TECHNICAL REPORT

Utilising social media to support HIV/STI prevention: evidence to inform a handbook for public health programme managers

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Utilising social media to support HIV/STI prevention: evidence to inform a handbook for public health programme managers

This report was commissioned by the European Centre for Disease Prevention and Control (ECDC), coordinated by Judit Takács, and produced by World Health Communication Associates.

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Acknowledgements
ECDC would like to thank the participants of the expert meeting 'STI/HIV prevention among youth in Europe using social media' for providing detailed comments on earlier versions of this document: Thomas Hayes, Evert Ketting, Roman Kuhar, Cary James Lied, Karen Lorimer, Zoran Milosavljevic, Katie Newby, and Alexandar Štulhofer. Irina Ljungqvist contributed greatly to the concept and methodology development.

Suggested citation: European Centre for Disease Prevention and Control. Utilising social media to support HIV/STI prevention: evidence to inform a handbook for public health programme managers. Stockholm: ECDC; 2017.

Stockholm, July 2017

Cover photo: © iStock

ISBN 978-92-9498-078-6
doi: 10.2900/407231
Catalogue number TQ-01-17-802-EN-N

Contents

Figures

Tables

Abbreviations

DM	Direct message
LGBTQ	Lesbian, gay, bisexual, transgender and queer
MSM	Men who have sex with men
STD	Sexually transmitted disease
STI	Sexually transmitted infection

Introduction

What does this report provide?

This report describes and analyses the social media space and the opportunities it presents for programmes to prevent HIV and other sexually transmitted infections (STI) among youth across Europe. It aims to gather evidence for the production of a handbook to guide public health programme managers seeking to capitalise on these opportunities [10]. Part 1 consists of a netnographic analysis of sexual health content on social media, outlining the social media platforms studied, methods used, findings, and discussion. Part 2 reports the methods and findings of in-depth interviews conducted with young people in Europe, and summarises emerging recommendations. Part 3 then identifies some promising approaches to the use of selected media and gamification, as well as other approaches that may be available to health programmes subject to resources, such as paid advertisements on social media.

The report builds upon a systematic review of systematic reviews (see Annex 1), grey literature reviews, and selected recent publication reviews – *Collating effective evidence-based interventions that could contribute to HIV/STI prevention amongst young people in the context of sexual health in the EU/EFTA countries* – yet to be published. These reviews reflect a growing attention to digital media platforms to support sexual health interventions among young people. Key findings of these reviews include the need to better understand how to track and best utilise current (and rapidly changing) digital media, especially social media networking to influence public health and gather relevant data [1]. While digital media technologies appear to offer a myriad of possibilities for epidemic intelligence gathering and public health interventions, understanding their specific dynamics and potential, in the context of STI/HIV prevention among young people in Europe, needs further investigation. These needs and opportunities were also acknowledged by the ECDC-convened expert consultation meeting (2015) on STI/HIV prevention activities for young people [2].

In further examining digital media approaches, this handbook development project has conducted research across major social networking sites, as well as online interviews with young people, and also looked at other promising intervention areas. Findings from these research activities are summarised, and newer analytic approaches like netnography, online focus groups, dashboards and social media advertisement-related analytics are introduced.

A basic introduction to social media and specific guide for social media strategy development is available in other ECDC studies and guidance (e.g. *Social media strategy development: A guide to using social media for public health communication* [3]), and readers are referred to this guide and other useful introductory guides [4,10]. The aim of this report is to provide information that can enhance current practice in addressing and measuring the impact of social media platform-based interventions to prevent HIV/STIs in young people in Europe.

Definitions

This report frames social media as an important tool not only to communicate, but also to monitor topics of discussion, prevalent sentiments, and define the characteristics of social networks among young people around different topics. Different social media platforms are also understood to offer unique and distinct channels of communication to build relationships with selected audiences [3] and measure the impact of both message delivery and behaviour change.

For the purposes of defining eligibility criteria for study participants, we use the United Nations official definition of 'youth' as any individual from 15 to 24 years old [5]; however, youth should not be seen as a homogeneous category within or between countries and cultures. It is a socially constructed concept incorporating a wide variety of meanings, practices, and connotations. This report will use the term 'young people' in light of this plurality and diverse subgroups, also recognising that today's young people are more gender-fluid than has been the case in previous generations. It is beyond the scope of this study to develop a taxonomy for different youth groups in Europe, unless they emerge in our research and guidance document as having a particular relevance to social or sexual networking. Restrictive identity categories have been shown [6,7,8] to be of limited usefulness in sexual health promotion. The searches were not limited to any specific sexual orientation among youth. The report also recognises that ECDC has already produced studies about men who have sex with men (MSM) in Europe [9,11] and draws on those resources.

Target audience

The target audience for this report and handbook includes public health programme managers working on and with STI/HIV prevention programmes for young people 15–24-years old in EU/EEA countries.

Part 1. Social media and content analysis

1.1 Introduction

The first objective of this project was to gain insights into the use of social media and their potential applications to promote STI/HIV prevention activities for young populations in Europe. The researchers attempted to determine which social networking websites are most popular among young European adults, in order to understand if and where certain groups cluster [12]. We found that individuals often use several social network sites for different objectives and socialisation needs. Young people use social networking sites in a multi-layered fashion, navigating across them and transitioning seamlessly between different behaviours and codes of etiquette. Video, text and images are shared with different social meaning across websites and apps. Figure 1 provides an overview of the reciprocal use of the main social media platforms, and indicates the leading role of Facebook, followed by Instagram.

Figure 1. Multi-use of social media websites in the US (18 years or older) [13]

Substantial 'reciprocity' across major social media platforms

% of users of each social media site who use another social media site

	Use Twitter	Use Instagram	Use Pinterest	Use LinkedIn	Use Facebook
% of Twitter users who ...	–	65%	48%	54%	93%
% of Instagram users who ...	49	–	54	48	95
% of Pinterest users who ...	38	57	–	41	92
% of LinkedIn users who ...	45	53	43	–	89
% of Facebook users who ...	29	39	36	33	–

Source: Survey conducted 7 March–4 April 2016, Social Media Update*, Pew Research Center [13]*

Due to this multi-layered use of social media platforms by young people, single digital platforms are not the most effective means for reaching audiences of young people. One should not define one's sampling frame or 'playing field' as a single website, online forum or chat room, but rather as a set of practices and activities carried out across multiple online platforms [14]. The way in which people connect to each other will vary across different social networking websites. While one person might use Facebook primarily to connect with friends and acquaintances, the same person may use Twitter to follow a famous band and find others who share their interests instead of talking about it with close personal friends who may not be interested in the same topic. Digital media have created a variety of new socialisation spaces for young people, and analysing the content of postings across platforms is important when trying to understand their collective impact as well as the roles of each medium individually [15].

1.2 Netnography

A 'netnography' approach was used to guide this multi-platform monitoring research. Netnography is ethnography adapted to the study of online communities, researching online cultures and other forms of social behaviour mediated by digital communication. It is an interpretive research methodology that adapts the traditional, anthropological method of participant observation to the study of interactions and experiences expressed through digital communication [16]. Netnography is unobtrusive; the researcher immerses himself/herself in social networks and conversations online. It is descriptive, and the researcher can capture rich contextual portrayals of the lived experience of online social life. This methodology allows researchers to observe young people's different online social networks and how they are reflected in communication across social media websites.

1.3 Methodology

The methodological structure and approach included the gathering of evidence through: i) a review of the social media landscape (including social networking websites and analytics software; ii) netnography; iii) online focus groups and in-depth interviews. Findings were then tested and refined based on a review and critique by expert groups[1]. The collective findings of this process were then used to develop a companion handbook of practical

[1] Review process included comments from four designated project reviewers as well as feedback from a larger group of experts convened at a dedicated ECDC meeting of HIV/STI social media experts in March 2017.

guidelines: *Utilising social media for programmes to prevent HIV/STI among youth.* Once this research was underway, a decision was taken to produce two separate documents: one, a research report, which is this document, and another, a handbook, which is a companion to this document that presents practical advice for programme managers.

Monitoring of all major social networking sites in Box 1 below (except Snapchat, because privacy features prevent monitoring) was conducted via media monitoring software and manually browsing on social media platforms. Sources and keywords are shown in Figure 2. The objective was to look at how different digital social spaces were being used (see Box 1), as well as the nature and content of conversations and posts shared among European youth about sexual health, HIV/STIs and their prevention.

Box 1. Social media platforms – reviewed

Instagram is an online mobile photo and video sharing social network that allows users to take, edit and share images and videos publicly and privately on the Instagram app. Users can follow each other and 'like' each other's posts. Content can also be shared onto other social media platforms outside of Instagram. Images can have textual captions on them and receive comments (which can themselves be 'liked' by other users). Recently, Instagram added a new feature called 'Instagram Stories', through which users can add short videos and images which will disappear in 24 hours. Fifty-five percent of the 150 million users of Instagram Stories are under the age of 29 [13].

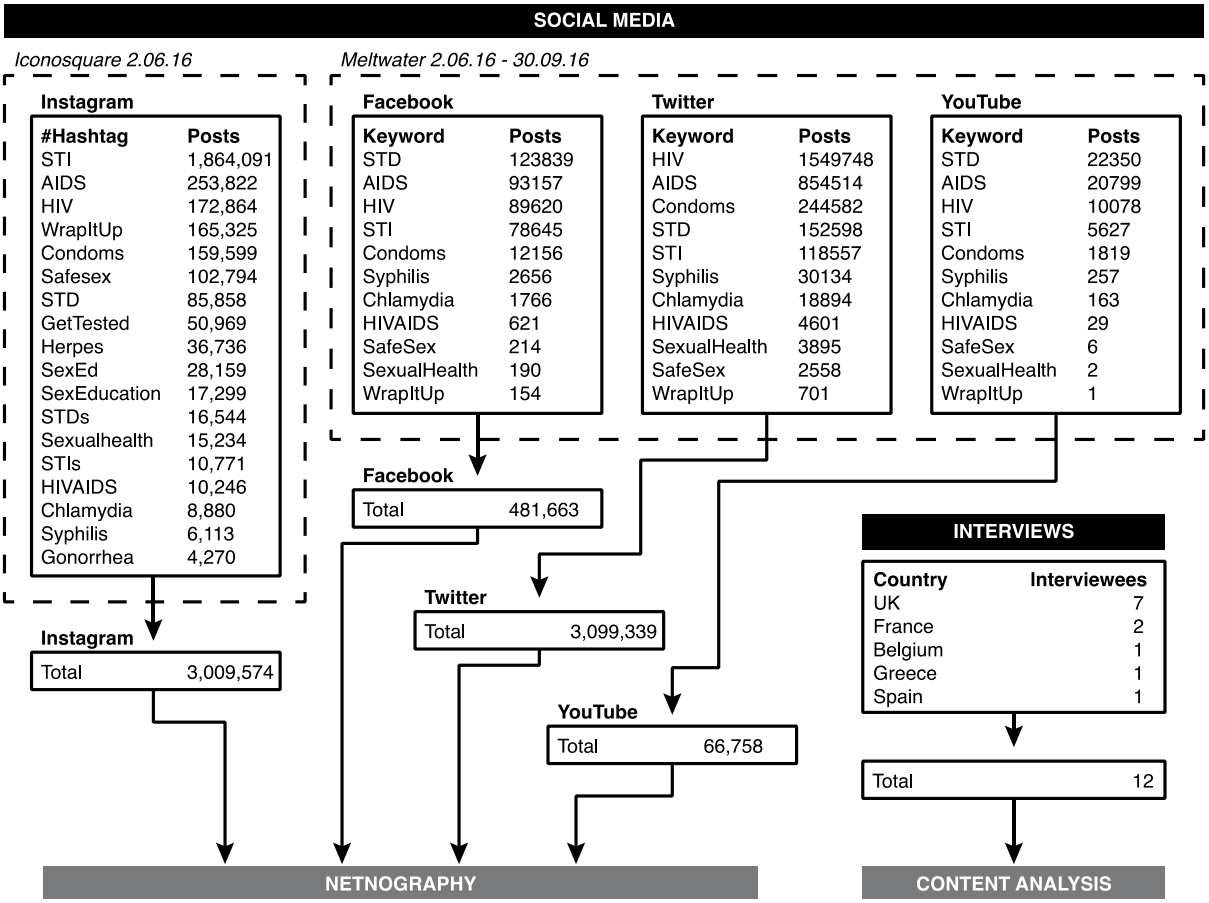
Twitter is a micro-blogging site for short messages or 'tweets,' consisting of a maximum of 140 characters of text, with the option of attaching pictures or URLs linking to additional content. While, like other social media, Twitter can be used to maintain contact with a network of friends, it is also frequently used as a platform for sharing and receiving news and promoting one's business. Discussions on Twitter are organised around themes and common interests and not necessarily friendship connections. Twitter's reach made it a significant channel for widespread sharing of information and comment on US Election Day 2016 [17].

Facebook is a social sharing site that connects individuals with friends, families and acquaintances. It is the most used social media platform globally with 1.8 billion active users as of 31 December 2016 [18]. It allows sharing of written content, images and videos. Friends in one's network can engage by 'liking' (and, more recently, expressing a variety of other pre-supplied emoticons) and commenting upon others' posts.

Snapchat is an app that allows video and photo messages to be sent to chosen friends. The images disappear a few seconds after opening. Users can also add images and video to their 'story' (lasts for 24-hours), which only followers can see. Snapchat is popular among teens and young adults. It does not include much text and is limited to a few words that can be superimposed on top of images.

YouTube is a video sharing platform that allows users to upload videos, as well as view, rate and write comments. Available content includes video clips, TV shows, shorts and documentary films, and how-to videos. Most of YouTube's videos have been uploaded by individuals, and the platform includes celebrities and well-known vloggers (video bloggers).

Figure 2. Sources and keywords



Online participant observation was conducted in anonymous fora, Facebook groups and other social media platforms. Google was used as a search engine to identify different anonymous fora. Selected social media platforms were searched using key terms (see Box 2). A netnographic analysis was made of relevant discourses, narratives and communication styles among young people regarding sexual health and sexual behaviour. Young people were identified by date of birth entered in their social media profile. Researchers collected data by taking screenshots of relevant posts (either textual, photographic, or both) and making field notes of what was observed in online social interactions. As with traditional ethnographic analyses, which involve progressive immersion in communities, this netnographic research was conducted by embedding in online youth cultures and 'listening' to exchanges on selected media platforms to identify relevant discussion topics and themes. Repetitive themes in the discussions as well as images were later coded around categories such as humour, mockery, moral judgement and gender stereotypes.

Box 2. Search terms

#STI, #AIDS; #HIV; #WrapItUp; #Condoms; #Safesex; #STD; #GetTested; #Herpes; #SexEd; #SexEducation; #STDs; #Sexualhealth; #STIs; #HIVAIDS; #Chlamydia; #Syphilis.

Social networking sites were monitored between June and September 2016. A set of English-language hashtags (see Table 1) were identified to guide the search for posts that were relevant to the study topic. Key words and terms associated to sexual health and STI/HIV prevention (condoms, sexual health, sex education, safe sex) and sexually transmitted infections (HIV, chlamydia, herpes, gonorrhoea) were identified. Researchers tested the identified search terms and used the ones which returned the most results: #Condoms, #SafeSex, #SexEd. All images identified using these hashtags which were posted in the month of June 2016 were saved[2]. Hashtags in

[2] During the data collection, two other hashtags were identified as being commonly used by our target group when talking about sexual behaviour: #FuckBoy and #BasicBitch. These hashtags were also monitored, although data collected using these hashtags was not deemed relevant to the specific research topic.

other European languages were not covered in this study, but could be easily investigated using the same methodology.

During June 2016, Instagram was the first social media platform to be monitored (Figures 3 and 4). It was chosen as the first one due to: 1) its frequent utilisation among young people; 2) reports in the literature of the relevance of Instagram for public health [19,20,21]; and 3) the capability to identify the geographical location of posts. Thousands of images were retrieved, collected and filtered by location. Images collected were analysed during the months of July and August.

Various analytic tools are available to study social media, including Zoomph [22], Tweetbinder [23], Iconosquare [24]. Iconosquare was chosen for its affordability and its ability to analyse Instagram.

Figure 3. Instagram posts containing #condoms, by location

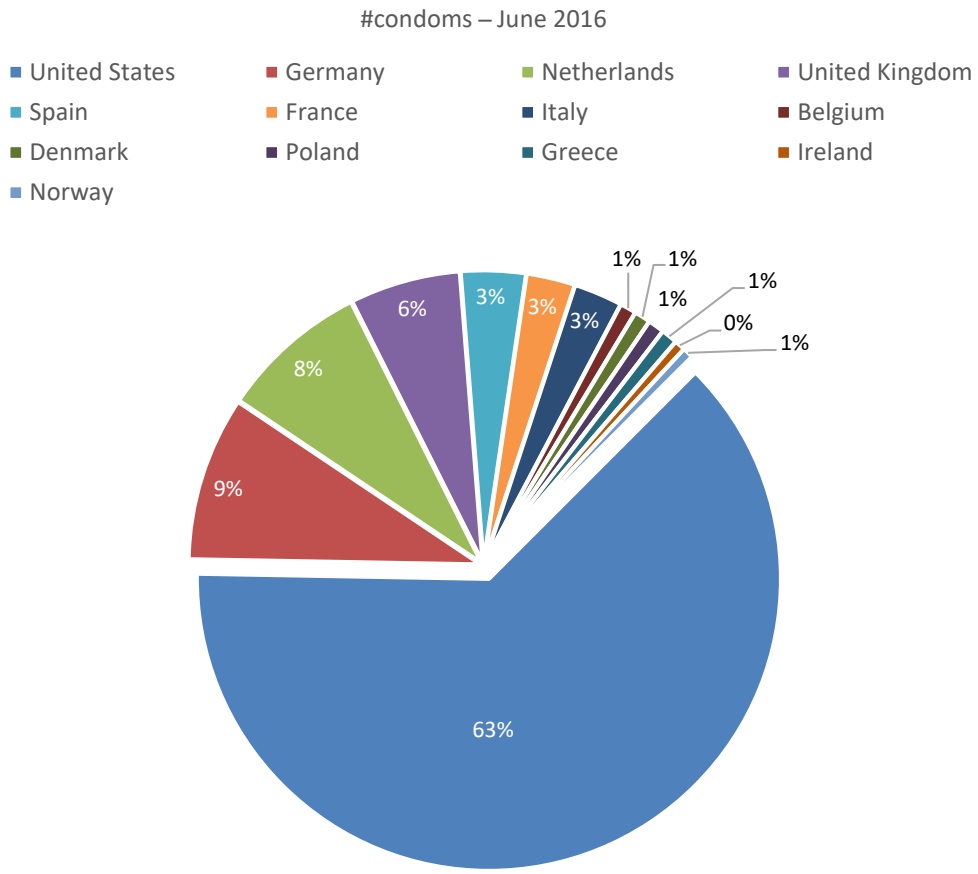
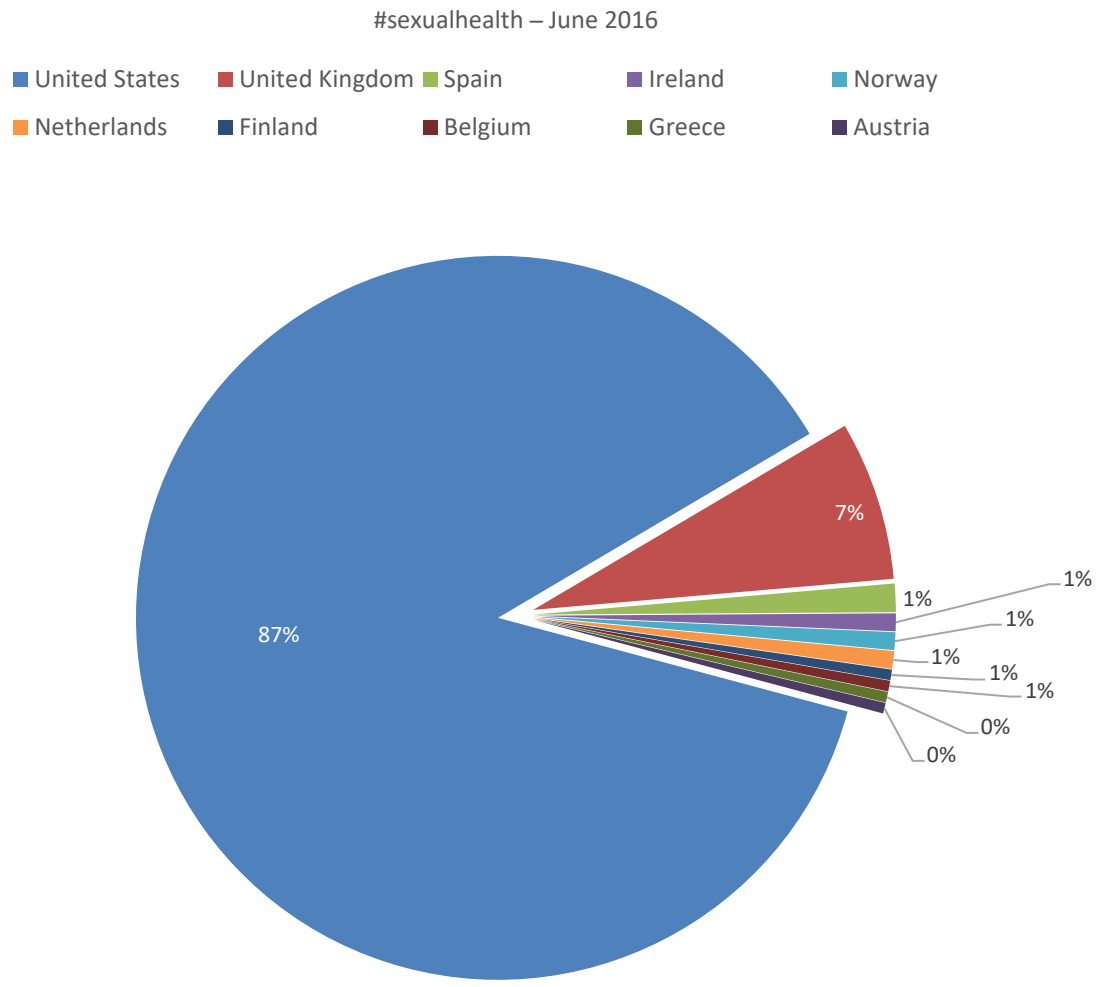


Table 1. Instagram posts by hashtag, June 2016

	#	Instagram
1	STI	1 864 091
2	AIDS	253 822
3	HIV	172 864
4	WrapItUp	165 325
5	Condoms	159 599
6	Safesex	102 794
7	STD	85 858
8	GetTested	50 969
9	Herpes	36 736
10	SexEd	28 159
11	SexEducation	17 299
12	STDs	16 544
13	Sexualhealth	15 234
14	STIs	10 771
15	HIVAIDS	10 246
16	Chlamydia	8 880
17	Syphilis	6 113
18	Gonorrhoea	4 270

Figure 4. Instagram posts using #sexual health by location



In September 2016, a different software called Meltwater [25] was used to monitor social media platforms other than Instagram. The choice of this software was due to the research group's previous successful monitoring experience using this tool. Meltwater allows monitoring of textual content on Facebook, Twitter and YouTube. It picks up Facebook posts, Tweets and Facebook comments according to search terms chosen. Meltwater also allows for retrospective searches and filtering of posts by geographical location, where possible. Researchers monitored archival posts retrospectively from May to September 2016. Data was again collected by capturing screenshots of tweets, comments and Facebook posts.

In addition to using Iconosquare and Meltwater, data were manually collected from several social media platforms to identify any possible gaps not captured through the automated software monitoring. Google was used as a search tool to locate relevant discussions, which were then analysed for content, the choice of social media platform and social network with whom the content was shared. Relevant platforms searched included Facebook, Twitter, YouTube, Vine, Reddit, Quora, Instagram, Tumblr, Pinterest and Snapchat. All relevant data were collected by screenshots and saved for netnographic analyses.

1.4 Findings and discussion

The findings presented here are based on an iterative developmental process applied to key insights and dominant themes identified by the project's principal investigator through the social media review and netnography described above. The iterative process also included reviews by designated project experts, knowledgeable colleagues, and most importantly, the online interviews with young people described in Part 2.

1.4.1 Facebook and sexual health messages

Facebook is still the most widely used social media platform [13], and many sexual health messages are available on Facebook, posted by NGOs and other health-related organisations. These prevention messages are the most common results when searching for sexual health-related themes on this platform. There is very little user-generated content discussing sexual health or commenting on the sexual health promotion messages. Facebook is characterised by 'context collapse,' that is, information or expectations from one social context may invade or encroach upon another. One can be connected on Facebook with family, friends and work colleagues, without much control over what content is displayed to which audience. As a result, users may take a 'least common denominator' approach and share less information about themselves overall. Also, for the same reason, behaviour on Facebook is more aligned with normative expectations. Facebook also provides strict privacy settings for its users, which limits the access of anyone outside one's network to read posts and presents a barrier for social media listening as a method of participant observation.

Content from organisations promoting sexual health on Facebook tends to resemble traditional advertisement techniques, transplanted to the digital space of Facebook. User-generated content has the advantage of being relatable and authentic, but user-generated messages may be counterproductive to programme goals, actually denigrating safe-sex practices and mocking people who use condoms, as well as promoting misogynistic views. Some user-generated posts do promote sexual health, especially those focusing on MSM. In general, there appears to be more engagement and positive messaging on sexual health within the LGBTQ and MSM communities, compared to heterosexual-themed content.

1.4.2 Instagram

Instagram is an app primarily for sharing images, and different self-representations and narratives are present. With less rigorous privacy settings, access to user-generated content regarding sexual health was possible. However, most user-generated content related to sexual health were jokes involving condoms or reinforcing stigma around STIs and HIV. More interesting on this platform was the plurality of personal narratives and social influencers. There is an opportunity here for prevention efforts to take advantage of positive personal narratives (female empowerment, for example).

A significant amount of safe-sex messaging on Instagram comes from accounts dedicated to marketing a particular company's sex-related products, where promoting sexual health messages is secondary to promoting the product or brand. Other institutional accounts are dedicated to particular causes, including feminist groups promoting female empowerment, where sexual health is more central to the message, and there is no overt commercial motive. Individual users also share sexual health messages with varying levels of seriousness: some re-post sexual jokes, which may or may not be positive depending on their content, while others share personal stories, which can be particularly powerful and motivating. As Instagram is a photo-based medium, sexual health content often comes with suggestive or explicit imagery, which in some cases may be helpful in engaging the audience, but which can also be inappropriate for some audiences and organisations.

1.4.3 Anonymous social network sites

Anonymous social network sites, such as Reddit [26] and Quora [27], allowed for more insightful and richer narratives than other social media platforms where individuals are identifiable. These sites, which allow anonymous discussion around a wide variety of topics, are digital social spaces where young people (users, though anonymous, can share information such as their age and gender identity) share concerns and questions about sensitive topics such as sexuality and intimate relationships in ways they might not be able to do in person with parents or peers. One factor that propels teenagers and young people to use anonymous social media is the increased parental vigilance on social networking sites such as Facebook which can make teens self-conscious about what they post on social media in an effort to hide it from adults [15].

1.4.4 Peer to peer education – YouTube

High-profile 'YouTubers' may have a large following amongst younger segments of the population, making them potentially powerful messengers and influencers. Young people are creating and consuming content on YouTube about a large variety of topics including sexual health. Laci Green, for example, is a 22-year-old who has a YouTube channel where she discusses all things related to sex. She has almost two million subscribers. On her channel, HIV and STIs are discussed in the context of relationships, gender, body image and sexuality. Although technically informative, she also discusses topics such as condom consent in an intimate relationship, sexting, and cyberbullying (Box 3). This YouTube format is interactive as the YouTubers invite their audience to pose questions in the comments section and on Twitter, mentioning them in their tweets. As found on Reddit threads and other anonymous fora, sexual health and STIs are discussed in the context of relationships, sexual practices and identities.

Box 3. Sexting and cyberbullying

'Sexting' is a portmanteau of the words *sex* and *text;* the act of sending someone sexually explicit photographs or messages usually via mobile phone but also via other digital devices. This may be done with or without the intention of having an in-person sexual encounter.

'Cyberbullying' is bullying that takes place using electronic technology and commonly uses social media to identify and persecute the target. Electronic technology includes devices and equipment such as mobile phones, tablets, computers and digital communication tools, including social media websites, text messages, other direct message chats (which can include video and image sharing) and websites.

1.4.5 Content co-creation

On the Internet, and specifically on social media, a wide variety of information is always just 'a click away'. Rather than using social media as just another vehicle for making information available, it is a valuable medium through which to engage young people with more impact than merely sending health promotion messages.

Young people are constantly producing content for their peers to consume and share. This allows the audience to engage with content and co-create it, making them feel part of the campaign by helping to shape it.

1.4.6 Emojis and the Internet's own language

Emojis are considered to be the fastest growing form of communication. It started with 176 images to convey emotions and tone of language in digital online messages and has now grown to 1 800 icons. People who use emojis adapt the icons to their communications needs. The aubergine emoji, for example, has been used so frequently with a sexual connotation that Instagram, in 2015, banned search results for photographs tagged with an aubergine emoji on the basis that it could be used to signify nudity or pornography.

1.4.7 Image sharing in social media

Image sharing in social media has gained momentum and has been increasingly recognised as being relevant to public health efforts to influence health behaviours as well as being valuable as a research tool to understand attitudes and gain insights on behaviours. Recent studies showed that user-provided, as well as automatically-generated, images posted in social media can provide information which can be used to infer health information [28], as well as measure the impact of a social media campaign [21]. The sharing of images and videos among young people is an important use of social media, and a form of communication and expression of self and group identity among peers, which can lend insights to inform the design and content of health communication interventions such as STI/HIV prevention.

In addition to image sharing, young people are expressing their sexuality on Snapchat (which automatically erases any picture or video a few seconds after viewing) and direct messages (or DM, a feature of most social media websites and apps) are used to share intimate pictures and videos – a messaging approach termed 'sexting' (see Box 3). Implications of these new forms of expressing sexuality, as well as their impact in young people and HIV/STI prevention, were discussed with young people during the interviews conducted for this study.

Some of the literature on the use of social media also suggests that social media can be used as a tool to promote inclusion and reduce health inequalities [29,30] as it can grant access to information and offer services to youth minorities (commercial sex workers and injection drugs users, among others).

Part 2. Online focus groups and in-depth interviews

In addition to the review of social media platforms and netnographic observations of online discussions among young Europeans described above, online in-depth interviews were conducted. Online interviews and focus-groups allow engaging a geographically dispersed sample of young people from different locations. Computer-mediated group discussion has also been found to be more appropriate to the engagement of young people than traditional face-to-face focus groups [31]. In our research, though, we found that during recruitment, young people preferred individual interviews rather than group discussion.

Online focus groups are ideally synchronous and can be conducted with Skype or WhatsApp. A synchronous group means all participants will be interacting at the same time, with the presence of a moderator. This differs from asynchronous groups where participants can add their inputs using fora and email at different times [31]. Although an asynchronous approach allows more flexibility for participants, its validity for a focus group discussion is debated [32].

Skype is free of charge and offers privacy/security features and excellent geographic reach. Access to verbal and nonverbal cues in Skype focus groups can provide detail and subtlety similar to face-to-face focus groups [33]. WhatsApp is a popular message app and is smartphone-friendly. Participation in groups on WhatsApp may be higher than Skype, although WhatsApp does not have a video interface like Skype. (Note: WhatsApp launched video calling in November 2016; research for this report was conducted in June 2016.)

2.1 Interview methods

The moderator invited pre-screened, eligible respondents to take part in an online focus group or individual interview either via Skype or WhatsApp. Participants from EU/EEA countries were recruited through convenience sampling via e-mail and Facebook. The recruitment included only participants from 18 to 25 years of age because recruiting any participants under 18 would need the approval of a parent or guardian, which would likely inhibit the willingness of the participants and slow down the process considerably. Researchers attempted to recruit a balance of participants in terms of countries relevant for this research. An invitation message to participate in the study was posted on relevant Facebook groups, and a Facebook page was created in an attempt to engage with potential participants. Members of the research team were asked to share the invitation among their own networks. Finally, using a snowball sampling approach, participants who successfully engaged were asked to forward the invitation to others to participate in the study.

Examples of questions included: Where/from whom do you generally get sexual health information (e.g. parents, online, peers, etc.)? Have you come across anyone or any initiative on healthy sexual behaviour using social media? What did you think of it? Are there particular social media platforms that you prefer to use to talk about sex or sexual health?

One challenge researchers encountered was interviewees' reluctance to talk about sexual health in online groups of people. Although questions did not explore personal sexual practices, none of the participants agreed to partake in a group discussion. All participants opted for individual interviews, and all agreed to do in-depth interviews via Skype, either with video or just audio.

All participants were given a participant information sheet and a consent form, which they returned, giving consent for their responses to be used anonymously for research purposes.

All due process for ethical approval were followed. The ethics approval process, though, took considerably longer than anticipated, and severely curtailed recruitment time, compromising the total number of participants that could be interviewed.

Twelve participants were interviewed. Nine participants were female – eight from the UK and one from France; the three male participants were from Greece, Belgium and Spain. Although this number is far from saturation, common themes nonetheless emerged across the participant interviews, giving valuable insights and also suggesting directions for future research.

2.2 Overall findings and emerging recommendations

All participants said they searched using Google when they needed sexual health information, and all said they would never use any of the social media platforms to seek such information. They also preferred to use Google instead of talking to peers to get sexual health information. The anonymity and confidentiality of doing so were the primary reason all interviewees gave for preferring Google searches to other information-seeking methods.

Only one of the interviewees could remember seeing HIV/STI prevention campaigns or information posted in social media, or even elsewhere online, unless they were actively searching for it. Researchers observed the same trend while conducting the netnography. Although information is readily available if one is actively searching for it, it will not be presented to those who are less proactive or self-motivated to seek information about their sexual health.

Most of the interviewees believe that video-based media – such as YouTube – could be highly valuable educational resources, but they would need to be readily accessible to those searching for them.

A few participants cited experiences of embarrassment when trying to access testing services for STIs such as chlamydia. They suggested social media platforms could be used to anonymously request at-home STI tests, which can be sent by mail.

One participant from the UK remembered an educational game, which was very popular on Facebook, designed to teach first aid skills. This game created a fictional narrative in which one of the players' actual Facebook friends was seriously injured, and the player was tested by making critical decisions to try to save the friend's life – a model that could be applied to sexual health, on the basis that reasoning through the process of preventing or getting treatment for an imaginary STI can help prepare one for the real experience.

Another participant believed that women had a greater unmet need for sexual health information as compared to men; however, other participants disagreed with this statement.

Several participants mentioned that social media celebrities already promote healthy lifestyles and even speak about mental health – so it is certainly plausible that such personalities might expand their subject areas to discuss sexual health as well.

Social media was also identified as an important tool to fight stigma against STIs and HIV in particular. As also illustrated in the netnography findings, social media provides an opportunity to talk about risk, prevention, testing, treatment, and living with STIs in a non-confrontational yet authentically personal way that normalises them and takes away the fear which prevents people from seeking help.

Sexual health information needs the 'correct environment', according to one of the participants. This means that it is not sufficient to make information available, but rather it is important that it comes from a relatable source, and it is ideal if it can be passed on by peers – and social media is an ideal platform for encouraging this dynamic. This is the only way, according to this participant, that people will be prepared when it comes to making choices that will prevent HIV and STIs. Echoing this statement, another participant considered it very important for young people to get sexual health information from peers rather than solely from their parents or their school.

One participant suggested that a social media platform such as Facebook could be used to promote YouTube videos and vloggers talking about sexual health to allow a greater reach within a younger audience. Along the same lines, another suggested that short videos could be posted on Facebook and Instagram, perhaps linking to other websites or services.

A theme which came up in all interviews was the interest in social media helping young people get better access to sexual health clinics and services. Most participants said that everyone knows that using a condom prevents HIV and STI, but not all people know how to access sexual health services, and many are embarrassed to do so. Efforts using social media, they felt, should concentrate on the services front.

Specific suggestions included the following:

- A video or post explaining the process of getting tested or treated for STIs could reach many young people who do not know what it involves
- Social media allows for private conversations, meaning young people could engage with sexual health services through them, if that option was available
- Sites like Facebook and Instagram allow ads to be shown, and information about sexual health services could be presented on these sites
- Information should be straightforward and clear: the language should reflect young people's usage.

The researcher also posed questions regarding new sexual practices mediated by social media, such as sharing intimate images or text with sexual content. Two of the female participants expressed their belief that acts of sharing body images were mostly performed by women out of male pressure and that they felt the motivation behind this practice was more due to insecurity rather than a healthy expression of sexuality. A male participant stated that sometimes private images received were shared with close friends, but not with the intention to bully or harm the sender.

Despite higher parental vigilance on Facebook, the platform was identified by all participants as most effective because out of all platforms, Facebook is the one everyone uses regularly.

All participants stated that having social media celebrities talking and posting about sexual health would have a very high reach, especially for a younger audience who are more easily influenced. Participants were unanimous with regard to the potential impact and reach of social media influencers, but the influencers need to be identified as trustworthy among the target audience for the information to be taken seriously.

Part 3. Promising practices

3.1 Rapid change is the norm

Although unequal access to the Internet and technology within the EU and within countries should be taken into consideration, today's young adults represent the first cohort to grow up in a fully wired and technologically fluent reality. The effectiveness of youth intervention programmes depends upon their ability to navigate online technologies and communicate in the language of 'digital native thinkers' [29]. These adolescents and young adults have been called 'digital natives', distinguishing them from the 'digital immigrants' who preceded them [34]. Today's youth can – and do – move quickly and fluidly across the digital media landscape.

Social media landscapes are changing. Facebook, for example, is slowly losing younger crowds and attracting an older audience [35], while sharing of images is gaining momentum among youth. More than 1.8 billion images are shared online every day (2017), compared to 500 million tweets (October 2014) [28]. Instagram is the fastest growing social network site globally, having now attracted about 400 million active users, with an average of over 80 million photos shared per day and 40 billion images shared overall [36]. Snapchat is another prominent platform with two-thirds of its users between 13 and 24 years of age, and views have increased 400% between May 2015 and 2016 (from 2 billion to 10 billion and projected to reach 18 billion daily video views by May 2017 [37,38]). A recent study [39] found that teenagers are leveraging social media as a conversation space and an outlet for self-expression to a greater extent than adults, displaying more self-disclosure. They are also more focused on posting photos. It is customary to share images after a social gathering instead of posting messages about the event [28]. They also engage with a wide variety of digital games and social apps and social media advertisements that are increasingly being used as effective health communication platforms.

3.2 Games

Meta analyses of serious game-based interventions have been found to be effective in modifying determinants of sexual health behaviours, primarily through knowledge enhancement [40]. Games provide participants with gender-tailored opportunities to learn about, and experiment with, specific safer sex precautions in a confidential nonthreatening virtual environment, free from any embarrassing parental control and peer monitoring [41].

Serious digital games are a type of computer-delivered intervention considered to be both educational and fun. Games differ from other computer-delivered interventions by aspiring to be highly enjoyable, attention-captivating and intrinsically motivating [42].

DeSmet et al. [43] note that

> 'serious games are theorised to derive their learning effects from at least three sources: 1) by creating immersion or transportation, a state in which the player becomes absorbed in the play without disbelief, while creating personally relevant experiences and deep affection for the characters; 2) by establishing flow, a state of high concentration in which the player experiences a balance between skills and challenge; and 3) by meeting the individuals' needs for mastery, autonomy, connectedness, arousal, diversion, fantasy, or challenge.'

Brüll et al. [41] note that users prefer first-person role play with highly customisable avatars and a real-world design with a first-person visual perspective over a fantasy-like third-person perspective. Bayley and Brown [44] note that engaging parents as agents to support their children, alongside capitalising on increasingly sophisticated technological options, could jointly enhance support.

Sexual health promotion games have also been introduced into online, multi-player virtual worlds/virtual reality (VR) such as Second Life (http://secondlife.com) and Sansar (next-generation Second Life, released in 2017, https://www.sansar.com). Evaluation [45] of these interventions (see http://healthcybermap.org/slsexualhealth/) shows that multi-user virtual environments can provide useful, rich educational experiences to those who visit them and serve as engaging venues for learning about important health topics. Second Life's immersive environment affords opportunities for independent/group learning, exploration and discovery through various interactive objects, special experiences, and the development of virtual communities through these activities. It is expected that these types of educational media and evaluation tools will be further refined and enhanced to more fully utilise the affordances of 3-D online social worlds into the future [46,47], including the latest developments in immersive virtual reality.

Many digital games today are downloadable as mobile game apps from app stores run by Google, Apple, Microsoft, etc.; others are playable online via ordinary Web browsers and/or from within social media platforms such as Facebook.

Researchers call for further studies with rigorous evaluations of game effectiveness, longer-term follow-up, and using measures of behaviour rather than their determinants.

3.3 Social apps

Dating and 'hookup' apps, which combine GPS (Global Positioning System) and instant messaging technologies to help users identify local sex partners, can include embedded safe sex/STI testing educational messages, chat opportunities with health educators, and links to resources like testing centres and symptom checkers. Indeed, in an ECDC report entitled *Understanding the impact of smartphone applications on STI/HIV prevention among men who have sex with men in the EU/EEA,* these have been found to be acceptable, feasible and cost effective interventions [11], especially with MSM populations.

Jenkins et al. [48] note that respect for community culture and the unobtrusive approach of app-based messaging was advantageous in establishing credibility and rapport with app users. App-based messaging could therefore be seen as an alternative, non-traditional venue for sexual health education in addition to HIV testing promotion.

This study reinforces ECDC and other research [49,50,51,52] demonstrating the acceptability and feasibility of providing sexual health information and HIV/STI testing referrals via established geo-social and sexual networking apps for MSM (e.g. A4A Radar, Grindr, Jack'd, and Scruff).

Further studies are needed to investigate the effectiveness of the content. Further insights are needed into how and where such sexual health educational materials can best be introduced into other apps, for example Tinder, to reach other young audiences.

3.4 Paid social media advertisements and promotions

Paid social media advertisements and promoted/sponsored posts (e.g. Facebook, Instagram, Twitter, Google Ads, etc.) can be effective ways of finding people based on demographics, behaviours, or contact information; getting people's attention through formats that are attention-grabbing, flexible and work on every device and connection speed. Ideally, impact can be measured through advertising reporting tools [53].

The Facebook ads platform, for example, allows advertisers to select and customise the characteristics of the audience/population to whom they wish to exclusively target an advertising campaign. The Facebook ads platform provides detailed data and statistics about a campaign's reach and performance.

Facebook ads have been effectively used to promote and communicate a wide variety of HIV/STI-related issues. Connecting people to free home-based STI test kits ordered online [54], recruiting for HPV trials [55], and addressing inquiries about an HPV vaccine are among the possible applications.

Conclusions

This research demonstrates that social media presents a variety of opportunities as well as challenges for programmes seeking to promote sexual health and prevent HIV and other STIs. The social media landscape changes very quickly, and so the first step for any programme manager interested in using these tools should be to assess which media are the most currently popular and relevant to their target population. Nonetheless, we can identify some core principles to guide such strategies, which hopefully will remain relevant as the landscape changes.

First, it should be possible for any programme manager or team to conduct their own rough netnography of sexual health content on social media, at little to no cost to their programme, in order to understand what their targeted populations are saying on these platforms, and which ones are most popular. More rigorous research can be commissioned that could include media analytics, focus groups, interviews, and surveys to inform their strategy. Research should include identifying the multiple narratives and their chosen platforms, in order to understand where the interventions might best fit. It is important to identify clear goals for using social media, rather than simply entering the space because it is perceived to be fashionable or a novelty. Engaging end-users and young people in the development process is important to ensure that a campaign is interesting and relevant for the intended audience. New campaigns can also garner attention by sharing content related to trending events and issues.

It is important to review messages carefully before sharing them. Although social media may seem like an informal space, users take social media messages as seriously as they might consider an informational flyer. Hence, any information distributed through social media must be vetted with as much care as any other health promotion message. Once a campaign is implemented on social media, there are many tools available to monitor and evaluate its reach and estimate the engagement it receives.

Finally, while users take social media seriously, it is still just one medium among many others. It presents new opportunities, but its relative novelty should not be construed to mean it is the most important or visible medium for promoting sexual health. It is no substitute for broad-based communication strategies, and its adoption should not detract from pre-existing health promotion activities. However, exploring social media can be a valuable way to expand one's audience, develop new capacities, and keep an eye on new communication formats which will continue to grow and change in the years to come.

Limitations and opportunities

The recommendations made here reflect the best efforts of the project researchers given available resources, time and the rapidly changing social media environment. Their applicability in different contexts and times will need to be tested by each new user and adapted to their own contexts. All are encouraged to share their learning and help co-create an ongoing ECDC community of practise around the use of social media to support HIV/STI prevention interventions for young people.

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Annex 1. Summary of systematic review of systematic reviews (ECDC/2014/013)

This review found that, at the individual level, health education (predominantly via new digital media) targeting young people was shown to support an increase in adolescent knowledge about sexual health and/or STIs/HIV. When interventions targeted both a parent and child, there appeared to be a decrease in the number of unprotected sex acts reported by the child. Individual reminders regarding STI screening/testing had a positive influence, while financial incentives offered to the individual indicated no effect on screening/testing uptake.

At the structural level, the only reported outcome was the uptake of STI testing. Provision of screening and testing via new digital media, clinics based at places of education, supplemented primary care, pharmacy-based dispensation, and other community-based health services, were all found to have a positive impact on uptake of STI testing among young people. This evidence provides some indication of preferred models of delivery of services among young people.

Regarding sexual orientation, the majority focused on heterosexual youth. Given that men who have sex with men(MSM) are a known high-risk group for HIV and STI infections in Europe, the findings suggest a need for greater specific attention to, and understanding of, young men's sexual health experiences. There was very little information available about the specific contexts in which interventions took place (e.g. social, cultural), and given that the majority of studies identified focused on the USA or Australia, there are limitations on how generalisable any effects would be in a more European environment.

Overall, the findings demonstrated that individual-level health education interventions, often those using new digital media approaches, can be effective in increasing knowledge about sexual health and/or HIV/STIs; and that structural level changes that involve the provision of testing and screening services through augmented primary care and supplementary service lines, can increase uptake among young people. However, the evidence base regarding the impact of a range of other HIV/STI prevention interventions on behavioural and biological outcomes is disappointingly limited. There is a particular lack of visibility of high-risk groups (including MSM, commercial sex workers, and injecting-drug users) and very little Europe-specific evidence.

Findings of grey literature were not robust enough to reinforce or disagree with findings in the published literature. Few evaluated interventions were found in the grey literature.

Although the number of relevant grey literature publications identified was small, most of them were focused on the MSM population, which complemented the peer-reviewed literature where this group was not visible. There was also growing attention in the grey literature to interventions with a digital component, such as smartphones or websites.

Overall, new digital media approaches were seen to be worth examining further, particularly as young people – the key target group – are part of a generation that has grown up using new technology-based channels for gathering and sharing information, and more fundamentally, see digital media as an indispensable part of their lives.

Annex 2. Questionnaire used for focus groups/interviews

Questionnaire – focus groups/interviews

Study title: Use of social media to support HIV/STI prevention in Europe

- What social media websites do you use normally and what do you use them for (connecting with friends you already know, to make new friends, to discuss interests, to get information, etc.)
- Where/from whom do you generally get sexual health information (e.g. parents, online, peers, etc.)?
- Have you come across any individual or initiative posting about sexual health in social media?
- Do you ask for information or post about sexual health social media? If yes, which social media websites do you use?
- Have you come across any sexual health information you that was useful/helpful? Which social media platform was it posted on? Can you make any recommendations on how it is best to communication sexual health information in order to be useful/interesting to you and your peers?
- How do you think 'sexting' (or the act of engage in texting of sexual content) could affect your peers?
- Who are the big social media celebrities to you? Do you think they could be important voices to post about sexual health?

Annex 3. Participant information sheet and consent form

Study title: Handbook for preventing HIV/STI among youth in Europe using social media

Invitation

Hello, I am Clarissa Simas from the London School of Hygiene and Tropical Medicine (LSHTM). You are being invited to take part in a research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and to talk to others about the study, if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

What is the purpose of the study?

The purpose of the project is to create a handbook of basic principles and approaches regarding the use of social media to promote prevention of HIV and other sexually transmitted infections (STIs) among youth across Europe. We wish to conduct online focus groups with young people from the EU/EEA region to understand how you engage with social media communication and how you use social media for sexual health information-seeking and sharing.

Why have I been chosen?

You have been asked to take part in this study because you are at the appropriate age and country group necessary to this study and a user of social media website(s).

Do I have to take part?

It is entirely up to you if you would like to take part in this study or not. If you decide to take part, you will be sent via e-mail or direct message this information sheet so that you can refer back to it at any time. You will be asked to electronically sign by typing your name, date and sending back to the researcher the consent form, confirming you understand the study and would like to take part in it. If at a later stage you change your mind, you are free to withdraw from the study at any point.

What will I have to do?

If you agree to take part in this study, we will ask you to e-mail back the consent form (page 5) with your name and date typed. We shall then arrange an appointment for when the online group discussion will take place and through which app (WhatsApp or Skype).

If you take part in the study you will be asked:

- To take part in the group discussion: Discussion groups are when a group of people are asked to discuss a topic together. A minimum of 4 participants will be included in each group. The researcher will ask you all about your uses of social media and ways you search sexual health information online. The group discussion will take place either through Skype video call or WhatsApp group and last about 45–50 minutes.
- Or to be interviewed by the researcher: The researcher will ask you all about your uses of social media and ways you search sexual health information online. The discussion will take place either through Skype video call or WhatsApp and last about 45–50 minutes.

We will ask you if we can record the discussion group and take notes on paper. After the group discussion a written copy of this audiotape will be produced (this is called a transcript). We will NOT include your name or contact details on any audiotape, transcript, notes or questionnaires; instead we will use a separate study code for each person taking part.

Finally, we will ask you for a telephone number or address at which we can contact you by phone or by letter. This is because:

- The appointment may need to be re-arranged.
- After the group discussion we may want to contact you to make sure that we understood correctly what you said.
- We would like to give you a copy of the final report of this study.

- When contacting you we will not discuss any information about yourself.
- Background information on you will be kept securely but separately from the research data.

Will the information be kept confidential?

Yes, data will be stored in a safe and confidential manner. Interviews and focus groups recordings will be kept safely the local research teams' computers. They will be coded by the LSHTM research team who will comparatively analyse the data for the publication of a report. At the end of the project, all original recordings of the interviews and focus groups, as well as the transcripts will be deleted.

In order to ensure that the group discussion remains confidential participants must agree to maintain confidentiality. This means that anything which was discussed during the discussion group should not be talked about with other people after the discussion group has ended. As noted above, no information in any reports or transcripts will be attributed to you by name. A code will be used in the transcript for each person, and the research team will keep the information that links the code to the background information you supply in answer to the questions before the group discussion starts securely and separately from the data.

What happens when the information collected during this study?

We will use the anonymised transcripts of the discussion to analyse different uses of social media by young people in Europe and how this information can help develop interventions to prevent the spread of HIV and STIs. The researchers will write up the findings in a report which will be made available publicly online.

In this type of study, it is helpful to quote in reports some of the exact things people have said in the discussion, and we would like your permission do this. It will not be possible to identify you as a participant in these reports, presentations or publications.

What are the benefits of taking part?

You may not benefit from this study right now, however, by taking part in this study you will contribute to understanding of the feasibility of using social media to prevent HIV and sexually transmitted infections among young people, with the possibility to impact the lives of many like you, helping them to remain healthy.

Are there any risks of taking part?

There is no risk to you in taking part in this study.

Who is leading this research?

London School of Hygiene & Tropical Medicine and World Health Communication Associates (WHCA).

Who has reviewed this study?

This study has been submitted for review to the ethics committee at the London School of Hygiene and Tropical Medicine.

What will happen if I don't want to continue on this study?

If you change your mind you can withdraw from this study at any point. You do not need to give a reason and it will not affect you in any way. We would like, however, to use any information collected up to the point of your withdrawal; nonetheless we would ask your permission first.

What if I have a problem?

If you have any questions, call +44 020 7972 2859 to reach Clarissa Simas or e-mail Clarissa.simas@lshtm.ac.uk.

You will be given a copy of the information sheet and a signed consent form to keep**.** Thank you for considering taking the time to read this study information sheet.

Consent form: Handbook for preventing HIV/STI among youth in Europe using social media

Contact: Clarissa Simas

Email: clarissa.simas@lshtm.ac.uk

Tel: +44 020 7927 2859

		Please initial box
1.	I confirm that I have read and understood the information in the participant information sheet and that I had the opportunity to ask questions and that these have been answered to my satisfaction.	
2.	I understand that my participation is voluntary and that I am free to withdraw at any time. I understand that I do not need to give a reason to withdraw.	
3.	I understand that anything I say during the discussion group or interview will be strictly confidential. I understand that anything said by others during a discussion group should not be discussed with anyone else.	
4.	I consent to storage of my personal information for the purposes of this study, including paper and electronic information. I understand that any information which could identify me will be kept strictly confidential. I understand that all information collected in the study will be stored in a secure way which ensures my confidentiality is maintained.	
5.	I understand that the researchers will ensure there is no personal information which would allow me to be identified in the final study report or publications. I understand that things I have said during the discussion group may be included in the study reports and publications. I understand that this would be done in a way that will not allow me to be identified.	
6.	I agree/disagree (delete as appropriate) that the researchers can send me a copy of the final report at the address I have provided	
7.	I agree/disagree (delete as appropriate) to the discussion group being audio-taped	
8.	I agree to take part in this study	

Participant

Name	Date and time	Phone number	E-mail
.....	.....	.....	.....

Researcher

I, ... (Clarissa Simas), hereby confirm that the above participant has been fully informed about the nature, conduct and risks of the above study.

Printed name	Signature	Date and time
.....	.....	.....

European Centre for Disease Prevention and Control (ECDC)

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