

## Case Study 2

# Organising a Europe-wide coalition to raise the profile of HIV testing (European HIV Testing Week)

### What was the issue?

Effective HIV treatment since the mid-1990s has changed HIV from a largely fatal condition to a frequently manageable one. People diagnosed promptly and who received the correct care and treatment were known to have a near-normal life expectancy, with those diagnosed late having far greater short term mortality and, if they survived, long term morbidity. Treatment is also known to reduce onward transmission of HIV. However, to access these benefits, people need to know their HIV status.

### Why was change needed?

Despite life-saving treatment being widely available in many parts of Europe by 2012, many people at higher risk of HIV (between 20% and 60% dependent on country and group) were still being diagnosed late due to a wide range of personal, social and systemic barriers. Nearly half of all reported new cases of HIV were diagnosed late across Europe as a whole [and one in three Europeans](#) with HIV were currently undiagnosed (ECDC data). Testing was recognised as a key break point in country continuums of care and there was general agreement by public health and clinical experts on the need to increase HIV testing rates.

### How could access be improved?

Expert opinion and research showed that increasing access to HIV testing, improving understanding of its personal importance and enhancing its social acceptability would all contribute to increased testing levels. There were multiple ways in which these could be achieved, including: community based testing (CBT), home testing, online ordering, media and public awareness campaigns, targeted testing drives, political support and healthcare system changes.

### What/who were the barriers to change?

Possibly the biggest barriers were governmental and health system inertia and lack of funding for HIV testing campaigns. This was often due to low levels of understanding by the public and politicians of the immense changes in HIV treatment and technologies. Many in-country health systems were failing to modernise ways of testing and managing HIV in line with best practice and had low levels of community involvement in testing. HIV clinicians and NGOs across Europe recognised the importance of increasing testing, but needed new ways to get the message across clearly to those most at risk but also to those who could support and make change. *“Very little was being published on testing – even major HIV conferences didn’t have a section on it, so people didn’t hear about new ideas or good practice”* (Dorthe Raben, [HIV in Europe](#))

### How long did change take and who was involved in making the change?

In 2012, a pan-European meeting of national/regional NGOs was called by [Gilead](#), a pharmaceutical company, seeking ideas on funding future HIV developments in Europe. A pan-European HIV Testing Week was one of several ideas suggested by participants and it was widely supported by stakeholders. A working party of NGOs from ten countries, with expert clinician input and supported by a public affairs company, developed the idea and the first

[European HIV Testing Week](#) (now HIV & Hepatitis) was held in 2013. It has been held annually since and has increased testing levels and testing awareness in many European countries. While campaign activities vary, overall they involve NGOs, clinicians, people with HIV, the media and politicians in activities tailored to the resources and concerns of the individual country.

### **How was change made?**

**Broad collaboration and secure funding:** The campaign involved HIV community activists from across Western and Central Europe from the start. Although funding, including the pharmaceutical company contribution, was invaluable in bringing people together, the ideas and drive for the campaign came entirely from the activists, informed by the latest clinical and social research.

**Using existing structures:** Secure funding allowed the use of existing structures for a secretariat at [HIV in Europe](#) (HiE), a pan-European collaboration between clinicians and communities which was already working for earlier and better testing and care. They were supported by [Four Health Communications](#) (formerly [Packer Forbes](#)), a public affairs agency used to developing campaign materials. Steering Group participants were involved from other existing European networks such as the [European AIDS Treatment Group](#) (EATG) and regional and national networks. However, the name and branding of the campaign “European HIV Testing Week” were new, as were the campaign website and all materials on it.

**Learning from existing experiences:** Some steering group participants, such as [Barcelona Checkpoint](#), were already running local testing campaigns and their experience informed the new European Week. The first English HIV Testing Week, run in 2012 by [HIV Prevention England](#) (HPE), was used as a pilot and generated examples of creative ways to participate.

**Priorities set by those who would operate the campaign:** The Steering Group agreed the aims, key messages and timing. They advised on priorities for translation and helped write the contents of the website and toolkit. They agreed to be pan-European, but to start with countries in Western and Central Europe with existing community involvement infrastructures and expand on request to include Eastern Europe (which happened swiftly). A proposed focus on “early testing” gave way to prioritising “normalising” testing alongside an emphasis on supporting community based as well as clinical testing, targeting those populations most at risk and provider-initiated testing.

**Political support:** The importance of political and governmental support was recognised from the start, with examples on the website of how to solicit governmental or other decision maker support to reprioritise HIV testing. The European launch of Testing Week (in Portugal) was attended by a senior politician alongside clinicians and community activists. “*The campaign shows that there is political validation and support to increase testing, which is particularly important for Central and Eastern Europe*” (Dorthe Raben, HiE)

**The art of the possible:** From the start, the campaign was realistic about what it could achieve at each stage. It started with the countries that had expressed an existing interest, but with an intention to expand. It considered being a grant-giver but recognised quickly that this would consume energy and be potentially divisive; it was happy to work with companies supplying tests but not to run distribution schemes for them.

**Flexibility:** Because of differing resources, it was agreed that any activities relating to HIV testing could be branded as being part of Testing Week. The central campaign made suggestions and

offered basic resources and advice, but decisions about projects were entirely made in-country by the participants. This enabled a much wider range of groups to participate than a programme with set activities.

**Centralised, simple branding:** Logos and straplines for the campaign, giving it a clear and immediately recognisable image, were made available for download from the website. The slogans used were pretested to ensure that they were understandable and translatable in a wide range of languages. The logo for Testing Week was designed so that it could be used on its own or alongside existing logos from other national campaigns.

**Language issues:** Translation is always a contentious issue where resources are finite. For Testing Week, all materials were available in English and key materials like the logo were available on request in any participant language. Some of the guidance material was also made available in the most common European languages and funding allocated for others to ask for materials to be translated on a “first come, first served” basis.

**Encouraging signups and publicising involvement:** Every organisation that signed up to participate or support Testing Week was publicised on the website, from huge multinational groups to local hospitals and tiny community groups. This egalitarian approach was combined with mass mailings and a slight encouragement of competition - “*these are the groups in your country that are doing it, have you signed up yet?*”. This ensured that 477 groups from 49 countries, many of them not originally expected to participate, signed up in the first year alone. “*Watching the signups from all over Europe appearing on the map was exciting,*” (Dorthe Raben, HiE)

**Giving people ideas:** The most common query at first was “what can we do?”. The Testing Week website gave examples and ideas at all levels, from getting a politician or celebrity to test, through having “open days” at clinics or outreach testing sessions, to simply giving talks or handing out leaflets. Some countries persuaded senior health officials to endorse the campaign and recommend that doctors increase offers of testing. Again, flexibility and an understanding of differing levels of resources, interests and skills were key to maximising participation.

**Encouraging but not enforcing collaboration:** Early on there was discussion of designating a lead organising agency for each country, but this was agreed as likely to be internally divisive as to be helpful. By publishing lists of participants by country, they were encouraged to link up locally and share ideas and experiences. Some countries or cities already had a Testing Week or Day campaign and were encouraged to collaborate, while any organisation that was not part of the existing initiative could also participate in European HIV Testing Week and many did. Those involved in both could simply put both logos on their own materials.

**Identifying and responding to skills gaps:** The campaign used both consultation and existing evidence to identify key needs for the materials they produced. For example, a simple dossier of evidence on e.g. cost-effectiveness and testing methods was needed alongside guidance on how to organise sample events and lobby politicians. The website for the 2015 campaign had 6,694 unique visitors who downloaded more than 1,000 separate pieces of materials.

**Engaging key stakeholder organisations:** The campaign engaged major stakeholders such as ECDC, WHO and UNAIDS early on and publicised their support. Their reputations acted as high-

level validation of the aims and “respectability” of Testing Week to the medical and political establishments. Their supportive publicity for the campaign also brought in even more signups.

**Evaluation:** Evaluation was a crucial component of Testing Week. It validates the concept and gives feedback on what worked and what needed change. It allowed better targeting of resources and website tools in subsequent years and has guided the evolution of Testing Week by showing what people most value and use from it. Though attributing numbers of new cases overall to Testing Week is difficult, it has been able to show that over a third of participants who did extra testing found new diagnoses, varying between one and 46.

**Continuity:** Holding Testing Week at approximately the same time each year, linked closely to [World AIDS Day](#), ensured that it became a fixed part of the working calendar for many groups and part of the annual planning cycle. Similarly, while the basic aims have not changed, they have been revisited in order to measure how well each is being achieved and where further effort may be required.

### **Are there any ongoing issues?**

The issue of maintaining equity within Testing Week across countries and regions with widely differing resources, restrictions, economies and priorities continues to need to be balanced. Similarly, there are tensions in striking a balance between HIV and Hepatitis since the latter has been included in what was an already existing HIV programme. The annual renewal and inclusion of new groups and activists also means that some issues are revisited regularly, most notably the timing of the Week. The aim of targeting key populations rather than general awareness and testing has also needed constant attention.

### **What lessons have been learnt?**

The importance of simplicity, a clear visual image and flexibility in the activities undertaken have been crucial to the success of Testing Week across Europe. *“Geographic diversity was important, so the campaign needed to be simple enough to be useful in many different communities... having pre-launch conversations with key allies was important so we could show immediate support”* (Sarah Avent, Packer Forbes). While controversial with some, *“continuity and having the same timing every year has made it an institution”* (Dorthe Raben, HiE). Secure funding without undue funder influence has made a lot of things easier to achieve. European HIV (and now Hepatitis) Testing Week is an interesting model of central management (with participative advice) of a wildly diverse project which continues to evolve and has genuinely helped to change the profile of HIV testing in many European countries.

### **Links**

European Testing Week website: <http://www.hivtestingweek.eu>

ECDC Evidence brief on HIV testing in Europe:

[http://ecdc.europa.eu/en/publications/\\_layouts/forms/Publication\\_DispForm.aspx?List=4f55ad51-4aed-4d32-b960-af70113dbb90&ID=1359](http://ecdc.europa.eu/en/publications/_layouts/forms/Publication_DispForm.aspx?List=4f55ad51-4aed-4d32-b960-af70113dbb90&ID=1359)

Waverley Care (Scotland) 2015 Testing Week site: <http://www.waverleycare.org/10-reasons-to-test-european-hiv-hepatitis-testing-week-2015/>

Dating apps involvement: <http://globaldatinginsights.com/2015/11/25/25112015-gay-dating-apps-give-free-ad-space-for-hiv-testing-week/>

European HIV Test Finder: <http://www.aidsmap.com/european-hiv-test-finder>

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