This makes it unclear how the InfCareHIV-cohort will be financed in the future.

Recommendation 4: Combat stigma and discrimination within health systems.

All too often, people living with HIV in Sweden experience discrimination, for example from dentists, or fail to receive the home care they are entitled to. The consequences of this extend beyond the individual and their personal negative experiences - the challenges escalate, leading to hesitation among those who suspect they have contracted HIV in testing themselves and seeking treatment.

The Swedish healthcare system needs significantly increased knowledge and understanding of the needs of people living with HIV, not least among professionals in primary care, dentistry and county-provided geriatric and home care. This need to improve knowledge and understanding also extends to students in medical and healthcare education.

Currently, there is no unified effort to reduce stigmatisation for people living with HIV. In the past, there were a few larger-scale efforts to improve knowledge in healthcare professionals, however, these have unfortunately failed to deliver the hoped-for results. HIV Outcomes Sweden believes that a powerful, long-term, national initiative will be of great importance in more effectively minimising the stigmatisation experienced by people living with HIV.

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

At the national level, involvement of people living with HIV in setting priorities works relatively well. For example, a representative of the patient organisation HIV-Sweden is a member of the InfCareHIV Steering Group. The national strategy for HIV/AIDS also emphasises that people living with HIV need to be more involved in the healthcare system and that patient organisations should be asked to participate in advisory groups or bodies. At the regional level, however, involvement of people living with HIV is wanting. Organisations such as HIV-Sweden are reaching out to and assisting regional patient organisations to help them become more involved in shaping, planning and organising local healthcare.

HIV Outcomes Sweden also identified three good practices that aim to inspire other countries to improve the treatment and care of people living with HIV. These case studies were presented at the HIV Outcomes Workshop: *Developing a best practice compendium on* *long-term chronic HIV care*, held at the 22nd International AIDS Conference in Amsterdam on 24 July 2018:

- **Cross-functional care**: clinic integrating psychiatrist, venerologist, general practitioner and conversational therapist;
- **Older people living with HIV**: enhance understanding of reality of growing older with HIV;
- **InfCare**: support for complex nature of/multi-disciplinary approach needed to care for people living with HIV.

Conclusions and next steps

Although Sweden has already made significant progress with the HIV Outcomes recommendations, it is evident that – in particular – efforts to minimise stigmatisation and discrimination of people living with HIV still need to be intensified.

HIV Outcomes Sweden sees a clear need for updated knowledge among healthcare professionals to help them improve how they serve both younger and older members of society living with HIV. The fact that effective treatment means that people that are HIV-positive are non-infectious is not known widely enough. For some people living with HIV, this makes it difficult to age with dignity. There needs to be greater efforts to minimise stigmatisation on both a national and global level; HIV Outcomes Sweden is eager to continue to highlight this issue through the initiative at a European level.

In order to minimise stigmatisation and discrimination within the Swedish healthcare system, HIV Outcomes Sweden suggests that a suitable authority – for example, the Swedish Association of Local Authorities and Regions (*Sveriges Kommuner och Landsting*) – investigates potential channels for efficiently spreading knowledge within the healthcare system. Alternatively, it suggests assessing whether offering certification or a diploma for healthcare professionals on working with people living with HIV would be an effective alternative. Such certification could then be aligned to the economic subsidies given to health and care providers.

To sustain long-term, high quality care for people living with HIV, HIV Outcomes Sweden recommend greater cross-functionality, forming efficient interaction between specialists, general practitioners, psychiatrists and other relevant medical and social competences. People living with HIV should be able rely on cross-functional teams as focal points for their care. This would provide the wider healthcare system with a clear resource that it can turn to for guidance and knowledge in treating and caring for people living with HIV.

Finally, time and resources should be allocated to formulating a fourth ‘90’ target that focuses on measuring and attaining quality of life for people living with HIV.

HIV OUTCOMES SWEDEN – CASE STUDIES

CASE STUDY 1
CROSS FUNCTIONAL CARE

Context

Venhälsan, the infectious disease clinic at Stockholm South General Hospital, is Sweden's second-largest HIV clinic. To improve its care quality and make its patient work more efficient, Venhälsan now has a psychiatrist, a venerologist, a general practitioner and a conversational therapist integrated as part of the clinic's expertise.

Introduction

Currently, Venhäslan has close to 1500 patients with HIV, making it Sweden's second largest clinic by patient numbers. It was established as a sexually transmitted infection clinic specifically for men who have sex with men (MSM) in 1982, shortly before the identification of HIV and AIDS in the country. Today, Venhäslen welcomes all categories of people living with HIV. Advances in antiretroviral therapy (ART) have changed the core needs of HIV patients, creating an updated perspective of HIV as a chronic condition where long-term health and well-being need to be prioritised. People living with HIV require access to a range of health services reaching beyond their HIV treatment. In Sweden, it has been challenging to have administrators stop viewing specialisations in isolation and to understand that care for people living with HIV needs to be provided across specialisations. Venhälsan, an early adopter of this updated perspective has, for the past decade, allocated resources from its own budget to provide this cross-functional care.

Aims

By adopting this updated perspective of people living with HIV, Vehälsan aims to:

- Manage its large patient group efficiently
- Improve care quality for people living with HIV, in line with their needs and reflecting advances in ART
- Use its leading role as one of Sweden's largest HIV clinics to champion a cross-functional, patient-centric approach

Method

Operationally, the approach at Venhälsan has been realised by employing a part-time psychiatrist, a venerologist and a part-time general practitioner with specific knowledge in STIs, along with three full-time and two part-time conversational therapists to complement its existing complement of 11 clinicians and nursing staff. The general practitioner is a relatively new addition to the clinic, while a psychiatrist has been integrated for the past ten years. While they all are specialists in their area, they also maintain a specific interest in patients with communicable diseases.

Results

This approach has improved care quality for patients, providing significant support. The Venhälsan clinicians are able to quickly share notes on patients with the integrated specialists and have their input factored into the patient’s care. This increases efficiency and greatly reduces the need for referrals. Mental health concerns among patients are becoming more evident and psychiatric care can be delivered quickly where necessary. Often, patients simply need to talk and they can meet with conversational therapists. These conversations can also reveal potential mental health concerns, which the psychiatrist or general practitioner can then address.

This cross-specialisation approach has helped create knowledge bases – for example, on how to combine HIV-treatment and anti-depressants for the best outcomes while minimising comorbidities. Broadly, the approach has sharply reduced clinicians’ workload, allowing them to focus on viral suppression while other chronic aspects are served by the integrated specialists.

Recommendations

The approach and results at Venhälsan provide a working model and case study for other infectious disease clinics in Sweden and Europe. The knowledge bases it has created can feed into studies on the long-term health of people living with HIV and increase awareness among policymakers and administrations on the benefits of working across specialities. However, the approach requires a critical mass of patients to be feasible; providing more personalised, cross-functional care sustainably at smaller clinics will require further investigation.

CASE STUDY 2

OLDER PEOPLE LIVING WITH HIV

Context

HIV-Sweden is a leading patient organisation working actively with questions on the wellbeing of people living with HIV. It recently launched a national project to enhance understanding of the reality of growing older with HIV and improve the quality of life of those people over 50 living with HIV.

Introduction

Currently, around half of people living with HIV in Sweden are over 50. In addition, this group accounts for an increasing number of those newly diagnosed compared with a decade ago. Often in this group, symptoms are misinterpreted, leading to delayed diagnosis, while Sweden's focus on 'risk-group thinking' excludes the elderly. This means that the realities of ageing with HIV remain poorly understood both within the healthcare system and in society at large. There is a dearth of research on the challenges facing older people living with HIV coupled with a lack of knowledge and concern among healthcare professionals. The effects of ageing on managing chronic HIV infection and the effects of chronic HIV infection on managing the ageing process need to be better understood. HIV-Sweden is running a national project to address this gap.

Aims

The project aims to:

- Directly engage with the target demographic (people living with HIV aged 50 and older) to gain first-hand understanding of the challenges they face, their concerns and their needs
- Increase awareness of the concerns identified and the needs within healthcare, elderly care and administration by engagement and discussions at multi-stakeholder forums
- Develop guidelines for professionals working in healthcare and elderly care to improve care quality and reduce stigma.

Method

The project is taking place in Stockholm, Gothenburg, Malmö and Borlänge. Four local working groups, consisting of six to eight people living with HIV aged 50 or older, as well as those close to them. The project team meets with them systematically to discuss their experiences and highlight the issues that are important to them. Their knowledge, experiences, thoughts and needs are deeply personalised and relevant, unlike broader fact-based or quantitative studies. A book based on the findings from these local working groups will be published in both print and digital formats. Nationally, the project findings will be presented in various contexts and raised as a topic for political change at various meeting and forums. The project is taking place over a three-year period and is expected to finish by the end of 2019.

Results

By using real world dialogue and national activities, this project is bringing visibility for the complex challenges of ageing with HIV. The working groups have raised a number of concerns that they feel should be addressed. There is a general concern over how these will be received by both healthcare professionals and society at large, given a worrying trend of increasing stigmatisation. Professionals working in elderly care – including assisted living, adult day care, long-term care, nursing homes, hospice and home care – lack any knowledge of HIV and the needs of people living with HIV, which further accentuates the problem. In addition, the elderly care sector has a large number of private operators that lack, or are unwilling to commit, the resources to educate their professionals. There is also stigma within the sector, with certain care operators refusing to take on the care of people living with HIV. The concerns identified are not region/county specific, but apply to Sweden as a whole.

In tandem with identifying these concerns, there has also been an emphasis on those practical measures that people living with HIV adopt to help themselves live lives that are mentally and physically healthy. The findings of the project will be presented in a book, which will be published in both print and digital formats. The book, primarily targeted to care professionals, should be seen as an educational guide on approaching and caring for people living with HIV. The digital format will be regularly updated to ensure it remains relevant. By including stories and experiences from the working groups, the book will help to establish a sense of belonging and community among people living with HIV, letting them know that they are not alone in the realities that they encounter.

Recommendations

Healthcare and elderly care needs to be designed around the differing demands of the elderly and must adjust to the needs of ageing populations with chronic diseases. Elderly care must safeguard and respect the individual's right to privacy and bodily integrity, selfdetermination and empowerment and needs to be personalised to offer a life of dignity and a sense of well-being. The skills and knowledge of professionals urgently need to be updated to provide equal, respectful and non-discriminating treatment.

CASE STUDY 3

INFCAREHIV

Context

InfCareHIV is the national quality registry that is actively monitoring HIV in Sweden. Caring for people living with HIV is complex and requires a multi-disciplinary approach. InfCareHIV addresses this, offering a decision-support tool, quality assurance, educational resources, opportunities for consultation and a research database.

Introduction

InfCareHIV has been used at the Karolinska University Hospital since 2003 and at all 29 Swedish HIV-clinics since 2008. Its steering group is diverse, made up of leading clinicians, nurses, academics and administrators as well as observer members from patient groups. In 2016, Sweden became the first country in the world to reach the UNAIDS/WHO 90-90-90 target. InfCareHIV played an important role here by ensuring people were linked to and retained in care. Initially, InfCareHIV found major discrepancies in care quality and outcomes across clinics in Sweden. By presenting national comparisons annually, those clinics delivering sub-par results were pressed to improve their performance. Over time, the major discrepancies across Sweden were levelled out, delivering more evenly-balanced, higher-quality care for people living with HIV – vital for meeting the 90-90-90 target.

Aims

The overarching goal of the quality registry is to improve and make care for people living with HIV more consistent across Sweden by identifying those individuals and groups within the patient population that are experiencing poorer treatment outcomes and reallocating existing resources to improve this situation.

Method

InfCareHIV's platform has four main components: decision support, quality assurance, consultation and research. At the core of all of these lies individual patient data, entered on a daily basis by healthcare professionals. Much of the laboratory analysis is transferred electronically directly to the platform. Patients can also complete an annual electronic questionnaire on their quality of life via a computer or handheld device. By bundling these inputs, the quality of data increases; several external analysis (e.g. by IBM Haifa) have confirmed that InfCareHIV has an exceptionally high quality of input data. Clinics and patients can, at any given time, monitor development and progress towards agreed goals.

Should clinics require advice or a second opinion on a particular patient case, they can use the InfCareHIV platform to have a quick and efficient consultation from leading clinicians. A comparison of all Swedish clinics is presented annually and is evaluated both nationally and internationally.

Results

The data suggests that >99% of patients are linked to and retained in care, 98% receive antiretroviral therapy (ART) and 96% have undetectable plasma viremia following >6 months of treatment. The InfCareHIV system provides an efficient way of educating patients, of whom a substantial number provide information on their quality of life through the electronic questionnaire. This survey, which has been conducted for the last six years, sees patients offering insights on aspects such as their physical, mental and sexual health as well as providing their perceptions on the quality of care received. Results suggest that quality of life is improving for people living with HIV and that engagement is increasing – today, 35% of all people living with HIV now respond to the survey.

The survey allows health care professionals to improve follow up on those patients that are experiencing a poorer quality of life using a more personalised approach. However, a clinical issue is that long-term comorbidities are not fully captured in InfCareHIV. As people living with HIV continue to age, it raises further questions and concerns. InfCareHIV is working to establish direct, automatic transfer of biomarkers from hospital eHealth systems to the platform's decision support tool. InfCareHIV's comorbidity module can also connect to, for example, the Swedish Board of Health and Welfare comorbidity register and the national prescribed drug register. In addition, the InfCareHIV database is frequently used for research and to improve HIV care in Sweden.

Recommendations

Clinical care and research in Sweden can be further improved by expanded use of the InfCareHIV platform through transfer of biomarkers and connection to other key Swedish registries. The platform brings together clinical and laboratory data for patient level research. Important parameters, gained from routine healthcare R&D work, enable professionals to initiate research on priority areas such as comorbidities and people living with HIV that are ageing. Greater emphasis on expanding aspects such as quality of life, as well as defining a fourth 90 for quality of life assessment, is a priority.

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Associate Professor of Health Policy & Vice Rector
University of Peloponnese, Greece

Richard Stranz
European Platform Coordinator
Coalition Plus

Anke van Dam
Executive Director
AFEW International

Vladimir Zhovtyak
President
East European and Central Asia Union of PLWH (EUCO)

With support from the HIV Outcomes Secretariat

ANNEX II: HIV OUTCOMES MEMBERS

HIV Outcomes Presidents

- **John Bowis**, OBE, former UK Health Minister and MEP
- **Marc Danzon**, former Director of the WHO Regional Office for Europe

HIV Outcomes Steering Group

- **AIDS Action Europe**: represented by Sini Pasanen
- **AFEW International**: represented by Anke van Dam
- **East Europe & Central Asia Union of PLWH (ECUO)**: represented by Vladimir Zhovtyak
- **European AIDS Treatment Group (EATG):** represented by Mario Cascio
- **Jane Anderson**: Homerton University Hospital NHS Foundation Trust, London
- **Nikos Dedes**: European AIDS Treatment Group and Positive Voice
- **Jeffrey Lazarus**: ISGlobal, HospitalClinic, University of Barcelona
- **Richard Stranz**: AIDES
- **Georg Behrens:** Hannover Medical School
- **Antonella d'Arminio Monforte**: University of Milan
- **Industry** represented by: Annick Manuel (Gilead Sciences) and Rhon Reynolds (ViiV Healthcare)
- **European Centre for Disease Prevention and Control** (observer status)
- **European AIDS Clinical Society** (observer status): represented by Georg Behrens and Antonella d'Arminio Monforte

HIV Outcomes Study Group

- **Dr Julia del Amo**: National Centre for Epidemiology, Spain
- **Professor Jane Anderson**: Homerton University Hospital NHS Foundation Trust
- **Antonella d'Arminio Monforte**: University of Milan
- **Yusef Azad**: UK National AIDS Trust
- **Dr Natasha Azzopardi Muscat**: European Public Health Association and the University of Malta
- **Georg Behrens**: Hannover Medical School and German AIDS Society
- **Dr Udi Davidovich**: Amsterdam Public Health Service
- **Nikos Dedes**: European AIDS Treatment Group
- **Dr Josep Maria Gatell**: University of Barcelona
- **Meaghan Kall**: Public Health England
- **Dr Annick Manuel**: Gilead Sciences
- **Dr Ellen Nolte**: London School of Hygiene and Tropical Medicine
- **Teymur Noori**: European Centre for Disease Prevention and Control
- **Professor Kholoud Porter**: University College London

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This initiative is enabled by sponsorship provided by Gilead Silences and ViiV Healthcare