Developing a Framework for Better living with HIV in England

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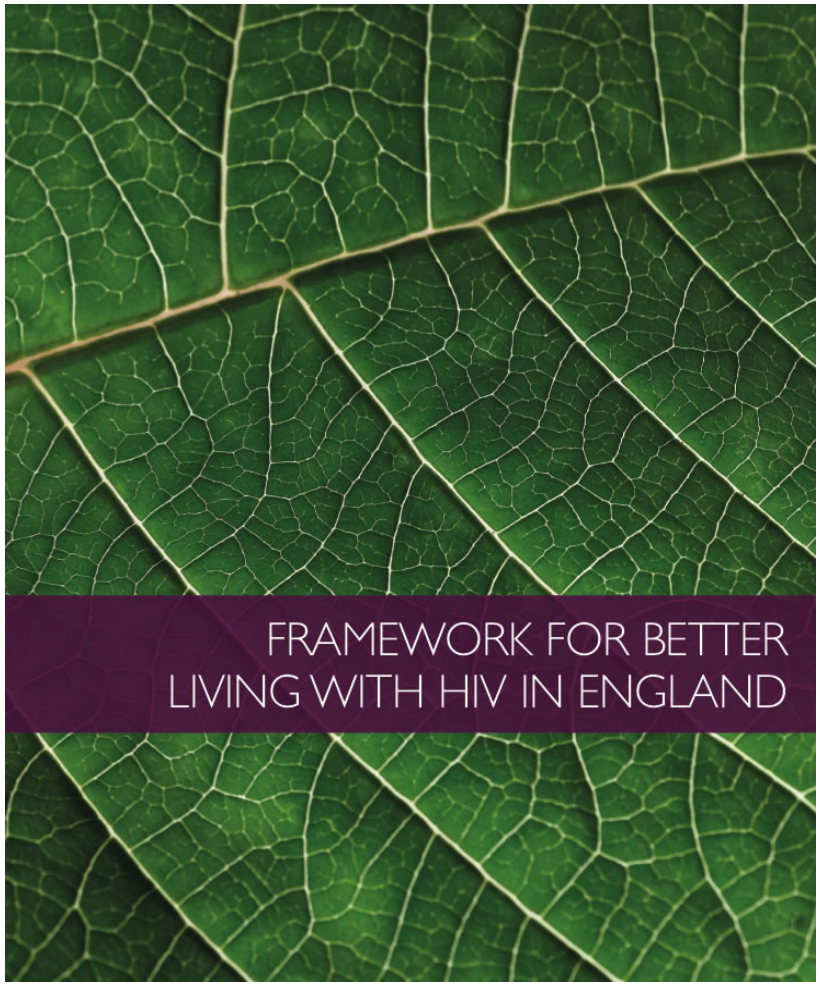
Implemented:

Not yet ?!



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Background: changing population

Changes to the size and make-up of the population of people with HIV in England.

- Improvements in morbidity and mortality.
- 85% of the population of PWHIV made up gay, bisexual, homosexually active men OR African migrants to the UK.

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Background: changes in services

Changes in statutory and VCS service response.

- Little or no strategic interagency service planning or coordination.
- HIV prevention, care and treatment in competition, and are often conflated.
- End of ring-fenced budgets and rise of PCT commissioning of services.
- Unplanned and uncoordinated shrinkage of voluntary and community sector.
- Mainstreaming of specialist HIV social care services.

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Background: changing context

Variable government policy & action.

- Prevention and treatment strategies, but nothing on social care.
- No coordination of disparate responses.
- HIV perceived to be losing policy prominence.
- Some policies detrimental to health and well-being of people with HIV.

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Overall framework goal

All people with HIV are enabled to have the maximum level of health, well-being, quality of life and social integration.

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Overall purpose (I)

An evidence–based framework to:

- Promote and protect the rights and well-being of all people with HIV in England;
- Maximise the capacity of individuals and groups of people with HIV to care for, advocate and represent themselves effectively;
- Improve and protect access to appropriate, effective and sufficient information, social support and social care services;

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Overall purpose (II)

An evidence–based framework to (continued):

- Minimise social, economic, governmental and judicial change detrimental to the rights and well-being of people with HIV;
- Build consensus among those with a responsibility for promoting the well-being and rights of people with HIV;
- Provide benchmarks against which the activities of a range of key stakeholders can be assessed, critiqued and coordinated.

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Framework is informed by:

- Theory
- Ethics
- Principle of co-production

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Theory: health promotion theory specifies 5 areas for interventions

Building better public policy

Putting health on the agenda of policy makers in all sectors and at all levels.

Creating Supportive Environments

Generating living conditions that are safe, stimulating, satisfying and enjoyable.

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Theory (continued)

Strengthening community actions

Strengthening and empowering communities enabling them to set priorities, make decisions, plan and implement strategies to achieve better health.

Developing personal skills

Supporting personal and social development through providing information, education for health, and enhancing life skills.

Reorienting health services

Individuals, community groups, health professionals, health services, and governments need to work together towards a health care system which contributes to the pursuit of health.

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Ethics

- The framework is a product of the ethics and values of those agencies and individuals involved in its development.
- The framework adopts a liberal ethical approach, defining rights in their broadest sense. That is, enshrined rights, case law rights (rights through remedy) as well as positive duties (with regard to organisations).
- The framework emphasises the right of the individual to make informed choice ('you decide') rather than proscribing or prescribing the 'right' course of action ('we decide') while being mindful of the conditions needed to allow choice.

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Co-production: development group

Peter Keogh	Sigma Research
Jane Anderson	Homerton University Hospital
Yusef Azad	National AIDS Trust
Michael Carter	NAM
Elisabeth Crafer	Positively Women
Sinead Cregan	Leeds City Council
Chris Morley	George House Trust
Priscilla Nkwenti	Black Health Agency
Will Nutland	Terrence Higgins Trust
Roger Pebody	Terrence Higgins Trust (then NAM)
Rhon Reynolds	African HIV Policy Network
Jack Summerside	UK Coalition(as was)
Peter Weatherburn	Sigma Research

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Research: development process

- Development group identified 20 areas of social care need.
- Researchers designed a survey with corresponding items.
- Survey items underwent consultation with 110 VCS, statutory and clinical service providers.
- Survey distributed through same organisations (in booklet form) and promoted for completion online.

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Research: areas covered

- Immigration / asylum
- Housing and living conditions
- Eating / drinking
- Sleep
- Household chores and self- care
- Mobility and ability to get about
- Money and income
- Alcohol and other drugs
- Anxiety and depression
- Self-confidence and self- esteem
- Relationships with friends
- Relationships with families
- Relationships with partners
- Looking after children
- Sex and sexual health
- Access to information about living well & HIV
- Taking anti-HIV treatments
- Skills and training
- Work
- Discrimination

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On-going research

- *What do you need?* (2007-08)

- Project *NASAH* (2002-03)
- *What do you need?* (2001-02)
- Proceeding with care (2000)
- Taking Heart: UK-wide survey (1999)
- Impact of combination therapies on the lives of PWHIV (1997-98)

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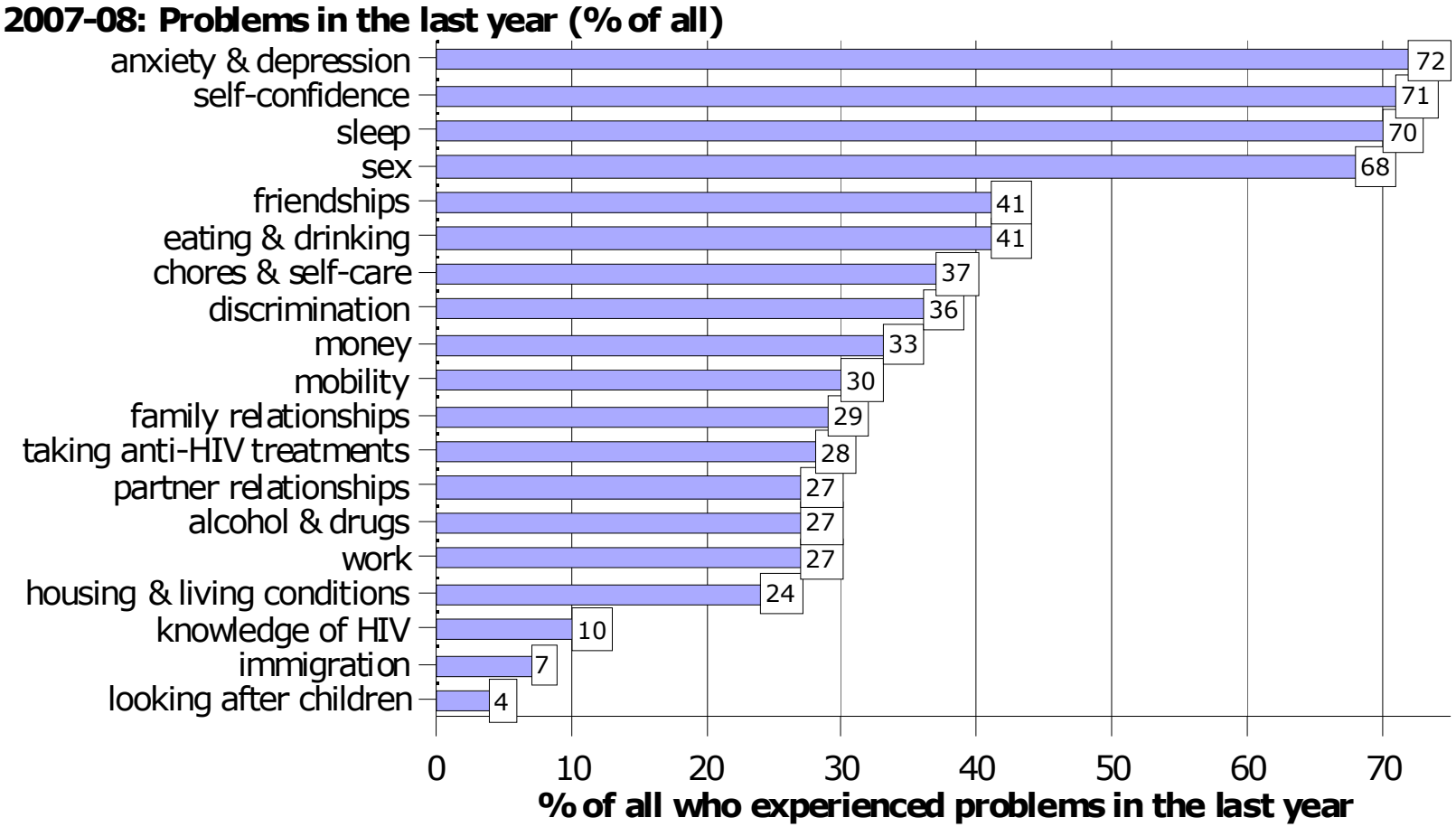
WDYN 2007-08



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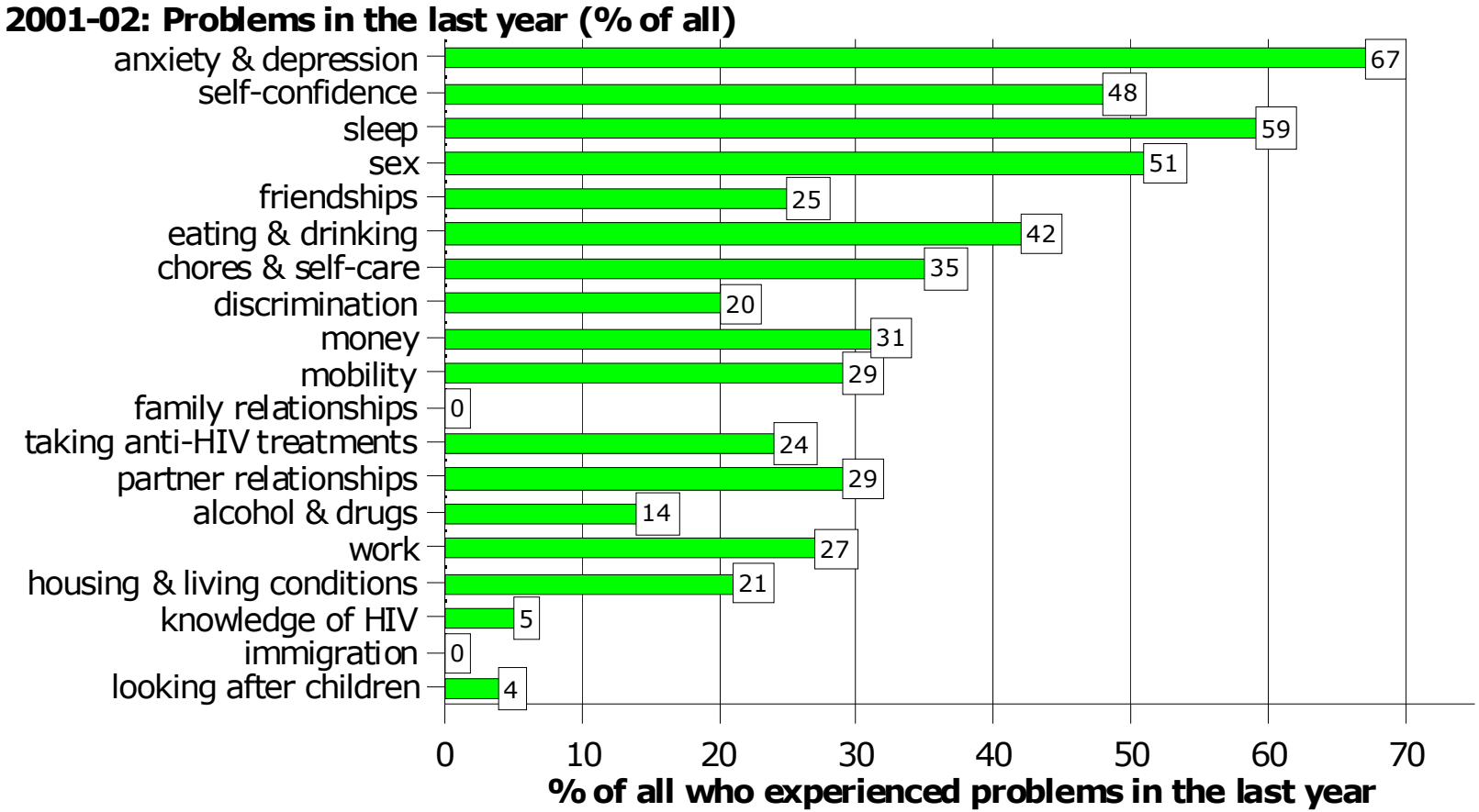
WDYN 2001-02



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Drafting the Framework

- The framework document was developed by the drafting group using the expertise of individual members and informed by the research findings.
- 17 key goals were identified in relation to the needs investigated.
- The drafting process was co-ordinated by the research team.
- The framework document went out to consultation to all members of the development group.
- The final document was consulted on across the sector prior to sign off and publication.

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Framework goals (1)

Basic requirements for health and well-being

- Goal 1: Freedom from poverty or destitution
  - Financial poverty aims
- Goal 2: Adequate accommodation
  - Housing aims
- Goal 3: Sufficient nutrition
  - Nutritional aims
- Goal 4:Child welfare
  - Aims for children
- Goal 5: Access to employment and, education
  - Employment and education aims
- Goal 6: Access to information
  - Information aims
- Goal 7: Sexual health
  - Sexual health aims
- Goal 8: Reproductive health
  - Reproductive health aims

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Framework goals (2)

Health and social care services

- Goal 9: Appropriate social care services
  - Social care service aims
- Goal 10: Appropriate primary care services
  - Primary care aims
- Goal 11: Appropriate mental health services
  - Mental health service aims
- Goal 12: Appropriate drugs services
  - Drugs service aims
- Goal 13: Appropriate alcohol services
  - Alcohol service aims

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Framework goals (3)

Government, society and community

- Goal 14: Government policy
  - Aims for government
- Goal 15: Freedom from discrimination
  - Discrimination aims
- Goal 16: Support from communities
  - Community support aims
- Goal 17: Immigration
  - Immigrations aims

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Goal 1: No person with HIV in England lives in financial poverty or destitution.

An HIV diagnosis is never the cause of an individual (or their dependants) entering a state of financial poverty.

All people with HIV are able to develop the capacity to end their state of financial poverty and enhance their personal wealth.

Communities have the capacity and the motivation to counter financial poverty caused or exacerbated by HIV infection.

All statutory education, health, social, custodial and legal services have the capacity and the motivation to counter financial poverty caused or exacerbated by HIV infection.

All voluntary and community sector (VCS) services and charities have the capacity and the motivation to counter financial poverty caused or exacerbated by HIV infection.

Central Government policy and practice does not promote or exacerbate financial poverty caused or exacerbated by HIV infection, and should seek to end it.

Local Government policy and practice does not promote or exacerbate financial poverty caused or exacerbated by HIV infection, and should seek to end it.

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Goal 4: All children with HIV grow-up in security

All children with HIV are supported to achieve optimal health and well-being.

No child faces discrimination or reduced life opportunities because they have HIV.

All communities have the capacity to care for their children with HIV.

The welfare of children remains the paramount concern of all government policy which impacts on, or concerns children and young people with HIV (including legislation and policy on child welfare, immigration, education, justice & poverty).

All clinical HIV services can offer or refer to appropriate paediatric services.

All clinical HIV services have appropriate models of care with integrated care pathways for transitional services.

All statutory health and social care providers can meet the needs of children and young people with HIV.

All voluntary and community children's agencies have the capacity to meet the needs of children and young people with HIV and / or to make referrals to other services.

All clinical mental health services have the capacity to meet the needs of children and young people with HIV and/ or to make referrals to other services.

All schools and educational settings have policies in place which are appropriate to children or young people with HIV and which include policies on confidentiality, management of medicines, pastoral support and reintegration after absences.

All schools and educational settings access HIV awareness training for staff.

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Goal 7: All people with HIV have the highest attainable standard of health in relation to sexuality.

All people with HIV can pursue a satisfying, safe and pleasurable sexual life.

All people with HIV have the capacity to deal with dilemmas and issues concerning disclosure and transmission during sex.

All people with HIV can have a consensual sexual life without fear of prosecution.

All people with HIV have free access to the full range of clinical sexual health services for treating and managing their HIV infection delivered in a range of settings, and these services are administered according to nationally agreed guidelines (from the BHIVA and BASHH).

All people with HIV have access to a range of other medical interventions including the diagnosis of sexually transmitted infections, vaccinations (such as Hepatitis A and B) and other medical technologies (for example post-exposure prophylaxis) to increase their confidence, capacity and enjoyment regarding sex and reproduction.

All people with HIV have access to a range of written and talking interventions, to increase their confidence, capacity and enjoyment regarding sex, reproduction and relationships.

All people with HIV have access to free high quality counselling and support to ensure good sexual and reproductive health including relationship support services.

All people with HIV have access to free information and treatments for sexual dysfunction.

All people with HIV have access to free information about the effects of super-infection, drug-resistant infection, infection with STIs and hepatitis, including how to avoid these infections, where and how to test for them, how to identify symptoms and the range of treatments available.

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Goal 17: No person with HIV suffers decreased health or well-being because they are a migrant to the UK.

All migrants to the UK (documented and undocumented) with HIV have the capacity to negotiate the immigration and asylum system appropriate to their situation.

All migrants to the UK with HIV have access to free healthcare.

All migrants to the UK with HIV have access to benefits and social care.

All migrants to the UK with HIV have access to community support.

All asylum seekers to the UK with HIV have an automatic right to seek employment after six months residence.

No business, employer or service provider discriminates against someone or provides inferior goods or services to them because they are a migrant.

Current government policy and practice on immigration and asylum is made consistent with good public health practice and enhances the health and well-being of migrants or asylum seekers with HIV.

The welfare of the child should be the sole and paramount concern of all government policy and practice which impacts on, or concerns children and young people with HIV (including legislation and policy pertaining to child welfare, immigration, education, youth justice and poverty).

All statutory and VCS migrant and asylum support agencies have the capacity to provide services to people with HIV and to refer to other services.

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Next steps …

1. How do we build consensus and buy-in?

2. The Framework cites *evidence, goals, aims* and *objectives*. How do we operationalise the Framework into *actions, interventions, approaches* and *services?*

3. How do we share knowledge around actions, interventions approaches and services?

4. How do we benchmark progress against the goals, aims and objectives of the Framework?

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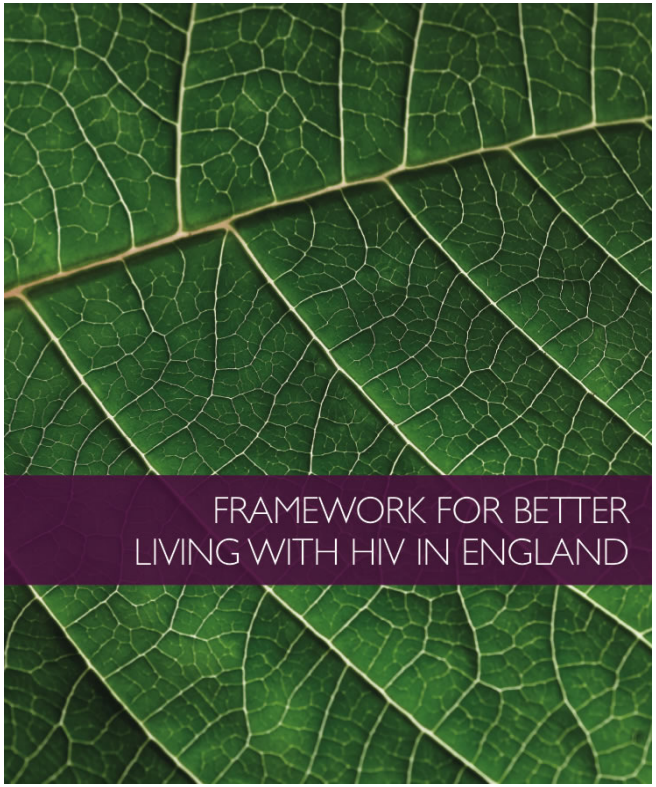
Available free of charge at

www.sigmaresearch.org.uk



www.whatdoyouneed.org.uk

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Thanks …

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