

LifePlus

A new range of services transforming care for people with HIV.



LifePlus is a revolutionary new set of online and face-to-face HIV support services in the UK which will:

1. transform the way people manage HIV as a long-term condition
2. reduce the number of people with HIV who drop out of specialist health care services and so are not adhering to expensive medical treatment, running the risk of drug resistance
3. help clinicians maximise the health of their patients and focus clinical expertise where it is most needed, thus relieving pressure on the NHS to address patients' non-clinical needs
4. produce data, over time, that tracks changes in health management with better health outcomes and time/cost savings
5. foster a strong patient-GP relationship, supporting prompt diagnosis, patient retention and more planned/costed treatment at GP commissioning level.

These services have been designed to combat the systematic and progressive social, financial and health disadvantages that face people with HIV throughout their lives post-infection (threatening the efficacy of their medical care), and maximise their ability to participate in and contribute to society and lead a full life.

The programme is designed to see HIV care as a continuum in which the type and intensity of support at different stages is tailored to the individual rather than 'one size fits all'. Unlike many care paradigms, it promotes wellbeing and health management rather than reactive support to ill health.

The services will be launched 27 January at St Thomas's Hospital, London by Sir Elton John and the Rt. Hon. Andrew Lansley MP, Secretary of State for Health, who will be shown a simulated demonstration of the services as they are typically delivered.

Why do people living with HIV need this?

HIV remains the UK's fastest growing serious health condition. There are around 86,500 people living with HIV in the UK and around 7,000 newly diagnosed each year. It is also amongst the most challenging illnesses, not least because of significant stigma still associated with the disease that prevents people from openly seeking information, advice and treatment or sharing their diagnosis with others.

Thanks to extraordinary advances in medical science and clinical management, life expectancy post-HIV diagnosis has changed from 18-20 months to 20-30 years in high income countries and all but eliminated transmission of HIV from mother-to-baby.

These fantastic developments mean we must now reap the rewards of so much time, effort, and resource by adapting healthcare

management so that people can live healthily with their condition over decades.

As one of the most challenging illnesses on earth, HIV has consistently catalyzed new developments – the 'living will', 'expert patients', massive drug price reductions. LifePlus is part of that tradition. It will move the agenda on chronic care in a way that helps people with HIV manage their condition; safeguards the medical investment in their treatment, and saves time and money for the health service. It

also holds potential for the management of many long term chronic conditions.

How LifePlus came about:

1. LifePlus has been funded by the Elton John AIDS Foundation, and developed by Terrence Higgins Trust in partnership National AIDS Manual (NAM) (for the most accurate, up-to-date clinical reference), and George House Trust (to test the range of non-clinical service delivery needs).

2. The services are a product of voluntary sector innovation, private funding and NHS partnership. They have been developed and informed not only by people living with HIV, but healthcare professionals and a programme advisory board (see Annex I)

3. With increasing pressures on healthcare, services are designed to save the NHS time and money. HIV is a complicated condition. Like many long term chronic illnesses, it has a significant social care dimension – employment, confidentiality, isolation, emotional toll etc. Research has shown that greater understanding, knowledge and ownership of factors that influence health results in better health for people with HIV, and less emergency and chronic care costs for the health service^{1,2}.

4. The project is entirely led by people with HIV right the way through from conception, to design, testing the website and every page of its information, to many of the health trainers having personal experience of living with HIV.

5. The services are outcomes focused and have been developed around quality standards and a clear monitoring and evaluation framework. There is a comprehensive evaluation and impact

How will LifePlus work?

1. Dedicated community and clinic-based Health Trainers provide support in five cities of highest HIV prevalence around the UK (Glasgow, Cardiff, Brighton, Birmingham and Manchester) for patients in periods of acute social care need, particularly immediately post HIV diagnosis when non-medical barriers can threaten HIV treatment uptake and adherence.

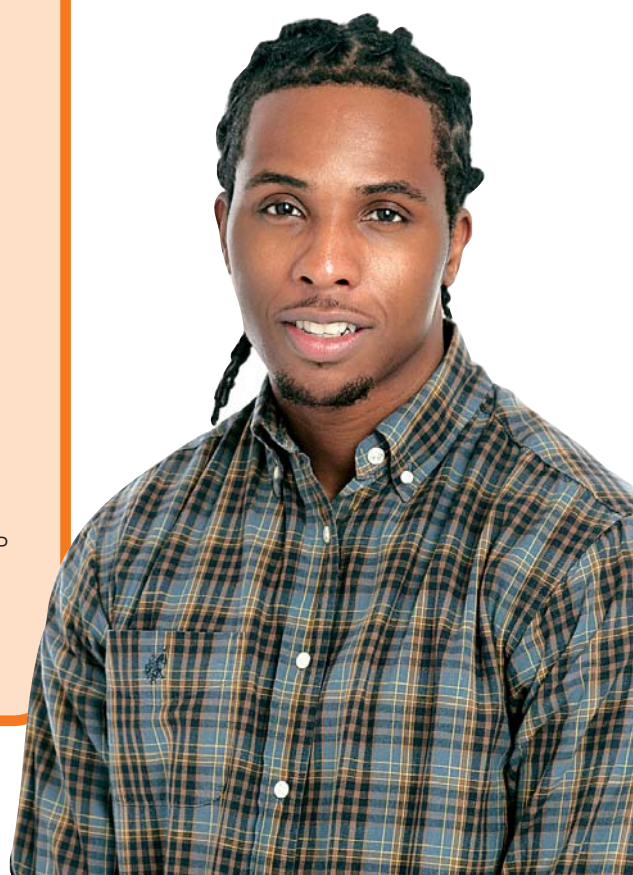
2. As patients absorb the implications of their diagnosis and start to think about managing their condition, (or for those already at this point) they graduate to an innovative web based platform (MyHIV.org.uk) that provides information and tools to help monitor and manage their own health (and medical data), access online, interactive counselling, and identify existing services that best meet their social care needs. This means current services are optimised before creating new, 'siloes' support.

3. The programme also uses new technology to foster peer-led support: personal films from an individual 'like you' on life after HIV diagnosis; a group of HIV-positive health trainers who are successfully managing their own condition, and secure, confidential online support and discussion groups.

4. Also a first, the LifePlus service not only links to Terrence Higgins Trust's own services but acts as a gateway to a huge range of other voluntary and statutory services (local and national). Where face-to-face support is not available or patients are having difficulty accessing online information, Terrence Higgins Trust's telephone support is available. The aim is that collectively these elements help individuals pinpoint their specific needs; find the most relevant services to address those needs and be able to monitor their health as a result (see Annex I for project pathway). The web based technology even allows them to recommend and 'rate' the service they receive, creating an evolving, dynamic quality assurance for new users.

5. The programme has developed specific metrics to measure short, medium and long term progress, including:

- treatment adherence
- time savings for healthcare providers
- clinic attendance
- register and engagement with GP provider
- improvements in healthy living (diet, addictions etc).



analysis built into the framework, enabling the service to respond to user feedback

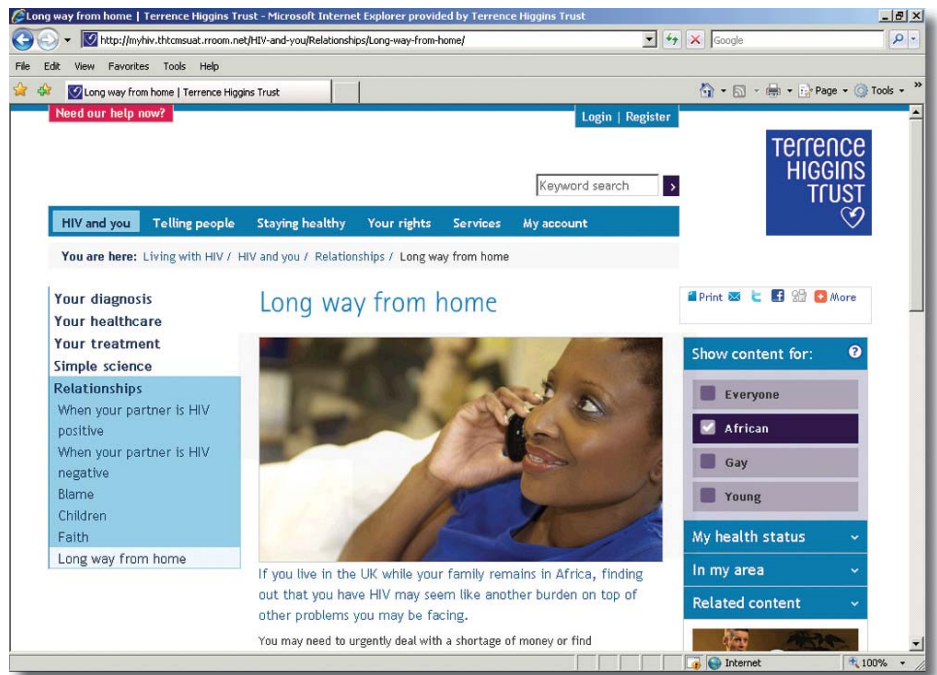
6. LifePlus was designed to have relevance for other conditions - although the services are tailored to individuals' specific needs, the model itself could easily and effectively be used to transform the management of other long-term conditions which currently affect an estimated 15 million individuals in the UK.

Will LifePlus help ease the burden for HIV clinics?

Yes. There are more people living with HIV in the UK than ever before, living longer than ever before. Inevitably this will place a greater strain on HIV clinics and other support services. With more people using services, many of which are at full capacity, we anticipate that clinical staff will have less time to answer questions that people may have about HIV or identify solutions to non-medical problems, even when those problems have a big impact on their medical treatment. We will monitor how/whether these new services will help relieve this pressure.

How does the website work?

MyHIV.org.uk is the very first online one-stop shop for people with HIV. The more



Above: Screenshot of MyHIV.org.uk

information people provide, the more tailored an approach the technology provides, addressing people's needs and concerns. It is individual-driven and solution focused. People living with HIV can register to access a range of interactive tools, all designed to help people to take an active role in managing their condition.

These interactive tools include:

- My Medication and reminders – select your medication and set up reminders to take your treatment by email or text message. 100% adherence is essential for the long term efficacy of HIV treatment, so this is critical.
- CD4 and viral load trackers – enter your viral load and CD4 counts after clinical visits to chart your progress. These data are life-long for people living with HIV; having and understanding it is a powerful tool in self-management and can create a virtuous circle in health improvement.
- HIV Life Check – too often, patients are missing fundamental facts about HIV that have been lost in the emotionally charged process of coming to terms with diagnosis. This section ensures individuals are not putting themselves or others at risk as they manage their condition.
- Personal notes – a space where you record notes and questions to ask. This helps put

patients in control of the dialogue with their consultant.

- Discussion boards – peer support is a proven intervention that reduces isolation, and offers a unique opportunity to discuss and problem solve.

Where will the face to face support be available?

Outside London, the largest numbers of people living with HIV are in major cities so it's important that face to face services will be available in these areas. For that reason face to face services will be based in areas with high rates of HIV prevalence in Manchester, Brighton, Birmingham, Glasgow and Cardiff. The service can be tailored to the individual seeing a Health Trainer at their clinic or another venue, chatting to them over the phone, or at their home if appropriate. A range of issues can be discussed from HIV treatment and adherence, to safer sex and disclosing HIV status to family and friends. The goal of this element of the service is to support people with acute, immediate needs that particularly impact on their ability to start or stay on HIV treatment (up to 30% of patients in the UK who attend their first clinical appointment do not return, and there are high rates of periodic 'lost to follow up' amongst London clinics³).

What's available for people outside these regions?

Outside those regions, online support will be available via the website. Registered users can submit any question on HIV via the website, which will be answered in two working days. Online counselling is also available upon request for those people who feel they need further support.

The innovative web service is designed to help people with HIV live healthier lives wherever they're based in the UK, so it's ideal for people living in remote or rural areas. The website will have an easy to use, comprehensive service finder so people can locate services that are closest to them. And by registering online, users can choose from a wide range of tools to help them manage their condition.

Why isn't the service running in London?

How people access services is slightly different in London, with patient referrals and one-on-one health trainer services split up separately (in LifePlus these are integrated into one service) and funding provided by The South London HIV Partnership and Pan London HIV Prevention Programme. However people living with HIV still receive the same services as in the rest of the UK and online LifePlus services are accessible in the usual way.

What about people who aren't able to access the website?

For people who don't have access to the internet in their own home, web and video access to counsellors will be available in Terrence Higgins Trust centres who are also piloting web and video access with the Bloomsbury Clinic in Camden. We hope that clinics other than those already involved in the programme will get on board and set up internet access for clients who don't have access at home. Support is also available by phone, via THT Direct.

Is there anything else out there for people living with HIV that's similar to this?

We don't think so – or even for other long term chronic conditions. The LifePlus service was developed in response to repeated requests from people living with HIV for a service that not only had quality assured information (rather than having to 'shop around'), but that linked what they were told at their clinic, what they read online and which community services they needed. LifePlus will bring all these elements together in one place, recognising that healthcare is a continuum in which one size does not fit all and that people's needs change over time. It seeks to deliver that in a tailored, streamlined and cost efficient way, taking self management to the next level.

There are lots of long term conditions, why should people with HIV get this service?

Significant progress has been made since we first became aware of HIV in the 1980s. Today people who are diagnosed in good time and put on medication can live full, healthy lives well into their 70s or 80s. Although this is tailored to the specific needs of people living with HIV, we are hoping to demonstrate improved health outcomes that would signal its value in an adapted format to transform the management of other long term conditions.

People living with HIV have to give personal data to use the website – how will Terrence Higgins Trust ensure this information remains secure?

Terrence Higgins Trust takes privacy and confidentiality very seriously and we have strict controls in place to ensure that data is kept confidential. Anyone can visit the website without registering but people will need to register some details if they want to use the interactive elements of the website. You won't need to give your real name but to get the most out of the website we do ask for information on your nearest city, age, ethnicity and sexuality. This is because the site is designed to be tailor made for each

person ensuring that the information is relevant and personal for each user.

How will THT measure the impact of this?

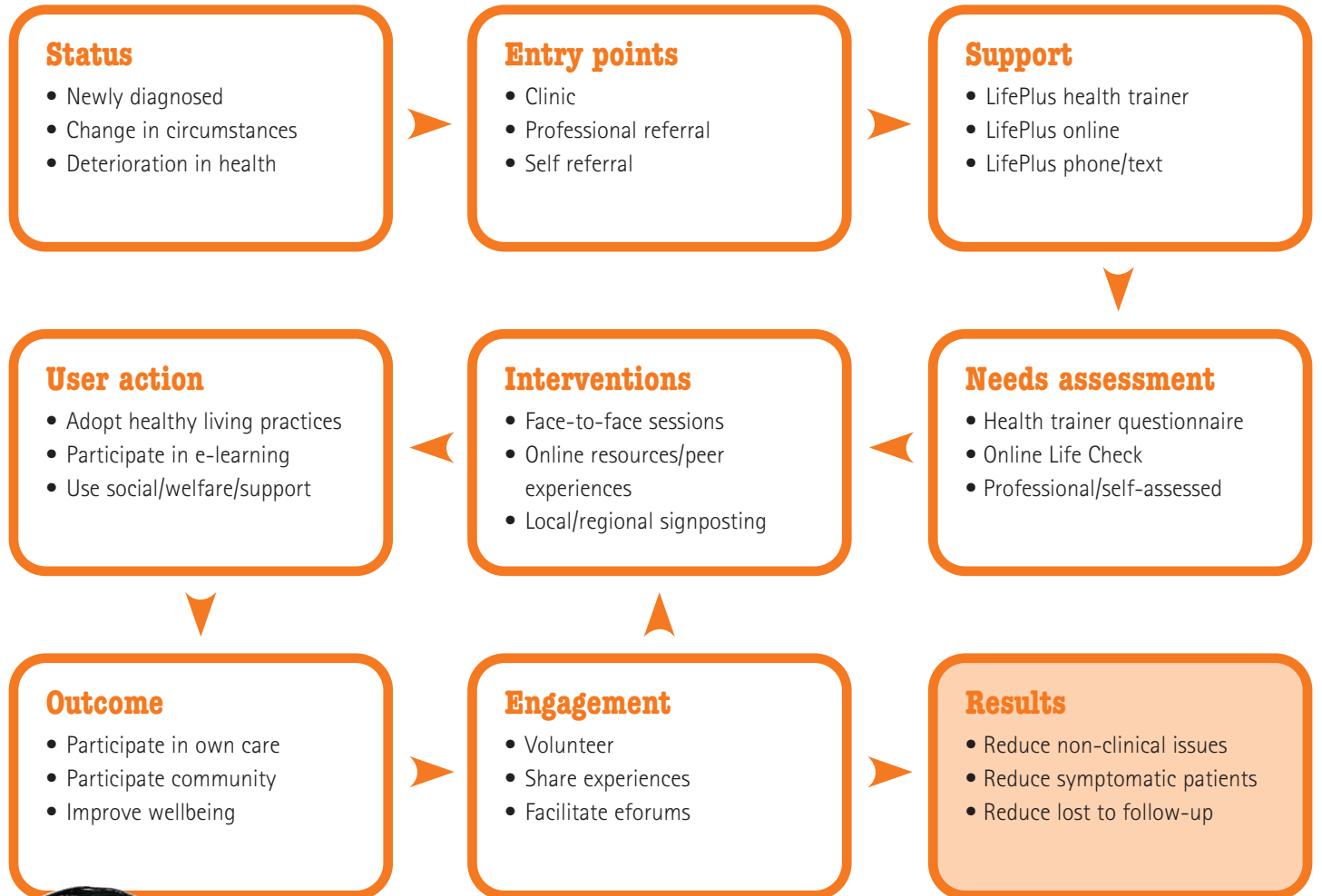
People who use Terrence Higgins Trust's face-to-face services will be asked a series of questions by our Health Trainers to find out their level of knowledge around HIV. These questions will be asked again when their sessions come to an end, setting out the progress from start to finish. We'll also regularly survey people who use the interactive website to find out how it's helping them. In addition Terrence Higgins Trust has developed a questionnaire for clinicians to assess whether our services will have a positive impact for clinics (see *Annex III for detailed Monitoring and Evaluation framework*).

References

1. <http://www.springerlink.com/content/96t1713736v23t27/>
2. <http://courses.washington.edu/socw580/readings/simoni-2006-socialsupport-HIV.pdf>
3. <http://www.aidsmap.com/resources/hatip/HATIP-138-9-June-2009/page/1323767/>



LifePlus overview



LifePlus Advisory Group members

James Locke	Chair of Advisory Group, EJAF Trustee
Abigail Chakanyuka	Volunteer Health Trainer
Babs Evans	UK Grants Manager, EJAF
Cynthia Murphy	HIV Coordinator, North Manchester General Hospital
Eileen Nixon	HIV Nurse Consultant, Brighton University Hospital
Godwyns Onwuchekwa	Patient Rep Homerton Hospital
Lionel Rabi	Positive Self Management Programme Facilitator
Dr Mary Poulton	Consultant Physician, Kings College Hospital
Thain Kleinhentz	Health Advisor, Harrison Wing, St Thomas'
Paul Ward	Deputy Chief Executive, Terrence Higgins Trust
Lisa Power	Policy Director, Terrence Higgins Trust
Leila Fazal	Head of Corporate, Trusts and Major Grants, Terrence Higgins Trust
Garry Brough	Membership and Involvement Officer, Terrence Higgins Trust
Verity Glasgow	LifePlus Project Manager, Terrence Higgins Trust



Monitoring and evaluation framework



The HIV and sexual health charity for life

Website: www.tht.org.uk THT Direct: 0845 12 21 200 Registered office: 314-320 Gray's Inn Road, London WC1X 8DP
Telephone: 020 7812 1600 Email: info@tht.org.uk