

How to Communicate STI and HIV Test Results Online to MSM?

The Barriers and Motives MSM Perceive in the Online Communication of STI and HIV Test Results

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Abstract— Testlab is an online service for Men who have Sex with Men (MSM) to get tested on STIs and HIV. Testlab is part of the MANtotMAN project. This project aims to improve testing behaviour and increase awareness on STIs and HIV among MSM. Currently, the users of Testlab do not receive specific test result online, because it does not seem appropriate to communicate potentially upsetting news online, without the presence of a health care professional. However, little is known about the barriers and motives MSM perceive in receiving online test results. Forty-four interviews were held with MSM to investigate barriers, motives and the importance of the tone of online communication regarding test results. The main conclusion of this study is that the vast majority of participants would like to have the option to choose whether or not to receive their specific test results online. They perceive little barriers in receiving low impact STIs (Chlamydia, gonorrhoea, syphilis and) test results. More barriers are perceived for HIV online test results.

Keywords - eHealth; STI, HIV; professional communication; empathic communication

I. INTRODUCTION

Men who have sex with men (MSM) have an increased risk for STIs (Sexually Transmitted Infections) and HIV (Human Immunodeficiency Virus). In the Netherlands, they are therefore advised to be tested on STIs twice a year and to be tested on HIV once a year. There are several options to get tested on STIs and HIV in the Netherlands. One can get tested at the general practitioner, at a STI-clinic of the GGD (Public Health Services), or a STI-clinic at a specialised hospital. Another option to get tested is via Testlab, an online service for MSM to get tested on STIs and HIV. Testlab is a part of the MANtotMAN website, which is part of the MANtotMAN project. This project aims to improve the prevention and treatment of STIs and HIV for MSM.

The MANtotMAN website was developed by the Dutch Aids Fund, Schorer (Dutch institute for homosexuality, health and well-being), the GGD Amsterdam and the GGD Rotterdam (Public Health Services of the municipalities Amsterdam and Rotterdam). The website was launched in the summer of 2008 and has since conducted several theme campaigns aimed to improve test behaviour and to create

awareness on STIs and HIV. The website attempts to increase testing and decrease risk behaviour among MSM. The website offers information on safe sex, what to do after having unprotected sex, living with HIV, dating and partners, etc.

The reason Testlab was developed is that a low threshold service to get tested on STIs (Chlamydia, gonorrhoea and syphilis) and HIV was not yet present for MSM. Testlab provides MSM with a new and innovative eHealth application. The difference in the Testlab procedure compared to the other testing alternatives is that the men can fill in the necessary paperwork online; they can choose their date and time to go to a nearest laboratory. Once there, all it takes is a couple of minutes for all the cultures and blood samples are taken. Whereas going to the general practitioner, a hospital or a STI-clinic is far more time consuming and the procedure allows less anonymity than the Testlab procedure. Another major difference of the Testlab procedure is that MSM receive their a-specific test results online. This means that MSM receive an online message either telling them that all tests were negative or that one or more tests were positive. If one or more tests are positive, they are asked to come to the STI-clinic. At the clinic, they receive their specific test results, counselling if needed, treatment and, if necessary, follow-up and confirmation tests.

The 2010 HIV monitor shows that the MANtotMAN project is successful in reaching their target population and that MSM familiar with the website have a higher intention to get tested on STIs and HIV [1]. Not only is their intention to get tested higher, evaluations of the project have indicated that there is a rise in the testing rate among MSM that are familiar with MANtotMAN and Testlab. This shows that there is a need for online interventions on STIs and HIV testing.

When Testlab users were asked about their experiences, some of them indicated that they would have liked to receive specific test results online [2]. However, one can think of several advantages and disadvantages of allowing people to receive online specific test results that can have a large impact. A qualitative study was conducted to answer the following questions:

- What motives and barriers do MSM perceive for receiving specific test results online?
- How important is the tone of voice in the online communication of results?

The theoretical background, the method and results of this study are described in the remainder of this paper. The paper ends with the conclusion of the study.

II. LITERATURE OVERVIEW

The first step in answering the research questions was a literature review about self tests and empathic communication.

A. *Advantaged and disadvantages of self tests*

Self-tests are becoming increasingly popular and more available to the general public in the Netherlands [3]. Four different types of self-test are indicated: 1) a self-test where the samples are taken at home and results can be viewed immediately; 2) a self-test where the samples are taken at home and then sent to a laboratory, with results received through post or internet; 3) a self-test where people are required to go to a laboratory for collecting of samples and then receive their test results through post or internet; 4) a street-corner test, these are tests offered by organizations in public places such as grocery shops, libraries, etc. Testlab is a type 3 self-test, this type of self-test has the least amount of disadvantages compared to the other types of self-tests.

Critics of self-testing state that self-tests involve high costs and will only increase test results among people at low-risk for disease, and that the high-risk population will not use self-tests. These critics also indicate that testing without supervision of a qualified health professional could lead to adverse medical and psychological outcomes [3-6]. This is one argument for not providing the Testlab users with online test results. A health care professional who tells them personally about the test results, explains these results and who can immediately answer any questions might be better, especially because STIs and HIV are serious diseases that can have a large impact on patients.

On the other hand, self-testing appears to be applicable in the present-day views on consumer autonomy and self-management, and it could also empower consumers to gain control over their personal health [3, 7, 8], which is an argument for providing Testlab users with online results. Protagonists of self-tests believe that the availability of self-tests will lead to increasing test rates as well as earlier diagnosis and treatment. They also indicate that self-tests are more convenient and provide more anonymity than current testing methods, and that it promotes patient empowerment.

B. *Empathic Communication in eHealth*

Receiving positive test results for an STI or for HIV can have a traumatic impact on a person. More STIs are curable nowadays, but HIV, even though it is a controlled disease, is

still incurable. So, it is important to deliver this news tactfully. Bad news in health care can be defined as “any news that drastically and negatively alters the patient’s view of her or his future” [9, p.15]. It can be delivered in different ways; there is no standard on how it should be delivered. The literature implies that the communication style is important; the use of an empathic style is best when the diagnosis is of a more serious nature, where a less empathic but objective, professional style is more accepted when the diagnosis is not life altering or life threatening [10, 11]. An empathic style is defined as responding to the receiver’s emotions. In this study, we use the term ‘informative’ for a less empathic, but professional and objective communication style.

A study on how different communication styles can affect risk perception by De Wit, Das and Vet [12] indicates that the use of narratives is more effective in communicating health risk than using objective and statistical communication.

Although a lot of research is done on the use of different communication styles in health communication, little is known about the use of text styles in the communication of online test results [12-16]. Kreps and Neuhauser [17] conclude that if e-health information meets conditions such as tailored messages, interactive, engaging, and can be delivered to mass audiences; it can make a difference in improving the quality of both health care and disease prevention.

This study focuses on informative and empathic text styles for the communication of online test results. Testlab has already shown that is successful in the prevention and early detection of STIs and HIV among MSM. The goal of this study is to find out how this positive trend can be continued in the communication of the test results.

III. METHOD

The method of the qualitative study is described below.

A. *Participants*

A total number of 44 MSM participated in this study (14 were HIV⁺, 30 were HIV⁻). Guest et al. indicate that that 12 in depth interviews is sufficient for a fairly homogeneous group [18]. Saunders, Lewis and Thornhill suggest a sample size of 25 to 30 people [19]. Since our target group is heterogeneous, we decided to interview more people than suggested in the literature, to be sure that the results would be relevant.

The participants were between 18 and 64 years of age (mean: 43). The education level varied from vocational education to university education. Some of the men had used Testlab before (N=25) others had no experience with Testlab (N=19). Participants were recruited through the Public Health Services of Amsterdam, Rotterdam-Rijnmond and of the region Twente (municipality: Enschede), and the hospital in Enschede (Medisch Spectrum Twente). STI

nurses and HIV consultants assisted the researchers with recruiting participants.

B. Sample Selection

The inclusion criteria of this study: participants had to be 18 years or older, they had to be men, they had to be homosexual or bisexual, they had to speak Dutch, and they had to be tested at least once on a STI and/or HIV. These inclusion criteria were communicated to the nurses who recruited the participants and were checked by the researchers when the appointment for the interview with a possible participant was scheduled.

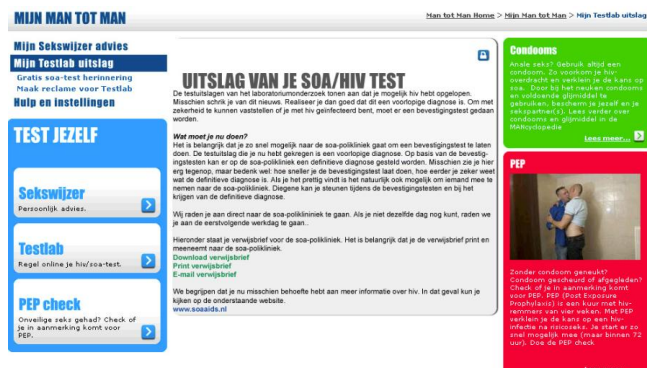


Figure 1. Empathic test result for HIV Translation:

1. The HIV test result. “Maybe this news upsets you; do realize this is a preliminary test result. You need to come to the STI-clinic for the final test result; there a confirmation test is done”
2. “What to do next?” Also an outline with the next steps, but with empathic additions. “Maybe you are reluctant to go to the STI-clinic, but remember: the sooner you come to the STI-clinic, the sooner you’ll have your final results. If you would like you can bring someone to the STI-clinic with you.”
3. Advise to come to the STI-clinic as soon as possible, either today or the next working day.
4. The referral letter (download, print, or email)
5. Link with information about HIV and treatment options, empathic addition: “We understand that you might wish more information on HIV, if you do, please click the link below.”

C. Materials

Prototypes of web pages with the online test results were constructed. Four screen shots were shown to the participants: positive test results for gonorrhoea presented in an informative style, positive test results for HIV presented in an informative style, positive test results for gonorrhoea presented in an empathic style and positive test results for HIV in an empathic style (see Figure 1). The contents of the test results written in an empathic style were the same as the contents of the test results written in an informative style. However, we added some empathic elements to the text. In the informative text, the men are told “Go to the STI clinic as soon as possible ...” while in the empathic version, the men are told “Maybe, you are reluctant to go to the STI clinic ...” The informative text states: Below, you can find more information on...” while the empathic versions state

“We understand that you might wish more information on ...”

The initial interview questions were constructed on the bases of the literature study on informative and empathic texts. These interview questions were formed into a topic list and supported by a PowerPoint presentation that was used during the interviews. This topic list was used to keep a semi-structured nature in the questions and contained questions on motives and barriers the interviewee perceived when receiving online test results. We specifically asked the preferences, motives, and barriers concerning online communication of test results.

D. Procedure

We used semi-structured interviews to gain insight in the motives and barriers that MSM perceive in receiving online STI/HIV specific test results, their needs for specific information when receiving these test results and in which way these results can be best communicated. In Amsterdam the interviews were held at the research department of the GGD Amsterdam, in Rotterdam at the STI clinic of the GGD Rotterdam-Rijnmond and in Enschede at the STI-clinic of the GGD region Twente. The average time for an interview was 45 minutes.

At the beginning of every interview a short introduction about the research was given. Participants who were not familiar with Testlab received an additional explanation about the website MAnTotMAN and Testlab (the application, procedures and current communication of test results) to make sure they understood how Testlab works. After the introduction, permission was asked to record the interview and to convert it into text afterwards. Assurance about anonymous collection of the data was given. A PowerPoint presentation was used to show prototypes of web pages with online test results. The participants saw positive test results for gonorrhoea presented in an informative style, positive test results for HIV presented in an informative style, positive test results for gonorrhoea presented in an empathic style and positive test results for HIV presented in an empathic style successively

E. Data Analysis

In this research categorisation of meanings was used to put the data in relevant categories so it could provide insight into the relationships in the collected interview data. Through open coding the general issues with online communication of test results were found and categorized. In all the issues derived from the transcribed interviews we searched for overlapping themes through axial coding. This resulted in the identification of several themes such as the relation between the severity of the test result (e.g. gonorrhoea vs. HIV) and the preference for the type of text (informative or empathic) used in the communication of the test result. All transcripts were imported and analysed with MAXQDA 2010, a software program for the analysis of qualitative data.

The research team consisted of 3 researchers, all with different backgrounds (psychology, communication sciences and biomedical sciences). The researchers with a background in communication sciences and biomedical sciences performed the interviews. The first 6 interviews were coded by both the researchers and discussed with the supervising researcher to reach consensus about the coding system. This was done to ensure equal coding of the two researchers. After these 6 interviews each researcher coded their own interviews, but discussion took place each time a new code was used. These discussions could lead to an adjustment or addition the initial topic list, or to the rephrasing, combining, or splitting of earlier formulated codes.

IV. RESULTS

The results of this study indicate that more motives than barriers were perceived to receive STI specific test results online. This applies for all participants, although men who had already used Testlab in the past perceived more motives than the men who had never used Testlab. This is why men in Amsterdam and Rotterdam perceived more motives than men in Enschede; Testlab is currently only available in these two cities.

The results showed a difference in the participants' opinions about the STIs (Chlamydia, gonorrhoea and syphilis) on the one hand and HIV on the other. As expected, more barriers were perceived for receiving online test results indicating a positive test result for HIV than receiving results indicating a positive test result for gonorrhoea. Furthermore, the participants had a preference for an empathic style when the results indicated that one was positively tested for HIV and a preference for an informative text style when the results were about gonorrhoea.

A. Motives for online test results

The most important motive mentioned for receiving positive STI and HIV test results online was that one **did not have to wait for appointment at the STI clinic** to get the results. The advantage of not having to wait for an appointment implied that one **could immediately start taking measures to protect himself and his partner(s)** and, more important, it **reduced the anxiety**. When test results are communicated a-specific, the participants indicated they feel a lot of anxiety when they already know that they are tested positively, but have to wait until their appointment at the STI-clinic before they know what they tested positive for.

“A bad feeling, especially since they only say, “you’ve tested positive on something, but what is it?”. This caused stress for a whole week.” (Rotterdam; no. 9; Testlab user, HIV-negative)

Another motive for receiving test results online is **patient autonomy**. Some participants mentioned that they found it important to be able to decide for themselves when and where they would get their results and what they would do after getting the results.

“Yes, I would prefer it [online HIV test result], because then I can decide when to see the result, when to process it and what to do next. Whether you want to go to your general practitioner or the STI-clinic [...]. Then you have had time to think whether you want to see your general practitioner for additional support or knowledge. And whether you want to talk to someone. But at least you have had time to process it yourself and to come to terms with it.” (Amsterdam; no. 4; Testlab user, HIV-negative)

Related to the previous motive, participants also mentioned that they **preferred getting bad news at home**.

“You know what’s it about [your online test result], and I was talking about preparation [...], and yes I would probably wait until my husband is home. That is much better, in my opinion, than going to the STI-clinic by yourself and to hear it from someone else.” (Amsterdam, no. 14; Testlab user, HIV-negative)

Another motive that was mentioned is that the possibility to get online test results simply **fits in the current digital world**.

“Yes, just look at it as demand [online HIV test results], a market condition. If there is demand from the market to give results in this manner, then yes, this might be a good tool to persuade MSM to get tested, as an additional means.” (Amsterdam; no. 20; Testlab user, HIV-negative)

B. Barriers for online test results

The barrier that was mentioned most often for both STI test results as HIV test results was **the need for contact with a health professional**. Although most of these men did believe that the option to choose specific online test results should be available.

“Yes, often when you receive something online and you have questions, you don’t receive an answer immediately [...] I’d rather go to someone who can tell me exactly what I have and what I have to do. I find that much easier.” (Enschede; no. 3; non-user Testlab, HIV-negative)

The barriers most mentioned for receiving HIV test results online were that **the impact is too large and that it can be**

unexpected. Therefore, participants considered it better to receive the test results from a health care professional.

“But I can imagine that you’ll freak out [after an online positive HIV test result]. And maybe make some decisions that you wouldn’t make when a professional guided you. I think that is a disadvantage of an online test result [...] because then you can do it all by yourself, processing it and then thinking “I’ll drink that bottle of gin and take those pills.” So, no I wouldn’t do it [give online test results for HIV].” (Amsterdam; no. 18; Testlab user, HIV-negative)

“Especially for people [...] who [...] test for prevention [...] and I believe that is a large group, who get tested and think, “It’ll all be all right”. This group, in my opinion, will be even more confronted when you read online “oh, and you have HIV”[...] I believe there is a large group that just [thinks] “I’ll get tested every 6 months or each year and I’ll test negative for everything” and then you suddenly receive a positive test result for HIV.” (Enschede, no. 7; non-user Testlab, HIV-positive).

Another barrier for offering online HIV test results mentioned was **“ostrich policy”**. Some participants feared that men who receive a positive HIV test result online would not take the appropriate actions.

“Yes, the biggest problem [with online HIV test results] is that people won’t take immediate action, that you won’t go to the STI-clinic immediately and that people won’t get treatment. And the biggest problem is ostrich policy. That you’re going to pretend it didn’t happen. That is not only a problem for the person that tested positive, but also for future sex partners.” (Amsterdam; no. 16; non-user TestLab, HIV-negative)

C. Empathic versus informative style

Most participants agreed that the informative style was more appropriate for test results for low impact STIs.

“Yes, the shorter and the more factual, the better, I think.”(Amsterdam; no. 9; Testlab user; HIV-negative)

Barriers perceived for the empathic test result for low impact STIs included aspects such as **patronizing tone, overbearing and too dramatic.**

“Well, it already starts with, “maybe this news will upset you” that’s already a patronizing tone. And then “You must realise” [that it is a preliminary diagnosis]. Then I think to myself, of course you should realise this, but this [...] is patronizing, not factual.” (Amsterdam; no. 9; Testlab user; HIV-negative).

With regard to online test results for HIV, the participants’ opinions differed from each other. There seems to be a slight preference for an empathic style. Some participants perceived the empathic test result to be **more reassuring and personal** than the informative test result.

“This is friendlier. Because it says, “don’t be too upset” it gives some empathy that is nice to read, I think. Because that is what happens, it upsets you a bit reading that you’ve tested positive. And then you explain that it’s a preliminary diagnosis. Which comes across better than in the other [informative test result], I believe.” (Enschede, no. 9; non-user Testlab, HIV-positive)

V. CONCLUSION

Considering all motives and barriers mentioned by the participants, the first conclusion of this study is that the vast majority of the participants believe that Testlab should offer the possibility to receive specific test results online. Especially Testlab users and participants from Amsterdam and Rotterdam would like this option. A little more resistance was found among MSM from Enschede. The reason for this could lie in the fact that Testlab is not offered in Enschede. It is possible that, even though a general impression of the Testlab website was given, the MSM from Enschede found it difficult to imagine what it would be like to receive test results online.

The answer to our first research question is twofold; the results showed a clear difference between the participants’ perceptions of getting online results for gonorrhoea and for HIV. Even though barriers for putting specific test results online have been mentioned for all STIs, all Testlab users in this research thought it would be best if positive test results for gonorrhoea (and other STIs as syphilis and Chlamydia) are given online. For HIV test results both Testlab users and non-Testlab users mentioned more barriers. On the one hand, a large portion of participants believed that people should be given the choice to receive all test results specific, while on the other hand some participants believed people should be protected and therefore positive HIV test results should only be given face-to-face by a health professional. The answer to our first research question

The results also show a difference in preference for a communication style between a diagnosis for gonorrhoea and an HIV diagnosis. The answer to the second research question is that the communication style is important for both diagnoses, but that an empathic style is preferred for an HIV-diagnosis and an informative style for a low impact STI. This is in line with the results from the literature study [10, 11]. Participants felt that a positive HIV test result should be more extensive than the result of a low impact STI. The main motive participants had for preferring

empathic communication is that they found it more personal and reassuring than the informative communication.

Most motives for choosing informative communication of test results involved low impact STI test results. The empathic version was sometimes found overbearing in the case of a low impact STI diagnosis. The main motive for preferring the informative style was that the communication was short and factual. This was highly appreciated for low impact STI test results. The barriers were that the informative communication was less personal and reassuring than the empathic communication.

Based on this study, it seems to be advisable to include the possibility to receive online test results for low impact STIs in self-tests as Testlab. However, providing online specific HIV test results raises several concerns. Since the men that we interviewed mentioned a number of barriers, but also some motives, we recommend doing more research before offering this possibility.

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