Evidence For Action
on HIV treatment and care systems

Evidence for Action on HIV Treatment and Care Systems

Key messages from five years of research in Africa and Asia

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1. Summary

1.1 About this report

This report presents key messages from research carried out by the *Evidence for Action on HIV Treatment and Care Systems* Research Programme. Evidence for Action is an international research consortium with core partners in India, Malawi, Uganda, UK and Zambia. The programme carries out policy-relevant research on key health system issues related to HIV treatment and care. The specific research themes covered in this report are:

- What 'package' of treatment and care services should be provided in different settings?
- How should HIV treatment and care services be delivered?
- How should HIV treatment and care be integrated into existing health and social systems?
- How best can new evidence from research be rapidly translated into new policies and actions?

Further information about the work of the programme, including abstracts and full texts of journal articles, policy briefs, case studies, reports and other outputs can be found on the accompanying CD-ROM, or **www.evidence4action.org**.

1.2 What 'package' of treatment and care services should be provided in different settings?

Evidence for Action research has looked beyond the basic clinical questions such as which specific antiretroviral or other drug combinations should be used to treat HIV-positive children and adults. It asks higher, system-level questions, such as "How can specific age and other sub-groups best be given access to HIV care?"; "Should screening and treatment for mental disorders be part of the basic HIV treatment and care package?"; and "Which indicators best predict treatment outcomes?". Research on the special needs of different sub-groups of the population has revealed key ways to strengthen HIV treatment and care for them.

- **Children**: Tablets are more acceptable to children and carers than syrups, as well as being cheaper, easier to transport and store, and if scored, it is easier to give children the correct dose. Specific fixed-dose combination tablets for children can make this even simpler.
- **Adolescents** are neither big children nor little adults but have specific needs, and adolescents living with HIV need customised psychosocial support and access to sexual and reproductive health information, health services and commodities. They face many barriers to accessing these services, so service providers should be trained in the provision of 'youth-friendly' HIV services.
- **Pregnant women**: Opt-out programmes for the prevention of mother-to-child transmission of HIV have had considerable success at testing pregnant women for HIV. However the opportunity to get these women onto ART for their own health is frequently being missed. Attention is needed to address the barriers these women face, which include complex patient pathways, and lack of coordination and monitoring between services providing antenatal and maternity care and those providing HIV treatment and care.
- **Older people** living with HIV who are on ART reported better quality of life than older people who are not HIV-positive in a study in Uganda. This illustrates the value of ART and other support that people living with HIV receive.
- **Refugees and internally-displaced people** face additional challenges to adhering to ART. Research in Malaysia has shown that refugees have good but slightly lower adherence to ART than host populations attending the same clinic, which would support a policy of offering ART to refugees. However, they may need tailored adherence support.

The mental health needs of people living with HIV in low-income countries are not well understood. Research in India, Uganda and Zambia has helped to highlight the high burden of mental disorders among people living with HIV, the impact this has on testing completion, and has validated simple screening tools that can be used by lay workers and non-specialists to screen HIV and TB patients for common mental disorders such as depression and excessive alcohol use.

Good data from programme information systems is vital for monitoring patient welfare and rationalising resource use. The wide scope of HIV care monitoring has resulted in a plethora of guidelines, recommendations and reporting requirements related to the monitoring of HIV programmes in low-income countries. Yet the validity and predictive value of current HIV treatment outcome indicators have never been evaluated. A situation assessment in four low and middle-income countries has documented this, and an evaluation of current indicators is urgently needed to provide recommendations for how programmes can ensure that reported facility-level outcome data accurately reflect the welfare of the treated population, and comparisons of performance between and within programmes are meaningful.

1.3 How should HIV treatment and care services be delivered?

The issue of how to deliver HIV treatment and care services is crucial to expanding access. Our work in this area has included asking whether and how to decentralise treatment programmes in low and middle-income contexts, and the potential roles of different groups such as formal healthcare workers, home-based carers and networks of people living with HIV in delivering these services.

1.3.1 Decentralising HIV treatment

Our studies in sub-Saharan Africa have shown that:

- Peripheral health centres can safely and effectively deliver ART to patients. This means patients have less transport costs, travel time and waiting time to access treatment.
- Trained lay workers can safely and effectively deliver ART to patients in their homes. This not only reduced the costs to the patients, but also to the health system.
- Routine laboratory testing is not needed for monitoring patients on ART, as long as good clinical monitoring takes place. As the lack of laboratories and laboratory technicians is a constraint in many low-income countries, these results are very encouraging, and further studies are underway to test how best to ensure good clinical monitoring as ‘lablite’ programmes are scaled up.

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1.3.2 Groups involved in providing care

Our studies have shown that:

- Half of health workers in Lusaka District, Zambia, felt burnt out, most with numerous symptoms of burn-out, and nearly a quarter reported feeling too burnt out to go to work at least once a week. In order to reduce attrition of health workers, efforts are needed to reduce workplace stress, and improve access, acceptability and confidentiality of health services for clinical providers.
- The scale-up of ART provision has changed and expanded the roles of lay health workers, both within clinical and community settings. For example, home-based caregivers encourage clients to test for HIV, to seek formal care, and to screen for other infections. They accompany clients to the clinics, and provide adherence support for clients on ART. However, caregivers face important challenges, including lack of training in how to support clients on ART, lack of formal recognition, and unrealistic expectations of clients.
- Networks of people living with HIV can improve the relationship between people living with HIV and their families. They provide valuable psychosocial support and act as a key source of information about HIV and treatment. These networks are a valuable mechanism for improving the quality of life for people living with HIV.

1.4 How should HIV treatment and care be integrated into existing health and social systems?

HIV programmes were often introduced as vertical programmes, which allowed them to scale-up HIV treatment rapidly. There are increasing calls for these programmes to be better integrated into the wider health system. Research in Zambia found that priority areas for further integration include increasing the efficiency of information systems, harmonising incentives for health workers, coordinating training, and improving linkages between HIV and other services.

Research among major funders of HIV treatment found that there were many different interpretations of what integration is. This could lead to an array of different strategies and initiatives to increase integration, which could increase the burden of coordination.

TB is the leading cause of morbidity and mortality among people with HIV in most parts of the world. This makes coordination of TB and HIV services vital. A systematic review identified a range of models for how this is being done, as well as a number of barriers. However few data compare outcomes between different models of care, so it has been difficult to know which model works "best". However, the review showed that this may vary with HIV prevalence among TB patients and proposed a new, practical way of classifying approaches to HIV and TB integration. Providing HIV testing on site for all TB patients, and regular screening for TB among all HIV patients, seem likely to benefit patients in all settings.

1.5 How best can new evidence from research be rapidly translated into new policies and actions?

We carried out research on how evidence about cotrimoxazole prophylaxis has been translated into policy in Malawi, Uganda and Zambia, and why there were important differences in the speed with which this happened in the three countries. Both the type of evidence available and the ways in which its significance was interpreted by clinicians and policy makers were important in influencing how quickly it was translated to policy. For example, in Uganda and Malawi the fact that operational research had been conducted which specifically sought to answer questions about how the intervention might be scaled up, and its potential cost, was central to the successful translation of research into policy. The economic and political context had a specific impact on the perception of the usefulness of the research results for the needs of the population. For example, in Malawi, where resources to scale-up activities for HIV treatment were very limited, the National TB Control Programme had secured funding and was actively looking for ways to reduce HIV deaths among TB patients. The National TB Programme worked in close collaboration with the researchers and quickly translated the research into policy. All three countries revealed the importance of having ‘champions’ to facilitate the evidence-to-policy processes.

> “Peripheral health centres can safely and effectively deliver ART to patients, saving patients time and money”

We also participated in research on where national policymakers get their information from. African policymakers emphasised the importance of the World Health Organisation, and especially their published guidelines, in influencing policy and sharing information. International donors were also seen as providing evidence and influencing some policies. Asian policymakers reported in-country research and surveillance as particularly important.

1.6 How Evidence for Action research has influenced policy and practice

Throughout the course of the programme, Evidence for Action partners have been engaging closely with key stakeholders, including national policymakers and practitioners. Many of our studies have influenced policy and practice in both the countries where the research was conducted, and globally. This influence will be even greater over the next few years. Some examples of this are:

- In Malawi, operational research carried out by Lighthouse has resulted in the national roll-out of new tools for monitoring and evaluating PMTCT
- Peripheral health centres in Uganda that were involved in the Wakiso project have continued to provide ART for patients since the end of the project, reducing the transport costs and time needed for patients in rural areas to access treatment.
- Operations research carried out at the Martin Preuss Centre in Malawi has increased the proportion of TB patients being tested for HIV and accessing ART
- An opinion piece by Evidence for Action researchers, published in the Lancet, has led to increased recognition of the importance of "getting research out of practice"
- We helped to produce the World Health Organisation Priority Interventions: HIV/AIDS prevention, treatment and care in the health sector, a toolkit which defines the essential interventions the health sector should deliver, and provides key references and resources

1.7 Conclusions

Our research has helped to identify the special needs of sub-groups of the population, strategies to expand access to ART, and priority areas for integrating HIV services with other areas of the health system. Our experience has highlighted the importance of operational research that addresses the priorities of policymakers and implementers. It has also drawn attention to the need to improve how services are monitored and evaluated, to ensure effective resource use, improve programme performance, and increase coordination between different parts of the health system.

Specific recommendations can be found in section 7.

Contents

2. Introduction

Massive progress has been made in the last five years in expanding access to HIV treatment and care in low and middle-income countries. The number of people in low and middle-income countries on antiretroviral therapy (ART) reached 5.2 million in 2009. The number of people on treatment is now thirteen times more than six years ago. However, much remains to be done. The majority of people in need of ART (according to the revised World Health Organisation treatment guidelines) in low and middle-income countries still do not have access to it. Many questions remain to be answered about key health system issues related to HIV treatment and care in low-income settings.

2.1 Purpose of this report

This report presents key messages from the results of research carried out by the *Evidence for Action on HIV Treatment and Care Systems* Research Programme. These messages have important implications for policy, practice and research on HIV treatment and care.
The research themes covered by the programme and by this report are:

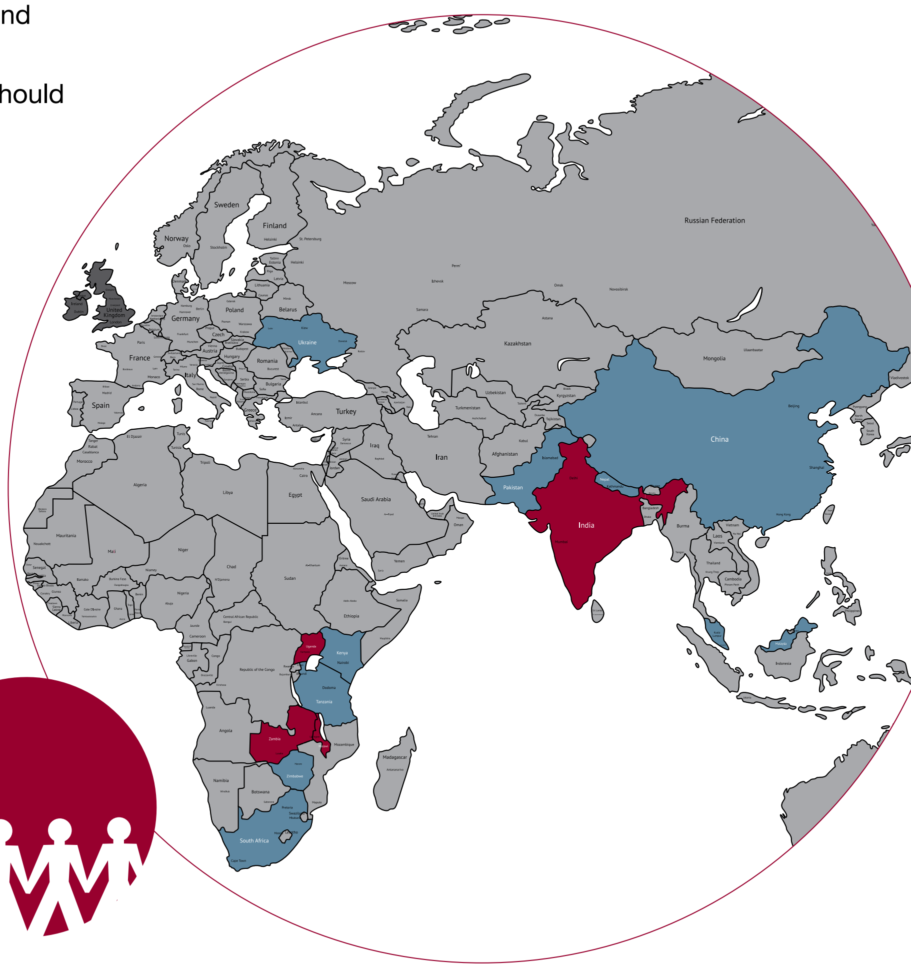
- What ‘package’ of treatment and care services should be provided in different settings?
- How should HIV treatment and care services be delivered?
- How should HIV treatment and care be integrated into existing health and social systems?
- How best can new evidence from research be rapidly translated into new policies and actions?

The report draws on research carried out in Malawi, Uganda, Zambia, Kenya, Tanzania, South Africa, Zimbabwe, Ukraine, India, Malaysia, China, Nepal and Pakistan, as well as global reviews.

2.2 About Evidence for Action

Evidence for Action is an international research consortium with partners in India, Malawi, Uganda, UK and Zambia, which carries out policy-relevant research on HIV treatment and care systems. The programme started in 2006, and is funded by the UK Department for International Development. The core partners of the programme are:

- International HIV/AIDS Alliance, UK
- Lighthouse Trust, Malawi
- London School of Hygiene and Tropical Medicine, UK
- Medical Research Council/Uganda Virus Research Institute Uganda Research Unit on AIDS, Uganda
- Medical Research Council Clinical Trials Unit / University College London, UK
- National AIDS Research Institute, India
- ZAMBART, Zambia



Red = core Evidence for Action countries
Blue = other countries we have been working in

2.3 Key achievements of Evidence for Action

Over the five years that Evidence for Action has been in operation, the programme has developed strong South-South and South-North collaborations between the partners. The geographical spread and range of expertise of the partners has allowed for considerable learning about different contexts and disciplines. This has allowed issues of importance across different settings to be identified, and collaborative research projects (such as our work on outcome indicators) or research communities of practice (such as on mental health) to be developed. This has enabled us to conduct multi-country research that is of regional or global significance. It has also helped us to strengthen our capacity to carry out research and communicate it effectively.

Since the start of the programme, active engagement with key stakeholders has been a guiding principle. This has allowed us to work with national and international policymakers and implementers to identify priority research questions, and then design and carry out research to answer them. Stakeholders such as Ministries of Health and international agencies are active partners in several of our research projects. This “getting research out of practice” has been crucial in ensuring our work is policy-relevant.

Another achievement has been in shedding light on issues that have been neglected up to now. Our body of work on the mental health needs of people living with HIV is a good example of this, as is our qualitative research looking at the challenges and needs faced by those delivering HIV treatment and care, such as formal and informal health workers and home-based caregivers.

2.4 Where to find further information

This report is far from exhaustive, and does not cover all the work of the programme, or detailed information about any specific project. Further information about the work of the programme, including abstracts and full texts of journal articles, policy briefs, case studies, reports and other outputs can be found on the accompanying CD-ROM, or on our website **www.evidence4action.org**.

2.5 What next?

Our research has raised further important questions that need to be addressed, such as which indicators are the best predictors of patient outcomes, and how HIV services can best meet the mental health needs of people living with HIV, given the limited resources available. Evidence for Action partners will continue to research important issues on HIV treatment and care systems. We hope that other researchers will also work to address the questions raised by our work so far.

One thing that is clear from our experience is the vital importance of good quality operational research to answer the practical questions faced by HIV treatment and care systems. Yet few funding agencies value and support such research, favouring more traditional academic and theoretical research. We hope that this report, which illustrates the value of such research, will encourage more research funders to provide resources for operational research, and other readers to advocate for this.

Some of the Evidence for Action team at the Annual Consortium Meeting in Uganda

3. What ‘package’ of treatment and care services should be provided in different settings?

3.1 The needs of different subgroups of the population

3.1.1 Children

It is estimated that 1.3million children under 15 years old in low and middle-income countries need antiretroviral therapy, 28% of whom are receiving treatment. Infants and children have different needs from adults in terms of drug formulations. Children are often given treatment in the form of syrups, which are bulky, difficult to transport and store, complex to administer and expensive compared to tablets. Key early findings from the ARROW trial show that carers and children prefer tablets to syrups. Scored tablets make it easier to give children the correct dose depending on their weight. Tablets can be crushed or dissolved to make it easier for children to swallow. The CHAPAS 1 Trial has found that the fixed dose combination tablets Triomune Baby and Junior are appropriate for children, and dosing is straightforward, based on simple weightband tables. These findings have important implications which may help to increase access to treatment for children.

Monitoring and evaluation of paediatric treatment programmes is important for assessing progress, identifying gaps and justifying resource allocation. However, a workshop of policy makers, paediatricians and researchers from Uganda, Malawi, Zambia and Zimbabwe found the WHO recommended indicators for paediatric HIV programmes do not focus sufficiently on HIV-infected children after infancy. Programmes face challenges related to data quality, harmonisation of indicators between countries, and measuring the impact of treatment programmes. Any efforts to address these challenges need to take into account the pressure on health workers due to the shortage of human resources.

3.1.2 Adolescents

Young people (age 10-24) living with HIV are an increasingly important yet often neglected group in HIV responses. In 2007, it was estimated that nearly half of new HIV transmissions among people aged 15 and older occurred within the 15-24 age group. While there are no good estimates for 10-14 year olds living with HIV, increasing numbers of perinatally infected children with access to ART are now reaching adolescence. Adolescence (age 10-19) is characterised by physiological, social and behavioural changes, including sexual maturation, increasing independence, and evolving legal capacity. Living with HIV amplifies the need for effective support and guidance in navigating this developmental phase, as highlighted in two pieces of Evidence for Action work (a literature review and a study conducted in Zambia). In Sub-Saharan Africa, adolescents living with HIV are often uncomfortably situated in paediatric or adult facilities that are ill-equipped to deal with the complex needs of this group. Adolescents living with HIV require a special ‘package’ of treatment and care services that are targeted to their particular developmental needs and that are linked across sectors (e.g. health, education and NGO sectors).

Safer sex, family planning, and disclosure of one’s HIV status to others (such as sexual partners) become pressing issues during adolescence. In many cases adolescents lack access to sexual and reproductive health information, services and commodities. Service provision for adolescents living with HIV should include quality counselling and psychosocial support to aid with:

- accepting a seropositive status
- disclosure to others
- treatment adherence
- social integration and life skills
- adopting healthy sexual behaviours
- coping with feelings of depression, anxiety or isolation

Quality ongoing psychosocial support should be prioritised using a combination of effective interventions such as personal counselling, group therapy and peer support groups.

There are also a number of barriers that may prevent adolescents accessing services, such as: a lack of confidentiality in clinical settings; judgemental attitudes of health professionals; poor post-test HIV counselling services; inaccessible service location or hours; low service-seeking behaviour of adolescents or lack of knowledge of available

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services; and requirements for parental consent to access health services. Service providers should be trained in the provision of 'youth-friendly' services that are confidential, non-discriminatory, appropriate and effective. There is also a need for outreach activities in communities and schools aimed to increase the service-seeking behaviour of adolescents.

3.1.3 Pregnant women

Prevention of Mother to Child Transmission (PMTCT) programmes in many countries have had considerable success at identifying pregnant women who are HIV positive. They offer an opportunity for women to access treatment services for their own health as well as to prevent transmission to their babies. However, research in Kenya and Tanzania has found that these opportunities are often being missed. At a hospital in Kenya only 36% of women who tested HIV positive in antenatal clinics (ANC) or delivery services registered at the adult HIV care and treatment services within six months of diagnosis. Only 45% of these women were assessed for their eligibility for treatment within six months of registering at the HIV clinic, and only 41% of those who were assessed to need treatment (according to national guidelines) had started ART six months after being deemed eligible for treatment. In Tanzania only 51% of HIV positive pregnant women were referred to the care and treatment centre before delivery, and only 18% of women identified as HIV positive through PMTCT who needed treatment (according to national guidelines) had started treatment within 4 months after delivery.

Qualitative research in Kenya and Tanzania has suggested that reasons for these missed opportunities include:

- Hospital factors, such as:
  - Patient pathways being too complex
  - Lack of coordination between ANC and HIV treatment clinics
  - Quality of care
  - Lack of a way of monitoring whether women who are referred take up that referral
- Personal factors (eg. cost of transportation, denial, competing priorities)
- Societal factors (eg. stigma)

These issues need to be addressed to ensure that women who are already in contact with the health system and are known to be HIV-positive do not miss opportunities to receive the treatment they need.

3.1.4 Older people

Older people are directly and indirectly affected by HIV. Older people living with HIV infection are more likely to have rapid disease progression than younger people and may also have a higher risk of psychiatric disorders. They often have other co-existing medical conditions. The effects of antiretroviral therapy (ART) in older people are still poorly documented. They may face increased risks of side effects of treatment. In addition, many older people are indirectly affected by HIV because they have to take care of orphans, because they have close relatives who are sick and need care, or because of AIDS deaths in the family.

A study among 510 older people from rural and urban areas in Uganda was conducted to assess their physical, social and mental well-being if they are either indirectly affected by HIV/AIDS in the family or if they themselves are HIV infected. Their health was compared with a comparison group of old people not affected or infected by HIV. Our preliminary results show that the self-reported health status was similar in all three groups. However, BMI and grip strength, two general measures of health status, were lower in HIV infected people. Old people affected by HIV in the family often suffer from a variety of problems, including increased poverty as they may lack the financial, social and moral support normally received from their adult children. Interestingly, HIV-infected older people who receive ART reported higher quality of life than all others which may in part be due to the better general health care enjoyed by this group. This shows the importance of ensuring older people can access health care including ART if required.

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3.1.5 Adherence to ART in refugees

Refugees have unique challenges in adhering to ART. The extent to which refugees manage the challenges of displacement in order achieve good clinical outcomes is unclear. Few studies have investigated adherence to ART and clinical outcomes in displaced persons. These have reported high adherence rates (92-99% missing less than 5% of their pills), and moderate mortality rates (3-8% per hundred person-years). To date, no studies of adherence to ART have focused on refugees and their local host communities.

To address this gap we are doing two detailed studies of ART programmes in clinics where refugees and local host communities share HIV services. Research has been carried out in an urban refugee setting (Kuala Lumpur, Malaysia) and is currently in progress in a camp-based setting (Kakuma, Kenya). In Sungai Buloh Hospital, Kuala Lumpur, a cross-sectional survey was conducted with a sample of 154 refugee and 148 Malaysian adults. 73% of refugees and 78% of the host community had suppressed viral load, and 92% of refugees and 96% of the host community self-reported being optimally adherent. Although both measures showed ART adherence was likely to be slightly lower in the refugees, neither difference was statistically significant, which would support a policy of offering ART to refugees, at least in urban settings like Kuala Lumpur. However, adherence support that is specifically tailored to the needs of refugees may be required. Qualitative research has also been carried out to understand the challenges and factors that may facilitate ART adherence among refugees and the host population in urban Malaysia. This will generate evidence-based recommendations to improve adherence, clinical outcomes, and equity among both refugees and host populations. Research is still in progress in Kakuma, Kenya.

3.2 Mental health needs of people living with HIV

In high income settings, research has shown that people living HIV are more likely to have mental health problems than the general population. Those with HIV and mental health problems tend to progress more quickly from HIV to AIDS and are more likely to die from the disease than those with good mental health. Most studies suggest that having a mental disorder makes it more difficult for people to have good adherence to antiretroviral therapy.

Although some recent research suggests that people living with HIV in areas badly affected by the disease tend to have high levels mental disorder, the role of mental health in the lives of people living with HIV in low and middle income settings is not well understood. As antiretroviral therapy continues to become more available, it becomes increasingly important to understand remaining barriers to achieving good health.

3.2.1 The Umeed Study: Mental health, HIV and service use in Goa, India

The Umeed study was carried out with 1934 people coming for testing for HIV in Goa, where HIV is a significant concern. The aim of the study was to measure the mental health and cognitive functioning of this group and to explore the effect of depression, anxiety and alcohol problems upon re-attending the clinic to receive HIV-test results. We were also interested to see whether those with mental health problems would be more likely to test positive for HIV.

> "Umeed participants with depression/anxiety, alcohol problems or impaired cognitive functioning were more likely to test positive for HIV"

The Umeed study is the first large study to measure mental health among people at this early stage on the pathway to care for HIV. We found high levels of alcohol use among study participants: few women drank, but 27 percent of men had problematic drinking. Although the level of major depression/anxiety was comparable to that found among the general population, those with mental health problems were around fifty percent less likely to return to the clinic for their test results. Umeed participants with depression/anxiety, alcohol problems or impaired cognitive functioning were more likely to test positive for HIV. These study findings highlight the potential role of mental health problems in determining HIV-related outcomes.

3.2.2 Addressing mental health problems among people living with HIV in Uganda

HIV/AIDS is associated with a considerable burden of mental health problems. While progress has been made in high-income countries to address this burden, mainly through the integration of mental health care into general HIV care and early initiation of treatment (to prevent the development of severe neurocognitive impairment), little has been done in sub-Saharan Africa.

Addressing the mental health needs of persons living with HIV in sub-Saharan Africa is beset by many problems including the absence of reliable data on the actual extent of the problem, and the lack of capacity of general HIV health care workers to recognise and screen for these problems. For neurocognitive impairment, the late initiation of antiretroviral therapy is also a problem.

To address some of these barriers, Evidence for Action carried out a study in Uganda which documented the burden of mental health problems among people living with HIV, and validated screening tools for common mental disorders among people living with HIV, which can be used by non-mental health specialists.

> "9% of participants had at least one mental health disorder and 64% had neurocognitive impairment. There is a need to integrate mental health services into all levels of HIV care in sub-Saharan Africa"

Preliminary results from this study indicate that 9% of the respondents had at least one mental health disorder.

- 8% had major depressive disorder
- 8% had suicidality (ever attempted suicide and having significant suicidal thoughts)

The majority of participants (64%) had neurocognitive impairment.

There is a need to integrate mental health services in all levels of HIV care in sub-Saharan Africa. To address what seems to be a heavy burden of neurocognitive impairment, there is a need to review treatment guidelines and to support the health systems in these developing countries to be able to initiate ART much earlier.

3.2.3 Mental health among HIV patients in Zambia

The Ministry of Health in Zambia has made remarkable progress in rolling out the antiretroviral therapy program. From 2002 when combination antiretroviral therapy became free-of charge in government health facilities, the ART coverage increased rapidly to 150,000 in 2006 and is now estimated to be at 283,000 in 2010; this is estimated to be 64% of those in need of treatment nationwide.

Despite this rapid scale up of ART, the Zambian Ministry of Health is still facing the challenge of integrating mental health services into the ART programme. This has been complicated by the fact that there is a critical shortage of health workers in primary health care facilities; let alone those trained in the diagnosis and treatment of mental health disorders. HIV-infected individuals are more likely to develop mental health disorders like depression than non-HIV infected individuals. If mental health disorders are not managed early in HIV-infected individuals, there is substantial evidence that they may negatively affect HIV disease progression in terms of decreases in CD4 cell counts, increases in viral load, and greater risk for clinical decline and mortality.

A validation study conducted in Zambia found that screening tools for mental health disorders among HIV-infected individuals can be used by trained lay workers with good diagnostic accuracy. There is need to introduce simple and easy to use screening tools for mental health in HIV care services. This will allow for early identification of mental health disorders in HIV at primary health care level, and referral for appropriate management.

3.3 Monitoring and evaluating HIV treatment services

The increased life-expectancy of patients receiving ART means that, with appropriate disease management, HIV can now be managed as a chronic disease. Good disease management and appropriate care are based on the ability to track a patient's status throughout the course of time in care. It relies on accurate information systems to provide access to key data. Aggregated data from these information systems are key to health managers and governments for monitoring patient welfare and rationalising resource use.

In low-income countries where much of the HIV epidemic is concentrated, significant political and financial efforts have been made in the past 15 years to make HIV care accessible to those who need it. As a consequence, many stakeholders are involved, including international organisations such as the WHO, UNAIDS, UNICEF, international donors such as PEPFAR, GFATM, World Bank, and national Ministries of Health. The goal of monitoring these programmes extends beyond tracking patient status over time, as it is also essential to ensure accountability for funds dispersed, to evaluate a programme's impact and to assess the national and global response to the pandemic. HIV care monitoring in low-income countries thus covers many aspects, including

- prevention
- treatment
- care
- laboratory capacities
- human resources
- health systems strengthening within HIV programmes
- the impact of HIV care on other aspects of health systems

The wide scope of HIV care monitoring has resulted in a plethora of guidelines, recommendations, reporting requirements, glossaries, tools and frameworks on how best to monitor HIV programmes in low income countries. In an attempt to consolidate HIV care monitoring, in 2008, the UNAIDS Monitoring and Evaluation Reference Group published 24 Core and Recommended Indicators. We reviewed the uptake of these recommendations on national monitoring reports for ART programmes in four low and middle income countries. We found wide variation in the Ministry of Health monitoring reports. Many aspects of care which were monitored provided baseline information on patients in care, but few data were gathered which were specific to the patient-important outcomes of the treated population. No paediatric specific outcome indicators existed and age-bands used in reports varied widely. Furthermore, the validity and predictive value of current indicators have never been evaluated. Although the burden on facility staff compiling routine monitoring reports is vast, there is uncertainty as to which indicators best monitor patient progress. This burden will grow as increasing numbers of life-cohorts are created for monitoring purposes, leading to data inaccuracies and compromising the internal validity of reported indicators. A number of fundamental indicators, including survival and retention, may not capture the construct they intend to measure, compromising the ability of programme managers to obtain reliable estimates regarding the welfare of their population in care. It is not known which indicators can best predict longer-term outcome in the patient population, and as such, can enable managers to respond to predictors of failure early.

An evaluation of current indicators is urgently needed to ensure that reported facility-level data accurately reflect the welfare of the treated population and comparisons of programme performance are meaningful.

Monitoring reports in low income countries tend to be paper-based, manual and intensive © Susan Hoskins

4. How should HIV treatment and care services be delivered?

4.1 Delivering ART through peripheral health centres

Many people living with HIV in rural areas in Africa have problems accessing ART, as the clinics where it is available may be far away, and transport is often poor and expensive. One potential strategy to increasing access to HIV treatment is to decentralise ART delivery to lower level health centres. However, these peripheral health centres often suffer from poor staffing and infrastructure. The Wakiso project investigated whether health centres (which serve a radius of around 5km) in Wakiso district, Uganda, can feasibly and effectively deliver ART.

The study compared patients who received HIV treatment and care from the district hospital with those who were treated by local health centres. 535 people participated. Patients were initiated on treatment at the district hospital before being referred to their local health centre. A sub-study investigated peripheral health centres initiating patients on ART, and results will be available soon. All HIV treatment, care and prevention services were provided by the government health services. Both qualitative and quantitative data were used to evaluate this strategy.

A nurse running an ART clinic in a peripheral health centre
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After two years there was no significant difference in the rate of CD4 count increase between the hospital and health centre arms, nor in virological failure rates. A higher proportion of patients were retained in care two years into the project than the national retention rate (75% compared to 68%). This indicates that the health centres can deliver ART as effectively as higher level health facilities. Importantly, 80% of the patients are happy with the services they receive at the health centres. For the majority of patients delivering ART through peripheral health centres means services are now closer to their homes and easily accessible.

This study was conducted in partnership with the Ministry of Health in Uganda, answering questions of great importance to the national programme. The positive results of the study could potentially help to make treatment more easily accessible for many people.

4.2 Delivering ART through home-based care

In Africa, health services face a very severe shortage of clinically qualified health workers. Clinics are often overcrowded and waiting times excessive. For patients, getting transport to clinical centres is often difficult and prohibitively expensive. Thus, accessing ART services is either not possible or is challenging for the vast majority of African people living with HIV.

One strategy to address this is the use of trained lay health workers to deliver ART directly to patients homes, using motorbikes. The Jinja trial, a cluster randomised trial conducted in south east Uganda, tested this against facility-based care. The trial was the largest of its kind, comprising 1453 subjects on ART followed for approximately 3 years. It found similar mortality, virology, and clinical outcomes between the home and facility-care. Visits to the health facility were 4-fold fewer in the home-based arm than in the facility-arm. Importantly, home care was marginally cheaper for the health service (cost saving was 5%, equivalent to £29 per patient per year, compared with facility care) and resulted in large savings for patients in transport and other costs (men saved 17% of their monthly income and women 25% compared to facility-care)

Community-based strategies like this could enable increased and equitable access to HIV treatment, especially where patient access to clinic-based care is poor. More evidence is required on cost-effective models of HIV care.

4.3 Delivering ART with minimal laboratory back-up

One barrier to ART roll-out in resource-constrained settings is the perception that all patients on treatment need routine laboratory tests to maximise the effectiveness and minimise the side effects of the antiretroviral therapy. This is a major obstacle, particularly in rural areas, because these laboratory tests need substantial infrastructure and trained personnel, which can be very costly to set up and then maintain.

The Development of AntiRetroviral Therapy in Africa (DART) Trial investigated whether it is safe and effective to deliver ART without the use of routine laboratory blood tests. In a parallel economic analysis, the costs and benefits of delivering ART with and without routine laboratory blood tests were compared from a public healthcare provider perspective. The trial did use laboratory services: participants were assessed with laboratory tests for eligibility to start ART; and laboratory tests were used for diagnosis if they fell ill, including with possible drug side effects.

The results of the trial show that doing laboratory tests routinely (every 3 months) to monitor ART toxicity and side effects makes no difference to patients over an average of 5 years; and is very costly. Providing CD4 testing to patients on ART to monitor the ongoing effectiveness of first-line ART had no benefit during the first 2 years on ART. After the second year, 3-monthly CD4 tests resulted in a small but significant reduction in death (3 percentage points), but was also a costly intervention. Analysis showed that use of routine laboratory testing is not cost-effective. The LabLite project is now looking at how these recommendations can be implemented in standard health care facilities in resource-limited settings. This work has the potential to free up resources to expand ART coverage, and use laboratory services where they will have the most benefit.

4.4 Groups involved in delivering treatment and care services

4.4.1 Burnout among healthcare workers

The shortage of health workers in many countries is limiting the expansion of HIV treatment and care programmes. It is particularly severe in Africa, where there are on average just 2 physicians and 11 nurses/midwives per 10,000 population. Approaches to tackling this problem include task shifting, recruiting lay health workers, and using technology. To date there has been little focus on maintaining the well-being of existing health workers.

HIV-related illness and death has led to absenteeism and loss of trained health workers. A qualitative and quantitative study carried out in Lusaka District, Zambia, found that concern about confidentiality and stigma put health workers off having an HIV test.

Members of the Positive Women's Network, a support group for HIV positive nurses, Kabuwe, Zambia © Nell Freeman for Alliance

Burnout of health workers is also a major problem. The study found that symptoms of burnout among health workers included:

- Feeling over worked, stressed or tired
- Having low energy
- Being irritable and rude to patients
- Providing poor treatment and being more prone to make mistakes
- Getting sick

Around half of health workers in Lusaka District felt burnt out, most with numerous symptoms, and nearly a quarter reported feeling too burnt out to go to work at least once a week.

Efforts are needed to reduce workplace stress for health workers, and especially for those working in HIV treatment and care, in order to increase their effectiveness and reduce absenteeism and attrition. Work also needs to be done to improve access, acceptability and confidentiality of HIV testing, treatment and care services for clinical providers.

4.4.2 Home-based caregivers: insights from Zambia

Home-based care programmes for people living with HIV in Sub-Saharan Africa have evolved in response to the increasing availability of ART. As many people living

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with HIV regain physical health and strength, and resume normal levels of social and productive activity, HIV care is increasingly defined by the demands of starting and adhering to ART. In this context, the roles of home-based caregivers are evolving.

A study conducted in Zambia explored how shifts in the nature of home-based care are affecting experiences of treatment and care for both home-based caregivers and for people living with HIV enrolled in home-based care programmes. It was conducted over the course of one year with three community-based organizations. The study used key informant interviews with clinic and programme staff, as well as in-depth interviews and observations with home-based caregivers and clients to document the day-to-day working lives of caregivers.

In line with the medicalisation of HIV care, caregivers increasingly support the formal health system and intervene at crucial steps of the care-seeking trajectory. They are often the first to recognise thresholds of ill health and distress, and encourage clients to test for HIV, to seek formal care, and to screen for other infections. They accompany clients to the clinics, and provide support for clients on ART. These interventions can involve lengthy interactions with clients, clients' relatives, and the health services. ART clinic staff welcome and rely on this support, viewing home-based caregivers as an extension of the public sector programme. The evolving role of Zambian home-based caregivers in HIV treatment and care is promising, yet raises a number of challenges that need to be considered:

- Home-based caregivers differ widely in training, skills, and legitimacy with regards to their formal links to the health system; training for home-based caregivers has not evolved adequately to equip home-based caregivers with the skills required to support clients' initiation and follow-up on ART.
- Clients of HBC programmes continue to place expectations for psycho-social and physical care, as well as food and material assistance on caregivers. This is challenging for caregivers, who themselves are from low-income backgrounds, generally 'volunteers' with minimal compensation, and in many cases living with HIV themselves.
- Caregivers feel that their increased responsibilities and accountability to the health system are not formally recognized or compensated.
- Caregivers' accounts suggest they are making a difference to the health-seeking of people living with HIV in Zambia, however we have yet to systematically gauge the extent and impact of their interventions on patient outcomes.

4.4.3 Networks of people living with HIV

Uganda has seen rapid growth in networks supporting people living with HIV, which play a vital role in increasing access to treatment and care, and advocacy. A qualitative study, completed at the end of 2010, provided insights into how networks of people living with HIV form, their role in the prevention of HIV and improving access to care and treatment, and the impact on members and people directly and indirectly linked to them. Data were collected from semi-structured interviews with eighty people living with HIV and key informants, focus groups with a total of fifty participants, and narrative analysis. Key messages include:

- People living with HIV join networks for a number of reasons, including material support, as a result of stigma, and for psycho-social support, treatment and care
- The community sees networks as an important support mechanism for people living with HIV, especially those finding treatment adherence difficult
- Networks improve the relationship between people living with HIV and their families, providing a valuable source of information about HIV and treatment
- Networks collaborate with other community groups, so increasing the overall coordination of care for people living with HIV and other vulnerable community members
- Networks play a vital role in supporting people living with HIV who disclose their status, by facilitating integration with the community and enhancing their contribution as role models for other people living with HIV

This study was valuable for gathering further evidence about the level of community and social support provided by networks of people living with HIV in Uganda, as perceived by beneficiaries and stakeholders. Challenges to the provision of universal access to prevention, care and treatment remain, but the positive impact of networks as evidenced in this study confirm their value as a mechanism for improving the quality of life for people living with HIV.

4.5 The influence of global health initiatives on treatment delivery

Global Health Initiatives, such as the US President's Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund to Fight AIDS, Tuberculosis and Malaria, have emerged as new mechanisms for development assistance in health. By 2008, Global Health Initiatives were providing two-thirds of all external funding for HIV globally. In Zambia and South Africa over the past five years, PEPFAR and the Global Fund have provided significant funding for the public sector provision of antiretroviral treatment. Qualitative research in the two countries confirmed that Global Health Initiatives influence the delivery of HIV related services in a range of ways. This includes changes to both policy processes relating to treatment roll-out, and on the actual delivery of services at clinic level.

Funding and capacity provided by Global Health Initiatives enabled rapid treatment scale-up for AIDS. As these Initiatives mature and change – to include a greater focus on health systems strengthening or address maternal and child health – it is important to build on and learn from the momentum and models created.

The processes and mechanisms by which funding is provided influences the delivery of services and health systems' of recipient countries. For example, the Global Fund worked solely through principal recipients in countries and relied on the public health system to provide its support. As a result the organisation was seen as 'embedded', provided more direct funding to governments, but was also much more susceptible to be influenced by the politics within the recipient country.
This contrasts with PEPFAR, which operated largely through US affiliated non-governmental organizations that supported treatment roll-out in many cases by creating parallel systems, rather than investing in the public health system.

The need for sustainable action: While sustainability featured heavily in the rhetoric of different Global Health Initiatives, it remained unclear how this was translated into practice. Treatment programmes examined during the research focused on the short term scale-up with little attention and clear steps towards a sustainable longer-term strategy.

Building long-term human resource capacity: Human resources for health emerged as an area where capacity was most needed and where Global Health Initiatives' impact was most visible. While Global Health Initiatives provided additional staff to the clinics to support service delivery these were often recruited from the public sector, weakening the public sector further.

Need for better coordination at sub-national level: While at national level there was often close collaboration between different Global Health Initiatives and their implementing partners, this was much less the case at sub-national level and especially in the actual delivery of services at clinic level. Coordination between different Global Health Initiatives presented a significant burden on policymakers and programme managers within national ministries of health. This was not considered as a cost by the Global Health Initiatives themselves.

Network support agents in Uganda © the Alliance

5. How should HIV treatment and care be integrated into existing health and social systems?

5.1 Integrating vertical ART programmes with the health system

Vertical ART programmes were established in many countries to enable rapid scale-up of ART delivery. This was partly driven by the growth of disease-specific funding. These vertical programmes have been successful in dramatically increasing the number of people on ART in low and middle income countries. However, the sustainability of this structure has been questioned, and there is consensus that ART needs to be more integrated into the wider health system.

Research in Zambia has found that the ART programme has eased the workload in outpatient and inpatient clinics that were previously overwhelmed, through the reduction in HIV morbidity. However, the vertical ART programme has also highlighted weaknesses in the health system that must be addressed. Priority areas for further integration include:

- **Health information:** work needs to be done to increase the efficiency of information systems (including reducing the number of data collection methods, reporting formats and harmonising indicators). Quality assurance also needs to be addressed to ensure there are no differences in quality of care between sites.
- **Health workforce:** Incentives for health workers need to be harmonised, as those who are not receiving HIV-related incentives may feel demotivated. Additionally, HIV-related incentives could draw healthcare workers out of general health services towards specialised HIV care. Coordination of training is important to minimise disturbance to service provision. Expanding ART training curricula to include basic training on other health issues (eg. TB, malaria, nutrition, child health) could help to strengthen the health system and promote integration.
- **Health service delivery:** Efforts are being made to improve linkages between HIV and other services (eg. TB, PMTCT). There may also be significant advantages to introduce screening for other conditions (eg. mental health disorders, diabetes, cardiovascular disease) within ART service delivery models. The benefits and drawbacks of integrating ART delivery within general outpatient clinics need to be explored empirically.

5.2 Global health initiatives' views on integration

Over the past few years a renewed focus on the principles of primary healthcare has led to calls for greater integration of disease-specific programmes, notably treatment for HIV, into health services with the ultimate aim of strengthening health systems. We carried out a study to understand how the Global Fund to Fight AIDS, TB and Malaria, the Global Alliance for Vaccines and Immunisation (GAVI), PEPFAR and the World Bank envision the integration of HIV services with health systems, and to examine their strategies to support this at country level.

Many actors emphasised the importance of integrated services. However the understanding of what constitutes an integrated service varied between actors, including those working within the same organisation. It ranged from integration at upstream level, to integration of actual services delivered at clinic level. Others took integration to mean harmonization of activities between different initiatives and actors funding or implementing services at country level. This suggests that at country level there will be an array of different strategies and initiatives employed to achieve integration.

Initiatives and agencies will need to pay specific attention at all levels to ensure the efforts to integrate services at sub-national and point of care levels are actually harmonized and integrated themselves. This is particularly important to avoid some of the burden of coordination on countries and health workers that had been part of the early criticism of the large-scale disease specific programmes.

Many of the actors interviewed referred to national health strategies as a potential instrument to ensure greater integration between donors or agencies. While actors' discussion of integration focused on these aspects of harmonization, this was not necessarily linked to the integration of actual services. A disconnect between these different, related efforts at country level may present a missed opportunity and unnecessarily increase the burden of coordination and work on recipient countries' health services.

5.3 Integrating TB and HIV services

TB is the leading cause of morbidity and mortality among people with HIV in most parts of the world. The need for collaboration between TB and HIV services is recognised internationally. Patients with both HIV and TB often have to navigate two separate health care programmes, which can lead to additional time and transport costs. Effective coordination of TB and HIV services is vital to ensure that patients access the care they need from both services to ensure the best health outcomes.

A systematic review of how TB and HIV services have been integrated in practice suggests five models of integration of HIV and TB services: TB service refers for HIV testing and treatment; TB service tests for HIV and refers for treatment; HIV service refers for TB screening and treatment; HIV service screens for TB and refers for treatment; TB and HIV services provided at a single facility.

Models based on referral require minimal extra resources, but are dependent on a robust referral system. When TB services provide HIV testing, and HIV services screen for TB and then refer for treatment, some additional staff training and infrastructure may be needed. This level of integration is likely to benefit patients in most settings. Single facility models reduce the transport costs and patient time needed to access both services, and should save staff time, but may require significant investment.

There are a number of barriers to integrating TB and HIV services:

Service delivery

- service users unaware, or unconvinced, of the importance of testing for HIV or TB
- users reluctant to undergo testing because of stigma
- in models based on referral, barriers to access of the relevant service include: distance between facilities, cost of travel, being too ill to travel, inconvenient opening hours; staff using inappropriate criteria to decide which patients need testing
- in models based on referral, poor communication between services, and failure to share information concerning the care of individual patients
- facilities not designed to facilitate infection control for TB
- lack of private space for HIV counselling and testing
- data recording systems poorly designed for integrated care

Human resources

- lack of staff trained to manage both HIV and TB
- high staff turnover, requiring continuing training activities
- in models where additional activities are introduced, staff already overburdened
- staff attitudes: not motivated to carry out co-ordinating activities, particularly if this is perceived as extra work; may be reluctant to implement HIV testing early in TB treatment

Supply of medicines and products

- unreliable supplies, including drugs for treatment and prevention, and tests for diagnosis and screening

Facilitators of integrated TB and HIV services

- training activities that bring staff from both services together
- having a member of staff with responsibility for integration activities

Integrated tuberculosis and HIV care in a resource-limited setting: experience from the Martin Preuss Centre, Malawi

The Martin Preuss Centre in Lilongwe, Malawi, offers integrated HIV and TB care in a single facility. The building is designed to help patient flow and infection control. Coordinated leadership, joint staff training and meetings, and data systems that prompt coordinated care help to integrate treatment for the two diseases. There has been considerable success with some aspects of integrated care from the start of the centre. For example, 96% of TB patients had documented HIV status in 2009. Encouraging uptake of ART among HIV-positive TB patients has been more challenging. The Centre has had good TB treatment outcomes among both HIV-positive and HIV-negative patients, with more than 85% cured or completed treatment. The Martin Preuss Centre shows that high quality integrated HIV and TB services can be provided in resource-limited settings.

Overall, few data compare outcomes between different models of care, so it is difficult to know which model works "best"; this may vary with HIV prevalence among TB patients. Providing HIV testing on site for all TB patients, and regular screening for TB among all HIV patients, are likely to benefit patients in all settings. Closer integration may require more investment and requires effective control of TB transmission among immunosuppressed patients, but has potential benefits for patients and efficiencies for health systems, particularly where HIV prevalence among TB patients is high. Standard outcomes measures are needed to facilitate comparisons, and research is needed to compare patient-relevant outcomes.

6. How best can new evidence from research be rapidly translated into new policies and actions?

6.1 How evidence on cotrimoxazole preventive therapy influenced policy

Researchers are often encouraged to conceptualise health policy making as an evidence-based process in which rational choices regarding cost and efficacy are weighed up and decisions made either in favour or against scaling up an intervention. Yet policy processes often stall even when there is ample, well disseminated evidence, while in other cases evidence is taken up quickly and programmes are swiftly implemented.

Concerns have been raised about the lack of scale up of cotrimoxazole preventive therapy for HIV related illness in resource poor settings, despite a substantial research base demonstrating its efficacy and cost effectiveness for both adults and children. To understand what had influenced the uptake of evidence into national policy we conducted research across three African countries (Zambia, Malawi and Uganda). The countries provided insightful case studies: each of the countries hosted high profile research projects on the efficacy of cotrimoxazole preventive therapy (thus providing a local evidence base) but had very different trajectories in terms of their policy process. We examined the way in which the available evidence (including research and international policy), national context and links between researchers and policy makers influenced the take-up of evidence into national policy in these three countries.

A nurse dispensing cotrimoxazole
© Benson Droti

Evidence

Both the type of evidence available and the ways in which its significance was interpreted by clinicians and policy makers were central to the ways in which the policy making agendas were constructed in all three countries. In Zambia, the country which created its policy the latest, three randomised controlled trials were conducted on adults and children, but no operational research was undertaken. In Uganda and Malawi, where policy was created more rapidly, the fact that operational research had been conducted which specifically sought to answer questions pertinent to policy makers about how the intervention might be scaled up, its potential cost, and impact on other treatments, was considered to have been central to the successful translation of research into policy.

Researchers also need to frame the research results in an effective manner. In Zambia, for example, as a well known and widely used medication, the evidence on cotrimoxazole preventive therapy was at first seen as something that would influence clinical practice but would not require new national guidelines or policy.

Context

The economic and political context in which the research on cotrimoxazole preventive therapy was undertaken had a specific impact on the perception of the usefulness of the research results for the needs of the population. Politicised debates about other issues, such as the discussions around ART, can dominate the agenda and obscure other research findings. But, just as policy context can hinder the take up of research results, it can also provide an enabling environment. In Malawi, where resources to scale-up activities for HIV treatment were very limited, the National TB Control Programme had secured funding and was actively looking for bio-medical approaches to reduce HIV deaths among TB patients. The National TB Programme worked in close collaboration with the researchers and quickly translated the research into policy, which could then be swiftly implemented within an existing programme.

Links

All three countries revealed the importance of having key actors to facilitate the evidence to policy processes. Key individuals, known as policy entrepreneurs, were able to make sure that cotrimoxazole preventive therapy remained a priority on the agenda, pushing through policy change when it appeared that the process was stalling. In each case, these key individuals were found to be well linked into critical national networks, in both the research and policymaking community.

Our research demonstrates that while the creation and dissemination of evidence is an essential element to most policy creation processes, it is only one aspect that governs the ways in which policy making occurs. Political and economic context and the links between researchers and policy makers constitute essential elements in health policy processes.

6.2 Where policymakers get their information from

It is important that policy decisions are based on the best available evidence. This is particularly the case with resources for HIV programmes becoming more limited. It is also being increasingly seen as important for researchers to communicate the results of their work to policymakers and other stakeholders working in related areas. In order to do this effectively, researchers need to know which sources of information policymakers use.

Evidence for Action, working together with TARGETS and COMDIS research programme consortia, asked HIV, TB and malaria policymakers in China, Nepal, Pakistan, Malawi, Uganda and Zambia which sources of information they used for important policy decisions. African policymakers emphasised the importance of the World Health Organisation (WHO) in influencing policy and sharing information. International donors were also seen as providing evidence and influencing some policies. Asian policymakers reported in-country research and surveillance as particularly important.

The influence of WHO was seen to be particularly important for decisions around treatment regimens. Technical recommendations from WHO were highly regarded. In contrast, policy decisions around targeting, scope and strategy were more often said to be influenced by national surveillance data.

These findings offer an insight into how researchers may target communication of their results in order to reach policymakers and influence decisions – and how the nature of the research question or issue may lead to differing strategies. In Africa, it appears that research findings will have more influence if they are communicated via WHO, or if the WHO recommends a policy incorporating that research, while in Asian settings it may be more important to work through local channels and ensure evidence is being driven internally. Other research programmes may find it useful to carry out similar basic research into where their target audiences get their information from, in order to guide communications strategies.

6.3 How Evidence for Action has influenced policy and practice

The purpose of the Evidence for Action research consortium was to carry out policy-relevant research on HIV treatment and care systems that influences policy and practice. Throughout the course of the programme, Evidence for Action partners have been engaging closely with key stakeholders, including national policymakers and practitioners.

The policymaking process is often complex, and is influenced by many factors, of which research is only one. It can take considerable time for research findings to be incorporated into policy and practice. Evidence for Action research has already started to influence policy practice. For example:

- In Malawi, operational research carried out by Lighthouse has resulted in the national roll-out of new tools for monitoring and evaluating PMTCT.
- A new training module on stigma and health workers, developed by ZAMBART and the International HIV/AIDS Alliance, has been adopted by a steering committee made up of UNDP, UNAIDS, ILO, GNP+, WHO, ICRW, International HIV/AIDS Alliance, and Engender Health. The module will be used for pre-service and in-service training of health workers, and is designed to reduce stigmatisation of people living with HIV and other key populations by health workers. The module is designed for use globally.
- Peripheral health centres in Uganda that were involved in the Wakiso project have continued to provide ART for patients since the end of the project, reducing the transport costs and time needed for patients in rural areas to access treatment.

Evidence for Action has also influenced the academic discourse. For example, an opinion piece published in the Lancet has led to considerable online comment on the concept of ‘getting research out of practice’.

It is likely that Evidence for Action research will have further impact on policy in the coming years. Areas where we expect to see impact over the next few years include increasing attention paid to the mental health needs of people living with HIV based on our research in India, Uganda and Malawi. The LabLite project that has recently started is focusing on demonstrating ways in which the recommendations from the DART trial can be implemented in resource-limited settings. We hope that this will lead to more countries adopting a ‘LabLite’ approach, which could help countries to expand access to ART despite the flat-lining of resources for HIV.

Evidence for Action has already had a considerable impact in increasing the capacity of partner organisations to carry out and effectively communicate policy relevant research. Activities carried out have included workshops on paediatric HIV care; communicating research; carrying out qualitative research; dealing with the media; and developing proposals. Exchange visits and twinning of researchers from different organisations have taken place. Staff members have completed training in a wide range of topics, including the use of SMS messages to encourage adherence to treatment. Links between the partner organisations have been strengthened. The impact of these activities will continue after the programme finishes.

7. Conclusions and Recommendations

A number of issues are raised repeatedly in this report. Firstly, the vital importance of ART: the increase in coverage over recent years has led to major improvements in the survival, health and quality of the lives of millions of people living with HIV. Older people on ART in Uganda even report better quality of life than HIV negative age-mates. Our research on how to deliver ART has identified several strategies for expanding access to these life-transforming drugs. Getting people onto ART earlier, as recommended in the revised WHO treatment guidelines, raises new challenges. Even when people are identified as HIV-positive, such as through PMTCT programmes, there are too many opportunities being missed for enabling them to get on to ART for their own health. Efforts are urgently needed to improve coordination between different parts of the health system to reduce these missed opportunities.

The need for improved monitoring and evaluation, and for better, more usable health information systems, also come up repeatedly. Despite the large amount of time spent by healthcare workers completing monitoring information, there are problems with data quality, the validity of indicators, lack of indicators about treatment outcomes for children, and lack of knowledge about which indicators best predict treatment outcomes. Even the data that are collected are not being made to work as effectively as they might, for example, due to a pervasive lack of sharing of health information between different health services (eg. TB and HIV clinics, antenatal clinics and HIV services). These problems make it difficult to assess how programmes are performing, and mean patients get lost between separate clinics or components of the health service.

Operational research to answer the questions faced by HIV treatment and care programmes in low and middle-income settings is vitally important, especially given the tight financial and human resource constraints they operate under. We hope that the findings in this report will encourage more research funders to provide resources for this kind of research.

7.1 Recommendations for policy

7.1.1 What ‘package’ of treatment and care services should be provided in different settings?

- Revise recommended indicators for monitoring and evaluating paediatric HIV care to include more focus on paediatric care of HIV-infected children after infancy
- Use scored tablets rather than syrups for treating children to reduce costs, transport and storage problems, and to simplify dosing
- Provide ART to refugees and internally-displaced peoples who need it, along with adherence support that is specifically tailored to their needs
- Integrate mental health screening and treatment into all levels of HIV services - screening can be done through simple tools that can be administered by lay workers

7.1.2 How should HIV treatment and care services be delivered?

- Explore strategies for further expanding access to ART at affordable costs, such as by using peripheral health centres and home-based care and a judicious mix of professional and lay health workers
- Expensive laboratory tests are not necessary or cost-effective for routine monitoring of patients on ART, only for diagnosis, or if they are clinically indicated

7.1.3 How should HIV treatment and care be integrated into existing health and social systems?

- Better coordination is needed of the activities of different global health initiatives, especially at the sub-national level
- HIV and TB services must be coordinated effectively. Providing HIV testing on site for all TB patients, and regular screening for TB among all HIV patients, are likely to benefit patients in all settings. Closer integration may require more investment and requires effective control of TB transmission among immunosuppressed patients, but has potential benefits for patients and efficiencies for health systems, particularly where HIV prevalence among TB patients is high.

7.2 Recommendations for practice

7.2.1 What 'package' of treatment and care services should be provided in different settings?

- Adolescents are neither big children nor little adults, and there is a need for health systems to provide specific ongoing psychosocial support and youth-friendly services for adolescents living with HIV
- HIV is one of multiple health problems of older women and men. Health services and community systems need to be in place to identify and address those problems in an age friendly manner
- Increase the efficiency of information systems, including reducing the number of data collection methods, reporting formats and harmonising indicators

7.2.2 How should HIV treatment and care services be delivered?

- Simplify patient pathways from antenatal and maternity services into HIV treatment programmes, both for infants and for women diagnosed as being HIV-positive
- Improve coordination between antenatal services and HIV treatment clinics, including integrated patient monitoring within a single, individually-linked health record system
- Provide training to health workers on identifying burnout and developing coping mechanisms, in order to reduce absenteeism and attrition
- Provide multiple options for health workers to access HIV testing, treatment and care, addressing concerns about confidentiality
- Home-based care programmes need to provide on-site supervision, regular on-the-job-mentorship and psychosocial and stress management support to home-based caregivers.
- Home-based care programmes should develop appropriate 'exit strategies' for caregivers in parallel with adequate provision to train and support family members to assume greater responsibility for caring for their relatives living with HIV

7.2.3 How should HIV treatment and care be integrated into existing health and social systems?

- Harmonise incentives for health workers within HIV treatment and other health services
- Coordinate training of health workers to minimise disturbance to service provision
- Major donors and international agencies should harmonise their efforts to integrate services at the sub-national and point of care levels
- Standard outcome measures are needed to facilitate comparisons between different HIV and TB programmes

7.3 Recommendations for research

7.3.1 What 'package' of treatment and care services should be provided in different settings?

- Research is needed on how to address alcohol use problems among people living with HIV
- Develop simple methods by which communities can identify older people in need of care and support in the context of the HIV epidemic, and identify and evaluate the most cost effective and feasible health services (integrated management of health care) for older people living with HIV (and on ART)
- Evaluate current indicators to determine which can best predict longer-term outcomes in the patient population

7.3.2 How should HIV treatment and care services be delivered?

- Document and systematically assess the potential impact that home-based caregivers can have on the health and health-seeking behaviours of persons living with HIV.

7.3.3 How should HIV treatment and care be integrated into existing health and social systems?

- Empirically explore the benefits and drawbacks of integrating ART delivery within general outpatient clinics
- Compare patient-relevant outcomes from different models of HIV and TB integration

7.3.4 How best can new evidence from research be rapidly translated into new policies and actions?

- Investigate where the policymakers you want to influence get their information from, in order to communicate effectively with them

Sarojana, HIV positive widow
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- What 'package' of treatment and care services should be provided in different settings?
- How should HIV treatment and care services be delivered?
- How should HIV treatment and care be integrated into existing health and social systems?
- How best can new evidence from research be rapidly translated into new policies and actions?

Further information about the work of the programme, including abstracts and full texts of journal articles, policy briefs, case studies, reports and other outputs can be found on the accompanying CD-ROM, or **www.evidence4action.org**.

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