

Reaching *Out* Online

Digital Literacy, and the
Uses of Social Media in
Health Promotion.

A pilot study funded
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Principal Investigator:

Dr Sharif Mowlabocus
(Univ. Sussex)

Collaborative Partner:

Mr Justin Harbottle
(THT, London)

Research Assistants:

Mr Rohit K Dasgupta
(Univ. Sussex)
Dr. Craig Haslop
(Univ. Sussex)



Executive summary

Reaching out online was a pilot project that built on the *Literacy, Expertise and Knowledge* scoping study undertaken by the CCN+ network. It developed a prior research relationship between the University of Sussex and the Terrence Higgins Trust (THT), the organization in charge of HIV Prevention England (HPE)¹. The project ran for a six-month period in 2013.

The research directly engaged with a key objective set out by HPE namely, to 'develop social marketing interventions using new information technologies'². In doing so, the project sought to provide an insight into the changing nature of HIV community outreach, by focusing on the experiences of health promotion workers as they moved between digital and physical forms of community outreach, working to reduce the risk of HIV transmission among men who have sex with men (MSM)³. The key research questions that underpin this research can be found in the relevant section of this report (see 'research questions and methodology').

Ethnographic methods were coupled with 1-2-1 and focus group interviews involving health promotion workers in order to generate data for qualitative analysis. Findings from this analysis were then subjected to further scrutiny via a stakeholder workshop in order to develop a set of recommendations that informed the building of the key dissemination tool: the *NetReach* website. This website provides 1/ a training resource for staff working in digital environments, 2/ a tool for supporting the creation of new digital intervention sites and 3/ an information and monitoring resource to aid health promotion workers in their day-to-day intervention activities.

The research identified the impact that digital migration had on workers' (and service users') perceptions of HIV community outreach work. Details of the project findings can be found elsewhere in this report (see 'findings'), however we highlight below a few of the key headlines that have come out of the research:

- In contrast to general assumptions that digital work can offer a 'quick fix' for health promotion, health workers often have to develop deep and lasting relationships with users of a site, regularly engaging in non-health-related discussions and 'chat' in order to build trust and social capital among the community. Multiple forms of literacy (informational, technological, cultural) are increasingly required of workers as they move towards more online forms of outreach.

- The disembodied nature of online community outreach work results in

¹ <http://www.tht.org.uk/our-charity/About-us/Our-work/HIV-Prevention-England>

² HIV Prevention England: [online] <http://www.hivpreventionengland.org.uk/Who-we-are> (accessed 12/3/13)

³ MSM (men who have sex with men) is a universally used term within HIV prevention and health promotion work that encompasses a host of sexual identities and practices including gay men, bisexual men, trans men who have sex with men, queer-identified men, heterosexual men who have sex with men and non-identifying men who have sex with men.

deeper and more honest disclosure by service users. This allows outreach workers to provide information, knowledge and support that is more closely aligned with the situations and predicaments that service users find themselves in. Owing to the depth of such disclosure, health workers require more detailed knowledge of sexual health when working online, and working in a group setting (offline) can aid in developing this.

- The disembodied nature of digital intervention work also creates challenges in terms of communicating health information in an appropriate manner. Workers are also more wary of the information that they give out online (compared to comparative offline work) and perceive themselves to be 'judged' more by what they say when online. Workers also find themselves having to more carefully frame knowledge and information online, and adopt a range of skills to impart that knowledge in an appropriate and user-friendly fashion.
- The relationship between the identity of the health worker, the information that they are giving out and the role that they inhabit changes when working online. Sometimes these changes support effective outreach work, at other times they present challenges.
- Online intervention work helps to reach 'communities' that are otherwise invisible, hard to reach. Online Intervention work also provides a method for both identifying and reaching communities of men who might not conventionally be considered 'at risk'.

During the course of the research, further funding was secured (from THT) to undertake a complimentary piece of work that focused on MSM⁴ users of digital media.

⁴ MSM – men who have sex with men.

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Introduction

Successive governments in the UK have sought to exploit the perceived benefits of digital communication technologies in order to reform and streamline the healthcare sector. It is fair to say that the success of many of these initiatives has been less than adequate. Large-scale infrastructure projects such as the NHS patient record system have been dubbed a costly failure⁵, while the soon to be launched medical record access system is already being met with ambivalence within the public sphere⁶. Echoing broader discussions about digital ICTs and data management, announcements of such projects often spark concerns regarding the efficacy, sustainability, cost and security of such large infrastructure programmes. Recent press coverage, for instance, has alerted the public to worries around how the reporting of illnesses or ailments might result in higher insurance premiums⁷ or mortgage costs⁸.

Nevertheless, the British government, and those it charges with maintaining and improving the health and wellbeing of the UK continue to seek digital solutions to current (and future) health issues. The reasons for this are manifold. First and foremost, digital integration is seen as providing cost-efficiencies at a time when public spending on healthcare is set to rise owing to an aging population and an increase in those living with chronic long-term conditions.

Secondly, opportunities to streamline information pathways and open up previously discrete silos of information are widely regarded as an important step forward in improving patient care, offering a more holistic and 'joined up' approach to treatment and prevention initiatives. Finally, digitally-based initiatives are seen as responding to an ongoing discourse around the personalisation of healthcare, whereby the patient/customer becomes central to decision-making processes, including how their allocated budget is spent⁹.

It is within this landscape that *Reaching Out Online* was conceived, and it is into these broader discussions regarding personalization of healthcare, data security and individualization that the findings of this project feed.

⁵ See <http://www.theguardian.com/society/2013/sep/18/nhs-records-system-10bn>

⁶ See <http://www.independent.co.uk/life-style/health-and-families/health-news/doctors-raise-fears-over-sharing-nhs-patient-records-9133807.html>

⁷ See <http://www.telegraph.co.uk/health/healthnews/10656893/Hospital-records-of-all-NHS-patients-sold-to-insurers.html>

⁸ See <http://www.telegraph.co.uk/finance/personalfinance/insurance/10667245/NHS-database-will-it-push-up-your-insurance-premiums.html>

⁹ See <http://www.personalhealthbudgets.england.nhs.uk/>.

What is community outreach? Lessons from history's front line.

In 1982, Terry Higgins, a 37-year old gay man who lived in London, died of pneumocystis carinii pneumonia and progressive multifocal leukoencephalopathy. Higgins was one of the first people in the UK to die of ARC's – AIDS-related conditions/complications. The HIV virus was discovered one year before Higgins died. At that time, the collection of diseases and conditions that resulted from HIV infection (and which became known as AIDS) were still known as G.R.I.D (gay related immune deficiency). Such a (mis)titling identified the community perceived to be most at risk of contracting the HIV virus. It also illustrated the moral and political dimension of the HIV/AIDS crisis that unfolded into a global pandemic that continues today.

It was as in memory of Higgins that the first community response to HIV in the UK was set up, in August 1983. The Terrence Higgins Trust (THT) became a charity in 1984 and throughout its history it has been at the forefront of the UK's fight against HIV transmission, prejudice and misinformation. At a time when the British government struggled to formulate a cohesive and fully-integrated response to the burgeoning crisis, handfuls of THT volunteers took the most current information on HIV – and how to avoid contracting the virus – into the community that was perceived to be most at risk; the gay male community.

Thirty years later, THT arguably remains the most well-known HIV charity in Britain. The structure of the organization has changed radically during this time, but in essence its mission has remained the same:

- Maximise sexual health in the UK, and minimise the spread of HIV and STIs, by encouraging people to value their sexual health and by leading innovation to increase access to local sexual health services.
- Empower everyone living with HIV in the UK to maximise their health and wellbeing by working to ensure the best possible HIV treatment and support services
- Lead public and political support for HIV and sexual health issues, and campaign to eradicate stigma and discrimination.¹⁰

Central to THT's early endeavors – and a key component of its on going work – is the concept of *community outreach*. Put simply, community outreach involves taking information, resources and support systems out (of the clinic, the health centre, the hospital) into the spaces and places where people meet to socialize – and 'hook up'. Community outreach can take many forms. It ranges from visiting local bars and clubs and handing out condoms, through to engaging in 1-2-1 discussions around sex and sexual health in cruising grounds (and, most recently, online). It is often undertaken by volunteers and

¹⁰ Taken from THT's mission statement: <http://www.tht.org.uk/our-charity/About-us/Our-mission>

sessional staff trained by an organization such as THT and it seeks to engage 'regular folk' in conversations about health promotion in informal, friendly and approachable ways.

At the heart of this kind of work is the belief that important information needs to get out into the communities that need it the most – and quickly. Such activity has been credited¹¹ with stemming the tide of HIV transmission in the UK and dramatically changing the trajectory of the epidemic (especially when compared to the USA). Getting information and resources into the environments where (for instance) men meet one another for sex, is considered to be an effective means of ensuring that safer sex becomes a part of such sexual negotiations – and that the right resources are in place to help support people to make appropriate choices.

For over two decades, the conventional model of community outreach – taking resources and information out into the physical spaces that gay, bisexual and MSM men meet and socialize in – proved to be extremely effective. However, the last ten years has witnessed unprecedented changes in the ways men source sex. As far back as 1999, the Internet was playing a central role in British gay male subculture¹². Popular culture references (from *Sex & the City* through to *Queer as Folk*) aligned Internet dating with gay male sexuality and such references were highly accurate in pinpointing the increasingly central role that web-based communication was playing in the lives of men who had sex with men.

¹¹ See Broadhead et al. (1998); Herbst et al. (2007).

¹² See Mowlabocus, (2010); Campbell, (2004).

Reaching out online

The development of social media platforms has recently contributed to a reframing of health promotion work¹³, particularly where at-risk communities are identified as having particular investments in online social/sexual networking practices¹⁴. This project feeds into the original scoping study identified above by exploring the methods and consequences of delivering sexual health knowledge and expertise via digital platforms.

Underpinning this research is a preoccupation with the way in which the 'at-risk community' is conceptualized by health promotion agencies. An increasing policy focus on the personalization of healthcare, twinned with shifts in the communication practices of marginalised communities, means that the 'at-risk community' becomes a slippery concept that resists concrete definitions and which cannot be geographically or temporally located. This in turn complicates community-based strategies that have historically been designed to build *community* resilience in the face of ongoing threats to health and wellbeing¹⁵. Through an analysis of social media use by health promotion experts, this project engages with the concept of the 'at-risk community', developing a new understanding of this term appropriate to the digitally-mediated contexts through which such communities are constructed and identifying ways in which new forms of resilience might be built online.

Aims

The research engages with health promotion experts in order to map: 1/ the literacy skills required for online intervention work, 2/ the relationship between the (dis)embodied expert and the knowledge they are charged with disseminating and 3/ the shifts in outreach workers' perceptions of the 'at-risk' communities that they engage with online. The research identifies the additional layers of digital-cultural knowledge and (sub)cultural capital required of experts as they engage with disembodied and disparate communities in digital environments.

The project additionally provided two early career researchers with the experience of working with a non-HEI research partner to develop a piece of actionable research that has a measurable impact on health education policy. Finally, the project serves to identify further research questions regarding social media's uses and limitations for maintaining the health and wellbeing of marginalised communities in the future.

¹³ See Thackery, R. et al. (2008)

¹⁴ See Mowlabocus (2010)

¹⁵ See Ramirez-Valles, J. (2002).

Reaching out online: meet the project team

Principal Investigator - Dr. Sharif Mowlabocus

Sharif is a senior lecturer in digital media at the University of Sussex and a member of the CCN+ core membership. He has published extensively in the field of digital media and gay male subculture (*Porn.com*, 2011; *Gaydar Culture*, 2010; *Pornification*, 2009). His work has most recently touched upon issues of sexual risk, identity and politics, and the mediation of these themes through digital and visual platforms. He has been collaborating with the Terrence Higgins Trust on research since 2009 and acted as principal investigator on the project.

Project Collaborator - Justin Harbottle

Justin is a project manager for the Terrence Higgins Trust. Now based at THT's London's headquarters, he has previously worked out of the Brighton regional office, where he collaborated with Dr Mowlabocus on groundbreaking research, currently informing policy decisions in gay men's sexual health services. Justin is THT's lead on social media intervention services and has a wealth of practice-based experience in the field of community outreach. Justin acted as the non-HEI project collaborator on this research. He brought to the project a wealth of expertise in the fields of sexual health and online health promotion. He also acted as a liaison between the partner institutions and played a direct role in shaping the research methods and identifying the findings. He was also responsible for stakeholder recruitment and services buy-in.

Doctoral Research Assistant - Rohit K. Dasgupta

Rohit is a final-year PhD student at UAL with a background in sexual health research. He has published research on the role of the Internet in HIV prevention (*Digital Culture & Education*, 2012) and his PhD thesis explores the use of the Internet by gay/bi/queer men in India. Rohit has previously worked as a research assistant on a range of projects including *From Aan to Lagaan and Beyond* (2012) and the *Sappho Equality Resource Centre*. In many ways, *Reaching out online* dovetails with his current doctoral research in terms of themes and research methods.

Postdoctoral Research Assistant – Craig Haslop

Craig completed his PhD at the University of Sussex in 2012, which involved using qualitative research methods to undertake an analysis of the role of sexual identity in television audience responses. He has recently published findings of this research (*Torchwood Declassified*, 2013) and brought to this project an expertise in focus group methods and qualitative data analysis.

Research questions and methodology

The research questions that underpin the project can be identified as follows:

- *What are the different forms of literacy skills required for online intervention work?*
- *What is the relationship between the (dis)embodied expert and the knowledge they are charged with disseminating?*
- *Are there shifts in outreach workers' perceptions of the 'at-risk' communities that health workers engage with online?*

In order to answer these questions, a three-stage methodology was employed. These three stages provided a 'cascade' effect, allowing the findings from stage one to shape the methods employed in step two and so on. Ethical approval for all stages of the research was sought from, and granted by, the University of Sussex, the award-holder of the grant that funded this research.

Stage one: ethnographic work

Ethnography, as a method of research first developed within the field of Anthropology, involves a high degree of (participant)-observation. Its outcomes are often considered a form of 'rich description'. The ethnographic dimension of this research included the principal investigator shadowing Brighton-based health workers as they undertook both offline and online outreach work over a five-week period in the summer of 2013. In total, 36 hours of outreach work was observed and documented, together with 6 further hours of in-depth interviews with key participants working on specific platforms (where ethnographic observation was not possible). In total over 40 hours of ethnography were undertaken, involving twelve health workers.

During the ethnography of the online community outreach, the investigator was able to not only observe the interactions that took place online, but was able to informally interview workers as they went about their duties. Often workers would talk the investigator through the intervention, explaining why they phrased replies and comments in particular ways. This also gave the investigator an opportunity to question the worker about the similarities and differences between physical and digital forms of outreach. Detailed notes were kept by the investigator but, in line with standard ethnographic practice, recordings were not made.

As mentioned, there was an opportunity to observe a limited number of offline outreach activities. While this was a secondary activity, it provided the principle investigator with first-hand experience of the similarities and differences between physical and digital outreach work. Owing to client confidentiality, the investigator was unable to fully participate in offline

interventions. However, the physical outreach work nevertheless proved useful as a comparative exercise.

Following a writing up period, three members of the research team worked to code the ethnographic notes in order to identify a set of themes that related back to the research questions identified above. This coding exercise involved two researchers working on each set of notes. This exercise was then discussed at a preliminary findings meeting in August 2013.

Stage 2. Focus group interviews with health workers

The findings from the stage 1 analysis were used to shape the development of an interview script. This document was developed by three members of the research team and was cross-referenced to the original research questions to ensure that all relevant areas of discussion would be covered.

In total, ten health workers were interviewed across three focus groups. Each interview lasted 120 minutes and was audio recorded. This recording was then subjected to transcription and the transcripts were then analysed by the research team using a pre-determined coding system that was developed in response to the research questions.

Stage 3. Stakeholder Workshop

This final stage of the methodology was originally going to be organised as a larger multi-agency stakeholder workshop, providing an opportunity to 1/ share knowledge and 2/ analyse the findings to extrapolate further meta-findings for digital health promotion work. However, during the planning of this workshop, the project team received additional funding in order to carry out complimentary, user-centred research. Therefore, a smaller stakeholder workshop, involving members of THT Brighton and the research team took place in December 2013. This allowed those present to discuss the findings from the research and to develop a set of recommendations for online outreach activities.

Key findings.

In this section of the report we detail some of the key findings from the project. The findings have been organised according to the research questions identified in the previous section.

Skills & literacy: what are the different forms of literacy skills required for online intervention work?

“[You need to] observe demographics language, types of conversation, what people are looking for. And just really, really kind of gather knowledge about who’s on that website what they are using it for and how are they communicating.”

(Worker focus group 2)

The research identified the fact that health workers have to become highly literate in the culture of individual social media platforms before they can undertake effective intervention work in that space. This literacy involves both an understanding of the social codes that are woven into the fabric of that space, and the negotiation of these codes in a manner that does not compromise either the cultural ecosystem of the site or the professional identity of the organization they represent (THT). This literacy can be loosely organised into three discrete categories: informational, technological and culture.

Information literacy refers to knowledge regarding sexual health matters, harm reduction strategies, treatment regimes and local services. While the need to have information literacy when working online is no different from an outreach worker is working in an offline setting (a bar or a club or a sauna, for example), the *level* of literacy expected of workers who operate in online environments is far higher (see points below ‘knowledge and disembodiment’).

Technological literacy refers to the broad set of skills that health workers require when working in spaces such as chat rooms, forums, via instant messaging or mobile platforms. As digital platforms vary in format so the set of skills required to communicate both effectively *and appropriately* on these platforms must encompass these variances.

Knowing how to chat in a chat room, and how that form of communication (including what and how you communicate, timing pace and style of language) might differ from a forum post, knowing how to interact correctly via a given medium, and knowing how to ‘listen’ appropriately within a specific context (when to pause, when to speak up, when to wait for an answer or continue to type) – these all amount to a form of literacy that is required of

health promotion workers when communicating online. Our research participants – all community outreach workers - stated that they had had to develop skills that allowed them to communicate appropriately according to the *platform* that they were working on.

Linked to the previous literacy, is the category of *cultural literacy*. If the former category highlights the broad communication strategies required when engaging different technologies during online outreach work, this category speaks to the *specificity* of the environment in which the health promoter is working.

To give an example, *Facebook* and *BBRT*¹⁶ both allow you to post public messages and in this respect they require the same knowledge of how to communicate via that platform of communication, namely the quick, short message that can be both synchronous and asynchronous in its use. However, the content of that message, together with the way in which that content is phrased will differ greatly. Hence, in this category of literacy, workers identified having to develop skills that allowed them to communicate appropriately according to their *context* of interaction.

In terms of becoming 'literate', the project identified two important issues that complicated the hitherto method of learning-by-doing that has come to characterize much community outreach work.

First is the issue of worker identity. In online cultures where authenticity and trust is measured or garnered through the use of images of the self, the exact identity that the worker inhabits raises questions regarding the boundaries between professional worker and private individual. This becomes further complicated if the worker already has a profile (for personal use) on that site.

Secondly, and linked to this former issue, is the fact that not all interactions are publicly visible, indeed, in some sites, much of the interaction occurs via private communication channels. Being able to learn the required literacy skills can be challenging if such skills can only be witnessed via (private) interactions with other users.

In the project, we identified that this issue **must** be addressed when planning training and managing workers. In sum, multiple forms of literacy are required in order to develop a strategy that is contextually appropriate, informationally appropriate and appropriate in terms of platform.

Skills & literacy: key findings

In summary, we found that:

- Visibly investing time and energy into becoming part of a website's community is central to the success of any health promotion campaign disseminated on that site.
- Having a tool or a specific service that can be offered by the health

¹⁶ A website dedicated to bareback sex – a highly controversial form of sexual practice among MSM that involves unprotected sex (sex without condoms) as well as other forms of behaviour including group sex, and sex while under the influence of recreational drugs.

worker (free postal condoms, free HIV testing packs) is a useful tool for developing interventions with users of a site.

- The success of online health promotion depends on the knowledge and experience that the campaign developers have of that site – and of life on that site.
- Understanding and adopting the vernaculars and modes of discourse used on a site allows health workers to communicate effectively and be seen as part of the site's culture.

Knowledge & (dis)embodiment: What is the relationship between the (dis)embodied expert and the knowledge they are charged with disseminating?

“People ask more in-depth questions online and they're more at a stage where they're ready to have a more in-depth conversation”

(Worker focus group 1)

Somewhat surprisingly, the project team found that the disembodied nature of online intervention often resulted in deeper and more honest disclosure by service users. This allowed outreach workers to provide information, knowledge and support that was more closely aligned with the situations and predicaments that service users found themselves in.

As a consequence of the depth of disclosure online, we found that health workers required a more in-depth knowledge of sexual health information when working with service users in digital contexts, and working in a group setting was seen to aid with this.

The disembodied nature of the intervention also created challenges in terms of communicating information in an appropriate manner. Workers were unable to use some of their embodied skills (body language, non-verbal communication, tone of voice etc) to frame the information they were giving. Knowledge became 'raw' and information was often stripped of the 'personal touch'. The ways in which information was sought out and understood within digital contexts (the 'Google effect') meant that service users were sometimes less willing to accept the fact that the accuracy of a given piece of knowledge or advice was contextual and dependent on a number of factors.

Some workers felt more wary of the information that they gave out online (compared to comparative offline work) and suggested that, online, what they said during an intervention carried more weight. They believed that they were judged more by what they said when online than when working in offline

situations. The disembodied nature of the interaction also meant that workers had to frame knowledge and information carefully, using a range of skills to impart knowledge in an appropriate and user-friendly fashion.

Knowledge & (dis)embodiment: key findings

In summary, we found that:

- Online outreach work allows service users to disclose complex issues quickly and at a much greater depth. This allows health promotion workers to provide more accurate and focused information during the intervention.
- Working in online contexts, the outreach worker is able to draw upon large silos of knowledge. However, that knowledge must always undergo a process of translation and adaptation in order to fit the needs, requirements and perceived capabilities of the service user.
- Workers have to develop techniques that allow online outreach services to avoid being seen as a 'search engine' for the single 'right answer'.
- Online outreach work provides a level of worker anonymity not found in offline work. However, issues of identity do pervade online work and policies on how to deal with personal disclosure are required in order that such work is undertaken in an ethically and safe way.

Risk: Are there shifts in outreach workers' perceptions of the 'at-risk' communities that health workers engage with online?

"I suppose it comes back to what we were saying about the confidence issues. So somebody who doesn't have the confidence to talk about something in a bar, face-to-face with you, erm, confidence isn't an issue if you are online really."

(Worker focus group 2)

When researching this specific question, we found that online intervention work helped to reach 'communities' that were otherwise invisible, hard to reach. These communities include:

- The barebacking community
- Younger HIV positive men
- Men who cannot access (for financial, cultural, geographical or other reasons) conventional gay spaces.
- Those who are 'shy' or who may be facing (sexual) identity issues.

These communities have historically been considered both 'hard to reach' and also, 'at-risk'. This risk can be classified as:

- A risk of being poorly or ill-informed about HIV transmission routes and of other STIs
- A risk of being poorly or ill-informed about prevention measures including correct condom and lube use – but also PEP and (latterly) PrEP
- A risk of being poorly or ill-informed about the risk involved in certain practices (irrespective of how many partners one has)
- A risk of feeling marginalised and stigmatised by conventional clinical and outreach messages because of the sexual choices that they have made (c/f barebacking)
- A risk of feeling that becoming HIV positive is an inevitable part of being a gay man.

Over and above these 'known' risk groups, the research identified that online intervention work also provided a method for both identifying and reaching communities of men who might not conventionally be considered 'at risk'. Such communities, based on interests that are typically identified as being 'marginal' or contrary to the commercial gay lifestyle, coalesce online. Such online communities are often populated by men who:

- Identify as gay, bisexual or queer
- Have a general knowledge (based on historical interactions with services) of HIV transmission routes and prevention methods
- Do not engage with services, testing, clinics or outreach on a regular basis
- Do not interact with the gay scene
- Perhaps do not consider themselves – or those that they sleep with – as being at risk (based on a non-engagement with sexualised gay culture).

We found that online intervention work allows contextually appropriate harm reduction messages to be effectively targeted at - and 'gated' within - specific communities, where in other more mainstream spaces they might be deemed politically problematic. As one worker described during the ethnographic period, in terms of the kinds of information given out, one must always 'have the right hat on' when on BBRT. If you talk about condom use alone - or as a first point - then it would be read as accusatory by the users and alienate them. Online intervention work, being located on the same platforms that men use to source sex, meant that outreach work occurred in spaces where risk practices were being negotiated.

While online outreach has the potential (and in some cases) can reach 'invisible', 'hard to reach' or 'at-risk' communities, there are several key issues that the research has identified that can act as barriers to effective

intervention work being carried out in gay men's digital spaces. These can be summarised as follows:

Platform design. The types of intervention that can take place and the visibility of the outreach worker are dependent on the design of the digital platform. While chat rooms that offer private 1-2-1 facilities provide an excellent medium for intervention work, short SMS-style messaging (common on social media apps) provides a less productive context for in-depth intervention work. Likewise, the visibility of the outreach worker might be challenged by the design of the platform.

Social practice. The method of communication best suited to intervention work on a given site might not align with the method of communication used – or the social practices engaged in – by the majority of that site's users. As such, the 'mainstream' users of a site might in fact become the 'hard-to-reach' community for intervention work.

These two barriers suggest that understandings of who the 'hard to reach' are vary according to the mode of engagement used or available to the outreach worker.

Risk: key findings

In summary, we found that:

- Online outreach work can be effective in reaching communities that are typically considered as (a) at risk and (b) hard to reach or invisible.
- Online outreach work can be effective in identifying at risk or hard to reach communities that have hitherto not been identified.
- Online outreach work provides a method for providing contextually relevant information to 'gated' communities that is based on their sexual practices, identities and HIV status.
- Online outreach work faces challenges in reaching at risk groups owing to the design of platforms and the ways in which users communicate via that platform.
- Online outreach work therefore operates most effectively when it is conceptualised as one element within a more expansive outreach programme that also includes offline methods of engagement.

Key issues

Reaching out online identified several key issues that require careful consideration by health professionals working in the field of community health promotion. As a result of the project's close partnership with THT, and the charity's investment in complimentary research, most members of the project team will shortly have the opportunity to articulate these issues to representatives of THT's regional offices, as well as to the executive committee of the charity. At the time of writing, this meeting has been scheduled but has yet to take place.

The key issues that we have identified in this project can be summarized as follows:

- Digital forms of community outreach have immense potential in terms of reach, scope and level of engagement. However, there is no 'simple win' with this kind of work and, in many ways, it requires the same amount of labour that one would expect of conventional forms of community outreach.
- That being said, we identify little 'choice' in whether organizations such as THT should engage in digital outreach. Sex sourcing practices among MSM rely heavily on digital platforms and in increasingly large numbers of men are bypassing the traditional gay scene in order to meet sexual partners. Community outreach **must** include a digital dimension.
- The training of community outreach workers in digitally-based work requires careful consideration. The research identified how difficult it was to 'correct' mistakes online, and how easy it was to be 1/misinterpreted or 2/ criticized or verbally attacked online.
- Finally, the shape and meaning of community outreach work is changing as it moves into online environments. Workers need to be trained in how to deal with a far wider range of psychological and emotional (as well as physical) concerns that service users raise or otherwise present (more) during digitally-based interventions.

We hope that the forthcoming meeting with THT (scheduled for March 13th) will offer an opportunity to discuss how policy can be developed in this area to ensure that best practice is maintained by workers, and that workers are supported appropriately while working in this new context.

Next steps

When this project began, the principal investigator imagined that the next steps in this research endeavour would be to engage with service users of online community outreach, in order to capture the experience of online community health interventions from the user's perspective. In October 2013, this next step began to be realized. At the time of writing this, some 1008 MSM have completed a survey that explores sex sourcing habits and online health information seeking. Over 50 MSM have been interviewed in focus groups and qualitative and quantitative data is currently being analysed. Thus, the initial 'next step' of this research has, in part, begun to be realized.

However, the project team is acutely aware that this research has been extremely local, focusing as it has done on the UK, and primarily the south-east of England. The trajectory of HIV transmission and the epidemiological narrative of this virus varies from region to region, country to country, and sometimes even from city to city. The stigma of disease, the censorship of sexual discourse and the criminalization of homosexuality continue to shape individual experiences of HIV – and opportunities for community outreach work. Meanwhile, the recent rise in internet-enabled mobile phone ownership in the developing world, and the development of 'local' apps for MSM suggest that existing community outreach programmes in countries such as India, China, Bolivia and Nigeria will soon need to rethink their strategies of engagement to include this digital integration.

In light of this, the next step in this research will be the development of a larger project that speaks to these, more international contexts, and which will provide an opportunity to speak to both MSM and health workers in order to collaborate on the development of new health initiatives, which exploit the popularity of existing social media platforms. We hope to submit funding applications to the ERC, the Wellcome Trust and the ESRC in the autumn of 2014. These applications will seek funding for this larger-scale 3-4 year study and will include a PhD studentship as part of the grant.

Impact

This research has been impactful in three key ways:

1. **Digital outreach website.** The findings from this research have been taken up by Terrence Higgins Trust and used to develop a website that provides three key functions:
 - A training guide that will provide an effective method for training outreach workers who are new to digital outreach work.
 - A development tool that will support THT managers in developing new intervention sites online.
 - A resource portal that outreach workers can utilize when undertaking online outreach work including a monitoring and recording mechanism (replacing an older paper-based solution) that allows workers to record monitoring data at both a quantitative and qualitative level.

The website is currently being developed and will be hosted at <http://tht.org.uk/netreach>. It has been developed in conjunction with the project team and is based solely on the primary research undertaken during this pilot project.

2. **THT Digital outreach policy.** The research findings are being used to help THT shape their national policy on developing and maintaining online intervention work.
3. **Consultancy with Medical Research Council.** As a direct result of this project, members of the research team have been invited to act as social media experts on the [PROUD](#) study. Learning and expertise developed during the pilot project are being drawn upon by the MRC as they develop a strategy for employing social media in their future participant recruitment and ongoing awareness campaign around Pre-exposure Prophylaxis.

Dissemination

The findings and research of *Reaching out online* will continue to be disseminated beyond the life of the project. This is, in part, due to the additional funding that the project team received in October 2013, allowing the project to be extended.

However, the following dissemination activities have either taken place or are scheduled to take place in the near future.

Conference and presentations.

September 2013 – oral presentation of preliminary findings made at CCN+ conference (Leeds)

January 2014 – oral presentation of findings made at MeCCSA 2014 conference (Bournemouth)

March 2014 – oral presentation of findings and recommendations to be made at THT stakeholder seminar (London)

April 2014 – poster presentation of findings at BASHH / BHIVA annual conference (Liverpool)

July 2014 – oral presentation of findings to be made at the (AHRC) ‘Cultures, Communities and Connections in the HIV Sector’ network - ‘Virtual HIV Communities’ seminar.

Publications

In addition, two academic publications have been secured. Abstracts have been accepted by *Convergence* and *Urban Studies*. In both cases, the project’s articles will be published in special issues:

- “‘Because even the placement of a comma might be important’: Expertise, Embodiment and Social Capital in Online Sexual Health Promotion’ in *Convergence* Vo1 21, no. 3 (August 2015).
- ‘From Scene to Screen: The challenges and opportunities of commercial digital platforms for HIV community outreach programmes – a case study’ in *Urban Studies*, (publication date tbc)

Funding

As has previously been mentioned, the Terrence Higgins Trust provided additional funding to the *Reaching out online* project team in the autumn of 2013.

Recognizing the need to engage with target communities and capture their experiences of online sex sourcing, as well as their opinions and attitudes towards digitally-based community outreach, the charity awarded an additional £11,500 to the principal investigator to undertake a second stage of research.

Bibliography

Broadhead R.S, Heckathorn D.D, Weakliem D.L, Anthony D.L, Madray H, Mills R.J & Hughes J. (1998) 'Harnessing peer networks as an instrument for AIDS prevention: results from a peer-driven intervention' in *Public Health Reports* Jun (113) Suppl. 1:42-57

Campbell, J.E. 2004. *Getting It On Online: Cyberspace, Gay Male Sexuality and Embodied Identity*. London: Harrington Park Press.

Herbst, J.H., Beeker, C., Mathew, A., McNally, T., Passin, W.F., Kay, L.S., Crepaz, N., Lyles, C.M., Briss, P., Chattopadhyay, S., Johnson, R.L., Task Force on Community Preventive Services (2007) 'The Effectiveness of Individual-Group-and Community-Level HIV Behavioral Risk-Reduction Interventions for Adult Men Who Have Sex with Men : A Systematic Review' in *American Journal of Preventative Medicine*. April, 2007: 38-67.

Mowlabocus, S. (2010) *Gaydar Culture: Gay Men, Technology and Embodiment in the Digital Age*. London: Ashgate.

Ramirez-Valles, J. (2002) 'The Protective Effects of Community Involvement For HIV Risk Behavior: A Conceptual Framework' in *Health Education Research*, 17(4): 389-403.

Thackery, R. et al. (2008) 'Enhancing Promotional Strategies Within Social Marketing Programs: Use of Web 2.0 Social Media' in *Health Promotion Practice*, 9(4): 338-343.

