

**EUROPEAN  
TESTING  
WEEK**

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## **Toolkit 5**

Working with key opinion makers: HIV and hepatitis experts, people living with HIV and/or hepatitis and influential figures

## Toolkit 5

# Working with key opinion makers: HIV and hepatitis experts, people living with HIV and/or hepatitis and influential figures

**Thank you for downloading this toolkit to support you when working with key opinion makers**

Engaging with opinion makers or HIV/hepatitis 'testing ambassadors' is one activity example that you may want to consider carrying out during European Testing Week. Opinion makers can support you with mass and social media activities, attend events and talks and help communicate your messages to as wide an audience as possible. In this toolkit you will find guidance to assist you in identifying and inviting opinion makers to become testing ambassadors for European Testing Week.

### **This toolkit includes:**

Section 1 – Introduction to HIV/hepatitis testing ambassadors

Section 2 – How to identify and work with HIV/hepatitis testing ambassadors

Section 3 – Supporting HIV/hepatitis testing ambassadors to work with the media

This toolkit aims to provide support and guidance only and it is not mandatory that your organisation uses the information outlined in this toolkit nor is it obligatory to work with key opinion makers. If you have any questions do get in touch:

[eurotest.rigshospitalet@regionh.dk](mailto:eurotest.rigshospitalet@regionh.dk)

Please also remember we are active on [Facebook](#) and [Twitter](#). Tell us about your plans, share information and photos and tweet us (using #EuroTestWeek or #TestTreatPrevent) to help build anticipation and excitement for the week.

## Section 1 – Introduction to testing ambassadors

### What is the role of testing ambassadors during European Testing Week?

‘Testing ambassador’ is a broad term to describe a range of individuals who want to help more people to become aware of their HIV and/or hepatitis status. Testing ambassadors are likely to have either personal or professional experience of HIV and/or hepatitis or they may be an influential figure and people will be interested to hear what they want to say about routine HIV/hepatitis testing.

In general, the role of a testing ambassador during the testing week will be to:

- Communicate the importance of routine HIV/hepatitis testing
- Help reduce stigma associated with HIV/hepatitis

### What activities could a testing ambassador get involved in?

They can:

- Be **interviewed by the media** (for example newspapers, TV and radio) to raise awareness of the testing week and the importance of routine testing
- Be a **speaker at an event**
- Put up posters and **promote the testing week** and/or planned testing initiatives
- Use **social media**, such as Twitter, Facebook and blogging sites, to raise awareness and communicate testing week messages

## Section 2 – How to identify and work with testing ambassadors

### How to identify and work with testing ambassadors

We have included a suggested list of who could take on the role of being an HIV/hepatitis testing ambassador, but this is not an exhaustive list – you may have others in mind. What is important is that your testing ambassadors are good communicators, are influential and have something interesting, positive and relevant to say. Once you have decided what you are aiming to achieve from your activities you can then look to identify how to contact your testing ambassadors. We have included some guidance to assist you with this, if needed.

People living with HIV (PLHIV) and People living with viral hepatitis (PLVH)	
Why work with PLHIV and PLVH?	How to identify them
<p>PLHIV and PLVH can provide a real-life, personal experience of HIV/hepatitis and can play an important role to help reduce stigma associated with HIV/hepatitis. They can share their story about what it is like to live with HIV and/or hepatitis and talk positively and openly about the importance of HIV and/or hepatitis testing, including why it is better to know your HIV and hepatitis status.</p> <p><b>PLHIV and PLVH make ideal media spokespeople, speakers at an event or blog writers.</b></p>	<p><b>Step 1 – set your selection criteria</b></p> <ul style="list-style-type: none"> <li>Consider what role you would like your testing ambassador to have and who you may wish for them to engage with – this will help you to invite the most relevant PLHIV/PLVH to be involved. You may want to identify a number of PLHIV/PLVH who reflect the variety of social and ethnic groups within the wider HIV/hepatitis patient population to ensure your ambassadors resonate with the needs of different audiences.</li> </ul> <p><b>Step 2 – make contact</b></p> <ul style="list-style-type: none"> <li>Some patient organisations have an active list of members who are PLHIV/PLVH. If your organisation does not have a list then you might wish to partner with an organisation which does and is happy to invite their members to be testing ambassadors.</li> </ul> <p><b>Step 3 – apply your selection criteria</b></p> <ul style="list-style-type: none"> <li>Consider your responses against your selection criteria and prioritise who to follow up with first. If you are looking for someone to speak at an event or be a media spokesperson, you will want to make sure that they can convey their experiences in a</li> </ul>

clear and compelling way, as well as communicating messages about HIV/hepatitis testing. The most influential ambassadors will be individuals who are able to provide an honest and emotional account of their experiences with HIV/hepatitis.

**HIV and hepatitis clinical experts – nurses, clinicians and other healthcare professionals**

<b>Why work with HIV and hepatitis clinical experts?</b>	<b>How to identify them</b>
<p>Clinicians and nurses have day-to-day experience of HIV/hepatitis and are experts within the field. They can communicate the clinical benefits of early testing and the impact of late diagnosis on an individual’s prognosis and quality of life. They can provide advice and guidance to build confidence amongst healthcare professionals to offer more HIV and/or hepatitis tests to those who need them.</p> <p><b>Clinical experts make good and legitimate media spokespeople or speakers for an event. They can also encourage healthcare professionals to offer more HIV/hepatitis tests.</b></p>	<p><b>Step 1 – consider the best way to identify experts</b></p> <ul style="list-style-type: none"> <li>• There are a number of ways to identify HIV and/or hepatitis clinical experts – the easiest way is to ask a healthcare professional with whom you have already established a good relationship. If you do not have any existing relationships you can contact EuroTEST, which has a wide network of clinical contacts across Europe. Alternatively, you can identify experts by auditing HIV/hepatitis journals and publications to see who’s being quoted, analysing speakers at past and forthcoming events and/or looking at the working committees of relevant professional bodies.</li> </ul> <p><b>Step 2 – make contact</b></p> <ul style="list-style-type: none"> <li>• When contacting clinicians explore their attitudes towards routine HIV/hepatitis testing and their potential willingness to work with you. It is important that you work with experts whose thinking is aligned to the testing week. Refer to the testing week key messages and share them with the clinician – these can be found on the testing week website in the <a href="#">About Testing Week</a> section.</li> </ul> <p><b>Step 3 – agree their role and commitment required</b></p>

	<ul style="list-style-type: none"> <li>• Make sure that your clinical experts can commit sufficient time to the agreed activities and agree the dates and times that they may be required.</li> </ul>
<b>Politicians and policy makers</b>	
<p><b>Why work with politicians and policy makers?</b></p>	<p><b>How to identify them</b></p>
<p>Politicians and other government bodies are critical in ensuring healthcare policies that meet European testing guidelines are adopted. They can communicate the importance of routine HIV/hepatitis testing, not just for the benefit of the individual but also for the wider community, linking it back to how treatment can prevent onward transmission to others.</p> <p><b>Politicians and other government bodies make good spokespeople as the media is often interested in talking to them, as influential figures in society.</b></p>	<p><b>Step 1 – identify the right politicians</b></p> <ul style="list-style-type: none"> <li>• Some politicians have a special interest in HIV and/or hepatitis and would therefore be willing to support you.</li> </ul> <p><b>Step 2 – make contact early</b></p> <ul style="list-style-type: none"> <li>• Politicians are busy so make contact as early as you can to outline what you are aiming to achieve and how you would like to work with them.</li> </ul> <p><b>Step 3 – be compelling</b></p> <ul style="list-style-type: none"> <li>• When you explain your testing week plans, be as captivating as you can and explain how the activities will help the wider community. Politicians will have many competing priorities so you will need to build a compelling case to secure their time.</li> </ul>

Well-known figures and celebrities	
Why work with well-known figures or celebrities?	How to identify them
<p>Well-known figures or celebrities, such as an actress, musician, gay porn star or sports personality, can bring instant attention to your testing week activities and can attract the interest of your target group. Work with people who are either well-known with a strong connection to HIV and/or hepatitis or people who are influential amongst your target population.</p> <p><b>Well-known figures or celebrities will attract media interest. Work with them to communicate the testing week messages, ask them to speak at an event or encourage them to take an HIV/hepatitis test and invite journalists to film or photograph this (a photo opportunity).</b></p>	<p><b>Step 1 – identify the right influential figures</b></p> <ul style="list-style-type: none"> <li>Start by considering who you want to communicate with and then map out the most appropriate well-known figures that will attract the most interest in your target group.</li> </ul> <p><b>Step 2 – make contact</b></p> <ul style="list-style-type: none"> <li>Most high-profile people will have a personal assistant or agency who manages their time; you should be able to find details on the internet to make initial contact. Make sure that you are specific about what involvement you would like, when you would like it and the amount of time required. Provide a compelling case, celebrities receive requests all of the time and may therefore decline the opportunity to get involved or request payment. Alternatively, you can contact the management agency first to find out which well-known people they have on their books and if any of them have a special interest in HIV/hepatitis and/or would be influential within your target group and are willing to back the testing week. Either way, prepare yourself for some knock backs but don't let these put you off approaching others!</li> </ul> <p><b>Step 3 – organise your event and agree their role</b></p> <ul style="list-style-type: none"> <li>You could arrange a photo opportunity, perhaps of them taking an HIV and/or hepatitis test, and invite journalists and photographers to attend. If they have limited time, you could draft and issue a joint news release – or ask them to provide a written statement of support to include in press materials. Alternatively you may want to ask them to make a short video that you can upload to YouTube, let people know that it is there and then watch it go viral! Well-known</li> </ul>

	<p>people will attract media interest but they might not communicate all your key messages (as they are likely to have their own key messages to communicate). Therefore, you may wish to supplement your activities with a news release to ensure your testing messages are included.</p>
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### **Working with celebrities? Please let us know**

If a well-known person agrees to be a testing ambassador for the European Testing Week, it would be great if you could let us know. It will help to avoid duplication of efforts across participating organisations (and the same person being contacted twice) and they might also be happy to be a testing ambassador on a European level – not just in your country. This is particularly relevant where the person is well-known in more than one country.

To keep us informed, you can either email EuroTEST at [eurotest.rigshospitalet@regionh.dk](mailto:eurotest.rigshospitalet@regionh.dk) or visit the website and share details in the [Get involved](#) section.

## Section 3 – Supporting testing ambassadors to work with the media

### Testing ambassadors and the media

This section includes guidance on how you can best work with your testing ambassadors to communicate key messages through the media to as wide an audience as possible. For more comprehensive information about engaging the media as part of testing week activities, as well as the testing week key messages, please see **Toolkit 2**.

### Helping PLHIV/PLVH to prepare for media interviews

Unlike well-known figures, politicians and some HIV/hepatitis experts, PLHIV/PLVH might be less experienced with talking to the media. It is therefore important to make sure they are comfortable with the activities and that they understand that their story will become public.

Whilst it is important to build enthusiasm amongst your testing ambassadors, it is equally as important to manage their expectations from the outset. Sometimes they may be interviewed, photographed or filmed – but due to lack of space in the publication, or a more pressing media story, the story may be dropped. This can often be disappointing for those who have given up their valuable time.

### Interview tips to share with your testing ambassadors

Here are a few pointers that you can share with your testing ambassadors to help them get the most out of the opportunity to raise awareness about HIV and/or hepatitis:

- **Be clear, precise and confident** and remember the key points you would like to get across during your interview
- **Talk simply and avoid medical terminology.** If you do use medical terminology, make sure you explain what you mean in more simple language as well
- **Avoid answering questions with ‘yes’ or ‘no’** – give more detail in a concise manner
- **Remember that anything you say is ‘on the record’** – don’t be tempted to say anything ‘off the record’
- **Rehearse what you want to say** and try to relax during the interview
- **Feel free to correct anything** that you accidentally say incorrectly during the interview

### What will journalists ask your testing ambassadors?

It is a good idea to provide your testing ambassadors with an idea of what a journalist might ask them such as their personal experience of living with HIV/hepatitis and why it is important for people who have been at risk to get tested regularly. Ahead of any interviews encourage your testing ambassador to think about what they want to communicate. You can help your testing ambassador feel comfortable by discussing their case history with them ahead of any media interviews. You may want to write this up and share it with the media to help build their interest.

### Types of questions that PLHIV/PLVH may be asked:

- Can you tell me a bit more about your experience of living with HIV/hepatitis?
- How did you feel when you were told you were HIV/hepatitis positive?
- What was the hardest part of finding out you were HIV/hepatitis positive?
- On a daily basis how do you manage your HIV/hepatitis and how does it affect your daily life?
- Do you experience any limitations on your day-to-day life as a result of HIV/hepatitis?
- What are the aims of European Testing Week?
- Why is it important for people to get tested regularly?
- Who should be coming forward to get tested?

It is important to let your testing ambassador know that they will probably be asked how they contracted HIV and/or hepatitis – and it is understandable that they might not feel comfortable answering this. However, it is important that they consider and prepare an answer. Here is an example of a possible response to help them prepare:

*“I knew I had put myself at risk of HIV/hepatitis, but the most important decision I made was to get a test as soon as possible. Of course I was scared of getting the results but when I tested positive I was able to deal with it (and start taking treatment).”*

If you encourage your testing ambassadors to consider their key messages first, every time they are asked a question they can use it as an opportunity to link back and communicate a positive message about routine testing. You may want to work with them to prepare some simple responses so they feel confident in communicating their key messages.

### Top tip

Never provide a journalist with the contact details of your testing ambassador before you have checked first that they are happy to progress with the interview. It is also important to check with your organization if your HIV testing ambassadors need to complete a consent form.

### Good luck!

We hope that you found this guidance helpful. If you need any additional support, please do not hesitate to contact EuroTEST at: [eurotest.rigshospitalet@regionh.dk](mailto:eurotest.rigshospitalet@regionh.dk)