

# Annual Report 2016





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### Our mission

NAM exists to support the fight against AIDS with independent, accurate, accessible and comprehensive information.

We aim to create and disseminate information resources rooted in the experience of those most affected, enabling individuals and communities to take action and control in responding to HIV and AIDS.

## Our values

We believe that, wherever you are in the world, having independent, clear and accurate information is vital in the fight against HIV and AIDS. It enables individuals and communities affected by HIV to protect themselves, care for others, advocate for better services and challenge stigma and discrimination.

### Introduction

Message from NAM's Executive Director

In the 1980s and 90s, even into the treatment era of this century, I lost so many friends as a result of HIV that I eventually had to stop counting. Some died not from the ravages of the virus but because they were unable to cope with their diagnosis and chose to end their own lives.

In 2016 Public Health England reported that 6,000 people had been diagnosed with HIV in the previous year in the UK alone. Worldwide, almost 40 million people are now living with HIV and each year over one million people still die as a result of HIV infection. Although we have seen a considerable increase in access to treatment, too many people still do not have access to the life-saving drugs that many of us take for granted.

2016 marked the 20th anniversary of the Vancouver Conference, where the effectiveness of combination HIV therapy was announced. As a result of effective treatment, the prospects for those of us living with HIV who have access to treatment are much better today than they have ever been. All too often though we face stigma, whether it's rejection by our families, a careless comment on social media or purposeful hate-fuelled rhetoric. Stigma is fuelled by ignorance.

I believe that this is a transformational period in the way that HIV is treated, prevented and understood. At the beginning of 2016 new data was released from the PARTNER study, showing no new HIV infections from condomless sex between sero-different couples when the positive partner was on effective treatment. At the end of the year a number of London clinics announced that for the first time they had observed a dramatic drop in new HIV diagnoses among gay and bisexual men, as a result of programmes of intensive testing, early initiation of treatment and support for those who accessed PrEP privately.

I am proud to have joined the team at NAM, whose work does so much to dispel ignorance and to give people living with HIV the information that they need to live full and healthy lives. Every year millions of people, those living with or affected by HIV and their healthcare providers, come to our aidsmap website or engage with our patient information materials to get clear, honest, reliable information about HIV and AIDS.

This is no time to rest on our laurels. There remain significant challenges ahead: ensuring that all populations globally have access to lifesaving HIV treatment; supporting people living with HIV in their adherence and minimising their risk of side-effects; addressing the co-morbidities that disproportionately impact people with HIV as their life-expectancy increases; establishing and building upon the evidence base that will support effective prevention methodologies to be adopted. All of this has to be accomplished against a background of profound and rapid change in global politics, the impact of which can be felt in a funding environment for NGOs and charities that is more challenging than ever.

These rapid changes that we have seen in the treatment and prevention of HIV underline the ongoing need for the accurate, responsive and independent information that NAM supplies. We will continue to support healthcare providers, to challenge the ignorance that leads to stigma and to empower people living with HIV so that they may live longer and healthier lives.

Matthew Hodson

# 2016 Annual Report

The trustees present their report and accounts for the year ended 31 December 2016 which are also prepared to meet the requirements for a directors' report and accounts for Companies Act purposes.

The accounts have been prepared in accordance with the accounting policies set out in note 1 to the accounts and comply with the charity's governing documents, the Charities Act 2011 and Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015).

In this report and elsewhere NAM Publications may sometimes be referred to by the abbreviated form, NAM, or with reference to one of its principle resources, NAM aidsmap.

# Structure, governance and management

#### **Governing document**

NAM Publications is a company limited by guarantee. Throughout the year under review the company was ruled by, and complied with, its revised Articles of Association dated 7 February 2011.

NAM Publications is also registered as a charity with the Charity Commission.

#### **Trustees**

The trustees, who are also the directors for the purpose of company law, and who served during the year and since the year end were as follows:

- → Dr Sanjay Bhagani
- → Dr Theodora Bloom (Resigned 2 August 2016)
- → Brian Cooper (Chair until 17 June 2016)
- → Robbie Currie (Resigned 14 April 2016; reappointed 2 August 2016)
- → Martin Pendergast (Chair from 17 June 2016)
- → Basil Skeete (Deputy Chair)
- → Dr Margaret Swain
- → Nigel Ware (Treasurer)
- → Duncan Jarvis (Appointed 4 October 2016)
- → Alastair Duncan (Appointed 11 April 2017)
- → Jason Schroen (Appointed 11 April 2017)

None of the trustees has any beneficial interest in the company. All of the trustees are members of the company and guarantee to contribute £1 in the event of a winding up.

#### **Recruitment and appointment**

NAM's Chair, Deputy Chair and Treasurer are elected by the trustees.

Trustees are recruited whenever a gap or deficit occurs in any of the following areas that are essential to NAM's successful operation: employment, finance, information provision, income generation, governance & management, asset management, external relations, quality standards and strategic implementation. Trustee recruitment may also occur whenever an opportunity arises to appoint an individual with a special combination of applicable experience, knowledge or skills; or when there is a sudden shortfall in Board membership.

#### **Induction and training**

New trustees are first interviewed by representatives of the Board and staff management team and invited to attend a Trustees' meeting prior to appointment. New trustees currently undergo an induction process which is devised on an individual basis, to introduce them to the charity's work and their role as a trustee. Trustees are advised to

engage with guidance for trustees provided by the Charity Commission. Should further training needs or appropriate opportunities arise these may be met from the organisation's dedicated training budget.

#### **Organisation**

The Board of Trustees governs the charity. The full Board normally meets every two months.

The charity's most senior member of staff is the Executive Director, who is also the Company Secretary. The trustees are responsible for setting the remuneration of the Executive Director, who is appointed by the trustees to manage the day-to-day operations of the charity. To facilitate effective operations, the Executive Director has delegated authority for operational matters including finance, employment and the provision of information services. The Treasurer and senior staff review the charity's management accounts and financial position on a bi-monthly basis.

Caspar Thomson, Executive Director since 2001, stepped down in July 2016. Brian Cooper, Chair of the Board of Trustees was appointed to act as interim Executive Director while a new Executive Director was recruited. Matthew Hodson was appointed Executive Director and took up the position in September 2016.

#### **Related parties**

The charity is not connected to any other organisations.

#### Risk management

The charity has a risk management strategy which comprises:

- O an annual review of the risks the charity may face;
- O the establishment of systems and procedures to mitigate those risks that are identified by the review; and
- the implementation of measures designed to minimise any potential impact on the charity should those risks materialise.

Following the resignation of the Executive Director in 2016 and the subsequent recruitment process for his replacement, a full risk assessment was not carried out in 2016. Issues which signalled potential risk, in particular those relating to the charity's finances or ability to meet our charitable objectives, were brought to the trustees meeting throughout the year. A full risk assessment will be carried out in 2017.

The trustees believe that the principal risks and uncertainties facing the charity are

#### A. Potential loss of long-standing editorial staff

In a small organisation such as NAM, the loss of long standing members of staff is always a concern. However, the trustees have been heartened by the ongoing loyalty and commitment of NAM's staff following the restructuring that took place in 2014. NAM also uses a number of freelance editorial contributors to bolster its HIV news reporting. In the event of NAM losing a long serving member of staff an appropriate recruitment exercise would be put in place without delay.

#### B. Uncertainty of future income

Although the funding environment continues to be challenging, NAM is constantly trying to expand its funding base. The Board is satisfied that adequate systems are in place to monitor, manage and, as far as possible, mitigate the risk of any further reductions in income.

# Objectives and activities

The charity's objective, and its principal activity, continues to be the relief of sickness, hardship and distress among people with AIDS, HIV and related diseases and conditions, including but not limited to hepatitis. NAM also aims to advance the education of the public, including people working with those suffering from, or at risk of being affected by, such diseases and conditions.

There are no significant restrictions in the way the charity can operate and there have been no changes of policy since the date of the last report.

The charity's mission, throughout the year, continued to be to support the fight against AIDS with independent, accurate, accessible and comprehensive information. The charity aims to create and disseminate information resources rooted in the experience of those most affected, enabling individuals and communities to take action and control in responding to HIV and AIDS.

The trustees believe that the Charity's mission, as set out above, delivers public benefit. The trustees have had due regard to the Charity Commission's guidance on public benefit and have complied with the duty in section 4 of the Charities Act 2011.

The main area of activity is the production and dissemination of regularly updated on-line, electronic and printed information resources.

#### The charity publishes information in five broad areas:

- 1. Information on the clinical aspects of HIV and related conditions; and, in particular, their treatment.
- 2. Information on viral hepatitis, in particular the treatment of, and policy surrounding, hepatitis B & C.

- Information on the testing, transmission and prevention of HIV.
- 4. Information on the social or non-clinical aspects of HIV and related conditions, including the history of the diseases, their impact on particular communities, and practical information about aspects of life with the diseases, e.g. the law, employment and mental health.
- 5. Information about organisations providing services to people at risk of or affected by, or working in the field of, HIV or that are concerned with related diseases or conditions, health programme co-ordination, policy, research, grant-making or community mobilisation.

NAM's main beneficiaries are people living with and affected by HIV and related conditions (for example, hepatitis or tuberculosis), healthcare institutions, and other professionals and volunteers providing prevention, testing, treatment & care, support & advice services or funders, advocates or policy makers.

The benefit to the public of NAM's information is that people with HIV are better able to participate in decisions relating to their treatment and care; and that the professionals who provide services are informed by up to date evidence and best practice. The intended outcome of this information is a reduction in the levels of disease and people with HIV and related conditions living longer, healthier lives.

# Achievements and performance

#### 2016 was a key year for HIV knowledge and information:

- The results of the START (Strategic Timing of Anti-Retroviral Therapy) study from 2015 led Governments and healthcare providers around the world to reconsider their policies on when people living with diagnosed HIV should start treatment.
- The evidence of the effectiveness of PrEP energised activists in the UK and internationally, with increased calls for greater roll-out of this preventative technology.
- The PARTNER study, which showed no HIV transmission in sero-different couples from partners with fully suppressed viral load, confirmed the preventative impact of HIV treatment.
- In the UK, as the year closed, a number of London clinics reported a steep drop in HIV diagnoses among gay and bisexual men.

In 2016, NAM's accessible, authoritative and responsive information about HIV, AIDS and related conditions was more necessary, and accessed by more people, than ever.

"NAM are the foremost community-based information providers for people living with HIV in the English-speaking world."

Dennis LeBlanc, Canadian HIV activist.

#### Conference coverage

This year NAM delivered tailored news bulletins from six international conferences, including the International Liver Congress. In 2016 NAM was also the official scientific news partner for HIV Glasgow 2016, the biennial Congress on Drug Therapy in HIV Infection and for the HIV Research for Prevention 2016 conference in Chicago.

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NAM was particularly proud to partner with the International AIDS Society (IAS) once again as official provider of online scientific news for the 2016 International AIDS Conference in Durban, South Africa in July 2016. NAM's scientific news coverage on HIV, viral hepatitis and tuberculosis is internationally recognised as a key means of disseminating the latest innovations in HIV treatment, care and prevention to a global audience. In 2016 we delivered email news bulletins from the conference to over 50,000 subscribers, with translated versions in Spanish, French, Italian, Portuguese and Russian.

Major highlights of our coverage in 2016 included news of the PARTNER study and numerous studies showing dramatic progress towards the UNAIDS 90-90-90 targets for HIV diagnosis, treatment and viral suppression. Following the conference NAM hosted a feedback session in London to report directly on some of the key topics covered.

Our reporting from the Conference on Retroviruses & Opportunistic Infections (CROI), which included the news of a rare case of PrEP failure was well received with NAM's email bulletins summarising the conference news reaching over 61,110 individuals across the globe.

At the end of the year NAM was the first to report in detail on the initial data showing a dramatic drop in HIV diagnoses among gay and bisexual men attending London clinics.





Over 50,000 subscribers, with translated versions in Spanish, French, Italian, Portuguese and Russian.

"NAM strives to continuously improve our resources for our audience, both in terms of technology and information."

#### Delivering the news from the International AIDS Conference to a truly global audience

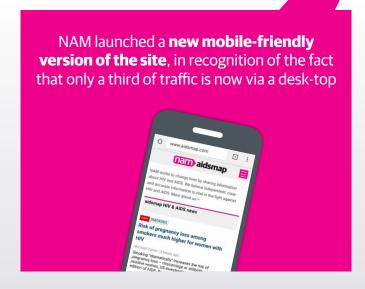


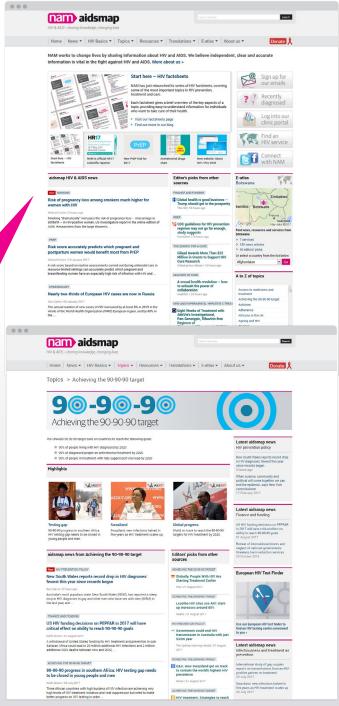
#### www.aidsmap.com

Our news and conference coverage drove an increase in visitors to our website. **In 2016 the aidsmap site recorded well over 6 million visits, adding almost 900,000 to last year's total.** Visitors to the aidsmap site came from all over the world and from every continent.

More than 44,000 people around the world receive NAM's fortnightly email bulletin aidsmap news and more than 32,000 people receive our HIV update. Our conference bulletins, translated into a variety of languages, were sent to 67,000 people. The infohep bulletin goes out to 2,000 individuals.

With support from UNAIDS, a new page on the site was established to collate reporting on progress towards their 90-90-90 target. In addition, we published 50 original news reports on the 90-90-90 themes and produced seven bulletins.



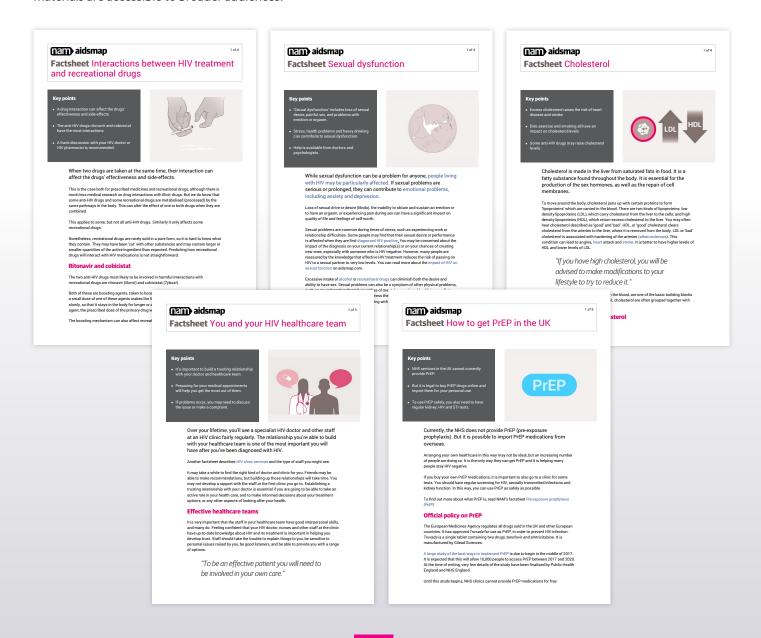


#### HIV factsheets

NAM redesigned and relaunched its series of HIV factsheets.

Each factsheet gives a brief overview of the key aspects of a topic, providing easy-to-understand information for individuals who want to take care of their health.

The redesign made our 100 factsheets more visually appealing with new images, pull quotes and key points highlighted. This also served to make them easier to view and navigate on mobiles and other handheld devices, ensuring that NAM's high quality patient information materials are accessible to broader audiences.

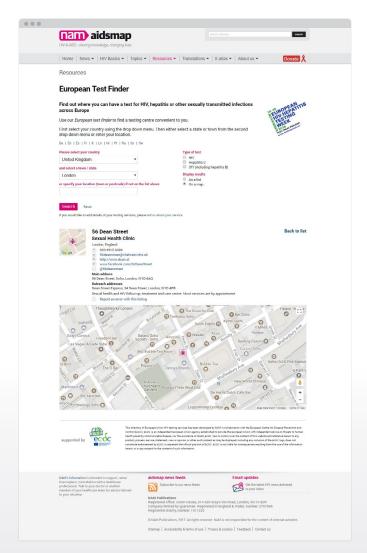


#### European Test Finder

For European Testing Week, NAM published a European test finder, listing over 3,500 HIV and hepatitis testing centres across the WHO Europe region (55 countries in total).

The Finder enables someone, in just a few seconds, to find their nearest service, along with a map showing its location. During 2016's European HIV & Hepatitis Testing Week, thanks to the collaboration between Europe's HIV and hepatitis sector and dating apps commonly used by gay and other men who have sex with men across the continent, the resource had nearly 135,000 page views across 66,000 visits. This represents an 81% increase in the number of page views and a 63% increase in the number of visits since the European HIV test finder was launched for 2015's Testing Week. 94% of people reaching the landing page went on to undertake a search for a testing centre, which represents exceptionally high 'conversion' rates.

NAM continued to explore new platforms to deliver interactive and engaging information for diverse communities. Following the International Liver Congress we hosted a webinar attended by 59 (over 100 registered); of those that provided feedback 92.5% said they found it useful & informative and 100% would be interested in attending future events.

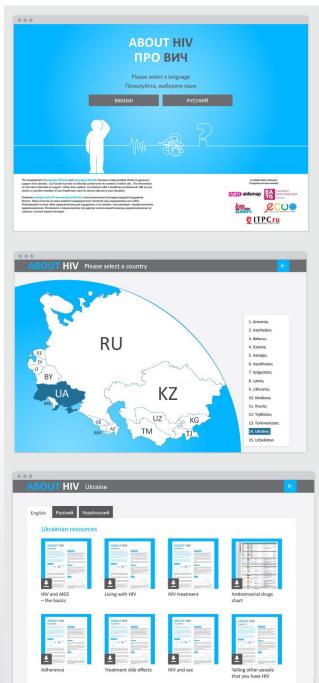


#### **About HIV**

The About HIV / Pro Vich website was launched in October at the HIV Drug Therapy Conference in Glasgow. The website provides information for people living with HIV in Eastern Europe and Central Asia on topics including HIV treatment and potential treatment side-effects, adherence, disclosure, sex, healthy living and legal rights in local languages. The site also provided links to local healthcare resources and support organisations.

NAM collaborated with a range of local and international partners (AVAC, EATG, MSMGF, GNP+, HIV i-Base, the International HIV/AIDS Alliance, ITPC) to develop a Community Consensus Statement on access to HIV treatment and its use for prevention. NAM also built the website to encourage community sign-up to the statement. Projects like these reflect NAM's ability to work collaboratively with other organisations, creating projects that represent people living with HIV.

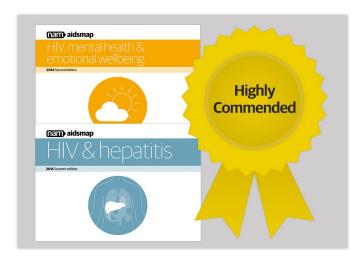




#### Quality

The quality of NAM's work was recognised by the British Medical Association (BMA)

Once again, the quality of NAM's work was recognised by the British Medical Association (BMA) with two titles in our Patient Information booklet series, 'HIV, mental health & emotional wellbeing' and 'HIV & hepatitis' being highly commended in the BMA's patient information awards, who praised NAM's ability to provide a lot of information clearly and concisely.



Award-winning series



Booklets

"aidsmap is a major reason why I'm alive, healthy and working today. Thank you."

- website user

#### PrEP

NAM provides information about PrEP programmes, trials and efficacy to providers and activists internationally.

NAM's reporting supported activism around PrEP, pushing forward advocacy to encourage early adoption of PrEP by European healthcare providers, including collaborating with European partners to produce a report on the current state of PrEP access in Europe. NAM's expertise was called upon in media opportunities arising from the High Court judgement calling for PrEP to be considered for provision by NHS England and NAM were involved in the 'Patients Together' social media campaign, arguing that the needs of one group of patients should not be pitted against those of another in NHS funding decisions. In light of increasing numbers of UK residents importing generic versions of PrEP drugs for personal use, NAM produced a new factsheet on buying PrEP in the UK. NAM also provided a detailed organisational response to the NHS public consultation on PrEP.

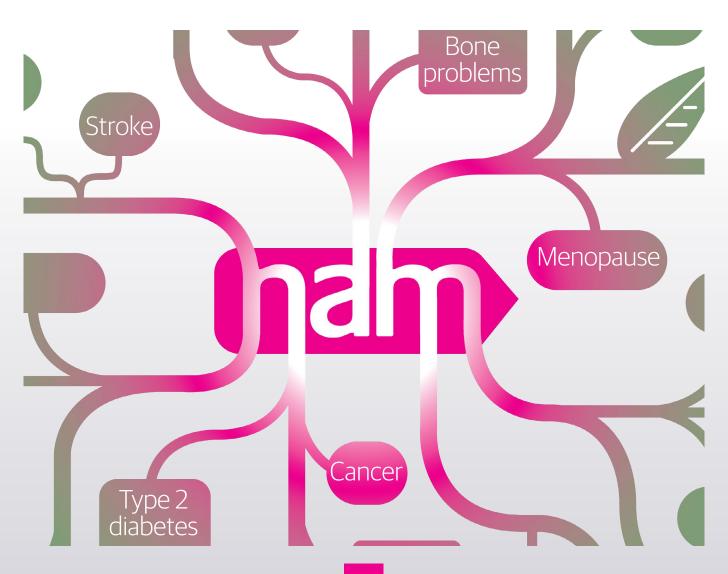




#### The Vine

Supporting people with HIV to live longer and healthier lives.

Acknowledging the fact that the European cohort of people living with HIV is getting older, and that it is necessary now to extend the goal of anti-HIV therapy beyond the achievement of undetectable viral load to include comorbidity prevention and management, the charity began a new project, entitled The Vine. The Vine will introduce a new set of resources, and update others, to ensure there is information available at all the key stages during an individual's long-term life with HIV.



#### NAM in 2016

Maintaining high standards in information provision during a time of change.

#### Maintaining a strong and responsive organisation

Despite a challenging funding environment, the Trustees were heartened by the charity's encouraging financial performance in 2016. NAM operates a sleek and responsive service, providing value to funders while ensuring that we continue to meet the varied and sometimes complex needs of our service users.

In September Matthew Hodson, former CEO of GMFA – the gay men's health charity, took on the role of NAM's Executive Director, bringing with him over 17 years' experience of working in the field of providing HIV and health-related information. Matthew was invited to join the organisation with a remit to raise NAM's public profile and explore new platforms for information dissemination, while supporting and maintaining the authority and reliability of the information that NAM provides.

The charity's patient information materials continued to be certificated throughout the year by the Information Standard, the UK's quality mark for trustworthy health information. NAM continues to provide the only Information Standard certificated printed patient information resources on HIV treatment available within the clinical setting.

### Financial review

The Statement of Financial Activities shows a reduction in our unrestricted funds of £26,554 in 2016. Total income decreased by £21,804 and total expenditure decreased by £905. Unrestricted income was reduced by £67,217. This was for two reasons: Firstly, our subscription income from NHS clinics for our patient information resources was significantly reduced as a number of clinics no longer had the financial resources to renew their subscriptions. Secondly, our consultancy income fell in comparison with 2015 when our consultancy income had been boosted by the volume of work commissioned by the World Hepatitis Alliance, so the reduction in 2016 was expected.

NAM is particularly grateful for the receipt of an unrestricted grant from MEDFASH (Medical Foundation for HIV & Sexual Health) following their closure in 2016. Total grant income from pharmaceutical companies increased by £115,385 to £458,146 in 2016, an increase of 34%, so that it now accounts for 65% of our total income. NAM is grateful to all its pharmaceutical funders for the support they give that enables NAM to continue to be at the forefront of the provision of independent information on HIV treatment, viral hepatitis and the transmission and prevention of HIV.

Although we have drawn on our unrestricted funds in 2016 our success in raising other grant income means that our restricted funds stood at £227,925 at the end of the financial year to support our continuing activities in 2017. This is an increase of £120,810 which means that our total funds at the end of 2016 stood at £790,457.

2017 is set to be another challenging year for income generation but the success in 2016 in securing grant income to help support projects carrying on into 2017 gives confidence to the trustees that NAM can continue to fulfil its mission at its current level of activity without having to draw substantially on its unrestricted funds in the short-term.

NAM holds its surplus funds in deposit accounts of UK clearing banks.

# Reserves policy and going concern

The charity continues to operate in an uncertain funding climate in which it is difficult to estimate when and whether grants and consultancy income will be received and it is not uncommon for grants to be unexpectedly delayed. Because of these uncertainties it is necessary for the charity to hold reserves to cover expenditure in the event of a shortfall of income. In a worst case scenario of charitable income suffering a disastrous decline it would be necessary to cease operations and the trustees hold reserves to enable an orderly winding up to take place.

To allow for the eventualities described above, it is the trustees' present policy to hold free unrestricted reserves (i.e. excluding designated and restricted reserves) of not less than six months' running costs. At 31 December 2016 free reserves stood at £562,532 which was equivalent to just under ten months' worth of projected expenditure for 2017. Although this is above the minimum level of the policy, the trustees consider it prudent to hold reserves at this level in view of the continued unstable charity funding climate and the fact that it is anticipated that NAM will have to move premises in 2018. It should be noted that NAM's income has decreased by 40% over the last four financial years and the holding of significant levels of free reserves has enabled the organisation to survive the restructuring that was necessary to bring income and expenditure into line.

The trustees have considered the charity's cash flow forecast for the period ahead. Notwithstanding the difficult funding environment, the trustees believe that with careful management the charity has a reasonable expectation of having sufficient resources to continue in operation for the foreseeable future. Accordingly, the trustees have continued to adopt the going concern basis in the preparation of the accounts.

## Plans for 2017...

Delivering information, broadening our audience and increasing our impact.

News reporting will continue to be important during 2017. NAM is honoured to have, again, been appointed to the role of official online scientific news reporter for the International AIDS Society Conference, which took place in Paris in July. NAM will also be the official reporter for the International Harm Reduction Conference and the 16th European AIDS Conference in Milan in October.

NAM will update its popular series of The basics leaflets, which provide a simple and easy-to-understand introduction to key HIV issues. Each of these leaflets focuses on one topic, covering key facts, and includes an 'important points' section and information on where the reader can find out more on the topic. The basics are particularly useful for people who do not have a prior understanding of HIV or whose first language is not English and are designed to support discussions between health professionals and people living with HIV.

We will continue to develop resources for people living long-term with HIV, focusing on co-morbidities and other conditions associated with ageing. We will also develop a 'side-effects checker', an interactive online tool designed to support people living with HIV in their conversations with their healthcare providers.

Reflecting the increasing number of people accessing NAM's websites and other resource using handheld devices, we will continue to develop our platforms so that they are accessible and easy to navigate. We will also continue to explore new ways of providing information about HIV and hepatitis, including greater engagement with mainstream and specialised media.

NAM will ensure that commissioners, organisations and individuals across Europe are kept up to date with the latest developments in HIV, sexual and reproductive health policy by picking up the mantle of the Policy EuroBulletin, previously delivered by Medfash. We will also continue to work with colleagues in the UK and across Europe, through our participation in the United4PrEP UK grouping and our stewardship of the PrEP in Europe Initiative to ensure that organisations, commissioners and individuals have access to data on PrEP, supporting efforts to see increased uptake of this intervention.

Under the leadership of the new Executive Director,
Matthew Hodson, NAM will strive to ensure that its vital
information reaches greater and more diverse audiences.
We will explore new platforms for delivering information
and consider how we can increase awareness of the impact
that effective treatment has on extending the lives of people
living with HIV and reducing the risk of passing on the virus.

NAM will pro-actively seek new partnerships and collaborations, both within and outside the HIV sector, and work with other agencies involved in conditions relating to co-morbidities that impact upon the lives of people with HIV. We will gather feedback from our service users and measure our impact.

We aim to increase NAM's public profile so that all communities, whether or not they are directly affected by HIV, are better informed about HIV and HIV risk.



HIV & AIDS - sharing knowledge, changing lives

#### Reference and administrative details:

Registered office: Acorn House, 314-320 Gray's Inn Road, London, WC1X 8DP

Company limited by guarantee, registered in England & Wales, number: 2707596

Registered charity, number: 1011220

The trustees' report was approved by the Board of Trustees on 1st August 2017.

Martin Pendergast (Chair) Trustee