School of Psychology
Ysgol Seicoleg

An exploration of PrEP-stigma and viewpoints on testing for HIV amongst men who have sex with men.

Thesis submitted in partial fulfilment of the requirement for the degree of:

Doctorate of Clinical Psychology (DClinPsy)

South Wales Doctoral Programme in Clinical Psychology

Cardiff University

Richard Lewis Hobbs

Supervised by: Dougal Hare and Aimee Pudduck

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Thesis Summary

An exploration of PrEP-stigma and viewpoints on testing for HIV amongst men who have sex with men

Richard Lewis Hobbs

Doctorate of Clinical Psychology
Cardiff University; South Wales Doctoral Programme in Clinical Psychology

May 2019

This thesis aimed to address gaps in the psychosocial aspects of Human Immunodeficiency Virus (HIV) prevention and testing literature as biomedical prevention methods have advanced. It is explored through three papers: a systematic review, an empirical study and a reflective critique.

The systematic literature review utilised a narrative synthesis approach to explore and aggregate qualitative literature, which considered a newly reported phenomenon of Pre-Exposure Prophylaxis (PrEP) stigma as experienced by men who have sex with men taking PrEP. Eight studies were included in the final review. The studies were heterogeneous in terms of the types of Men who have Sex with Men (MSM) they recruited and their methods. However, across the studies, it was demonstrated that PrEP-stigma was present at multiple levels. Five key themes identified were: 1. Stigma directly associated with PrEP; 2. Imposed stigma from others; 3. Internalised stigma; 4. Acts to mitigate stigma; 5. Sex-related stigma. The review concluded by arguing that PrEP-stigma can be imposed on the individual by others. PrEP-stigma can be internalised by PrEP users. There are various strategies that could be developed to overcome PrEP-stigma experienced by MSM who are PrEP users at different levels within the system. The application of the findings to policy and clinical practice are considered alongside recommendations for further research.

The empirical study utilised Q methodology to explore gay men's views on testing for HIV in Wales. Three distinct perspectives were identified: "testing PrEP and shame/stigma", "the psychological distress of testing and the search for certainty" and "HIV Testing a prosocial act and self-learning". The findings highlight that some aspects of HIV testing for gay men are consistent with previous research. The findings also describe how PrEP relates to the psychosocial context of HIV testing in Wales for gay men, and that some PrEP users

regularly test for HIV in order to gain long-term certainty over HIV status, but that this process can be stigmatising and shaming. The findings highlight the need for considerations of psychosocial context as HIV prevention methods develop. The implications of the findings for clinical practice and future research are considered.

The third paper is a critique and reflection on the research undertaken and its process. This consists of: an extended discussion of the decisions made in the research process; plans for dissemination; strengths and weaknesses of the studies; specific implications for theory; clinical practice and policy and further research. Reflection and critique are also given on the thesis.

Acknowledgements

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Finally, I am forever thankful for the support of my Mum and Dad. Without their kindness, patience and belief in me, I would not be completing my training.

Paper One: Systematic Literature Review

A Systematic Review into Stigma Amongst Men who have Sex with Men Taking PrEP: A Narrative Synthesis

Manuscript prepared in for the *Journal of Sex Research* (Appendix 1)

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Title

A Systematic Review into Stigma Amongst Men who have Sex with Men Taking PrEP: A Narrative Synthesis.

[a]Richard Hobbs*, [a]Aimee Pudduck, & [a]Dougal Julian Hare

[a]Department of Psychology, Cardiff University, Cardiff, United Kingdom

Abstract

This paper is a report of a systematic review of qualitative research exploring PrEP related stigma in Men who have Sex with Men (MSM). PrEP is a biomedical method of HIV prevention. To date reviews have been completed into PrEP-stigma as a barrier to MSM contemplating taking PrEP. No such systematic review has been completed for MSM taking PrEP. A narrative synthesis was used, with quality appraisal guided by the Critical Appraisal Skills Programme method. The data was analysed thematically, exploring MSM PrEP users' experiences of PrEP-stigma. This allowed for both descriptive and narrative synthesis to occur. Eight articles met the inclusion criteria for the final review. The themes identified were: 1. Stigma directly associated with PrEP; 2. Imposed stigma from others; 3. Internalised Stigma; 4. Acts to mitigate stigma; 5. Sex-related stigma. MSM taking PrEP experienced PrEP-stigma on multiple different levels. PrEP-stigma can be imposed on the individual by others. PrEP-stigma can be internalised by PrEP users. Various strategies could be developed to overcome PrEP-stigma experienced by MSM PrEP users.

Key Words: PrEP, PrEP-stigma, narrative synthesis and men who have sex with men.

Introduction

HIV is seen as the first postmodern pandemic (Kallings, 2008). Highly Active Antiretroviral Therapy (HAART), since its development in the late 1990s, has radically altered the way HIV infections are prevented and managed. Biomedical prevention for HIV infection has become accessible in the form of daily oral pre-exposure prophylaxis (PrEP) (Calabrese et al., 2018). It is argued that uptake of PrEP could significantly reduce new infections of HIV (Reyniers et al., 2017; Krakower et al., 2015). However, the global uptake of PrEP is slow. Viability of PrEP as an effective prevention strategy for HIV cannot only be measured on its pace of dissemination but also on its sustainability as an intervention by those taking it in order for it to become effective (Calabrese et al., 2018; Golub, 2018).

PrEP in the Context of Medication Adherence

Adherence refers to a medication regime where an individual takes medication as prescribed by their healthcare professional either to prevent or cure illness. In contrast to medication compliance, it is acknowledged that the individual has agency within their treatment. The factors that affect a person's ability to adhere are broad and unique to each medication. It is suggested that when a factor associated with non-adherence is identified it should be described and explored in depth. This allows for the appropriate understanding of the theories and interventions that apply to adherence (Schulman-Green et al., 2016). Identifying patients as non-adherent is known to be stigmatising for the individuals across many different medications (Ogden, 2012; Rintamaki et al., 2006). The language around adherence and the associated stigma of non-adherence should be assessed when new drugs are introduced to a population (Osterberg, 2015). In the context of PrEP, adherence is essential to prevent HIV contraction (Grov et al., 2019). Recent systemic reviews have highlighted that the level of PrEP adherence can vary across MSM. PrEP-stigma is one of the central issues

regarding PrEP adherence (Amico, & Bekker (2019). Therefore, this review will focus on understanding PrEP-stigma with an acknowledgement of the role it may play in non-adherence.

PrEP and Gay Men

One group at significant risk from contracting HIV, in comparison to the general population, are men who have sex with men (MSM) (Beyrer et al., 2012; Stahlman et a.,2017). Research has shown that the provision of PrEP to MSM is effective at reducing new HIV infections. However, the uptake has been slow, and there are delivery issues surrounding PrEP (Fonner et al., 2016; Golub, 2018; Kirby & Thornber-Dunwell, 2018; Koester & Grant, 2015; Venter, 2018; Ford et al., 2015; Amico & Bekker, 2019). Another key driver identified across the literature for PrEP's lack of uptake is stigma (Calabrese et al., 2018; Golub, 2018; Amico, & Bekker, 2019). Reviews have considered studies looking at the willingness and acceptability for MSM to take PrEP (Koechlin et al., 2017; Young & McDaid, 2014; Peng et al., 2018; Hannaford et al., 2018). However, no such study has yet systematically considered the body of current literature which considers stigma purely from the perspective of MSM taking PrEP (Peng et al., 2018; Golub 2018). In order for PrEP to be a sustained, effective intervention, the individual is required to take PrEP daily (Marcus et al., 2014).

This paper reviews the role that PrEP-related stigma may have in MSM taking PrEP. PrEP-stigma is often experienced at the individual level and can be reinforced by public health programs, policy, and research. The reason for this is that those who access PrEP are disproportionately from minority and disadvantaged groups such as MSM (Golub, 2018).

The Nature of PrEP-Stigma

A sustainable, comprehensible theory of stigma is required to aid HIV-related stigma research and intervention planning. If the structures around stigma are understood, steps can be taken to observe, understand and evaluate it (Deacon, 2006). In the context of HIV research, stigma has been conceptualised by Parker and Aggleton (2003) as; "a social practice that 'marks' or associates something with a form of difference that is negatively valued". This implies that stigma impacts people who become associated with a concept or symbol that is generally viewed negatively by society, such as HIV medication.

HIV has historically been conceptualised as a stigmatising disease, due to associations with those who have traditionally been stigmatised by society such as: gay men, minority ethnic groups, drug users, sex workers and the isolating aspects of the conditions themselves (Kallings, 2008). PrEP was developed from HAART for HIV-positive individuals, and it is argued that PrEP has also inherited the stigma associated with such treatments. Furthermore, PrEP is associated with those at high risk of contracting HIV, those of minority status and the stigma of PrEP being perceived as an alternative to condoms. It is argued that PrEP risks multiple stigmas that can differ according to specific cultural norms and these may be projected onto its users (Haire, 2015).

Many MSM participants from several studies reported PrEP-related stigma both before and after taking the drug across continents (Cowan et al., 2016; Wei & Raymond, 2018; Young & McDaid, 2014; Peng et al., 2018). The stigma associated with PrEP is reported to be socially harmful and can impact on medication adherence (Haire 2015). Wheelock et al. (2013) highlight that the stigma itself has aspects to it which impact on MSM users taking it. Thus, PrEP users may experience worry about being seen as engaging in socially discrediting

behaviours that are linked to HIV (Brooks et al., 2019; Golub 2018; Goffman, 1963). Interestingly, in some contexts, PrEP for MSM is not always associated with stigma (Golub et al., 2017). While, studies independently define PrEP-related stigma there has not yet been a systematic review of the literature, which brings together this understanding.

Qualitative research is well placed to explore phenomenological dimensions and the broader context of issues surrounding HIV and drug-related treatments (Zhou, 2010; Rhodes, & Moore, 2001). Furthermore, qualitative approaches offer a way of exploring MSM behaviour within the broader social and cultural context and so play an important role in the development of theory and methods used in HIV and MSM research (Parker & Carballo, 1990). Dixon-Woods et al. (2006) discuss that qualitative literature should be systematically reviewed in an appropriate way that parallels quantitative systematic reviews. Recent meta-analytic data shows that stigma related to PrEP is a barrier to the acceptability of MSM considering taking PrEP globally. A systematic review of the qualitative literature on solely MSM who are currently taking PrEP has not been done (Peng et al., 2018). Qualitative articles add to understandings of the experiential aspects and the broader context of PrEP-related stigma (Hughes et al., 2018). Furthermore, it may allow for an open enquiry, for participants to show their perspective in this area and so assist the identification of factors that need to be addressed in order to develop effective interventions and policy.

Method

Search Strategy

A systematic search of databases containing literature on qualitative research in PrEP was undertaken using PSYCINFO, MEDLINE and Web of Science. The searches were

restricted to research published up until the 30th November 2018. The following key terms and phrases were used in the database searches to identify works on (*Pre-Exposure Prophylaxis or Truvada, Tenofovir or PrEP or PREP or prep or Emtricitabine) AND (man or gay men or gay or male or male* or homosexual or MSM or men who have sex with men or bisexual).* Due to the context of PrEP-related stigma being a recently reported phenomenon (Haire, 2015) and few studies being explicitly tagged under stigma or associated terms, it was agreed that the lead researcher would manually search the studies sourced from the search for references to this topic.

There are limits to current methods of coding qualitative research in health bibliographic databases as highlighted by Shaw et al. (2004). The following broad-based and free test terms were used to enhance the capability of the searches to identify qualitative research articles: *qualitative, interview, interview*, ethnography, Enthogr*, discourse, focus group, phenomenology, phenomenological, narrative*.

All searches were limited to articles written in English. Reference lists of retrieved articles were cross-checked to highlight additional studies. The database was initially scanned, and any non-empirical studies were removed from the database.

Inclusion Criteria and Study Selection

The search results were imported into Excel to manage the database, and all duplicate articles were removed. The residual titles and their abstracts were screened independently by the lead researcher who used the following criteria to locate relevant studies:

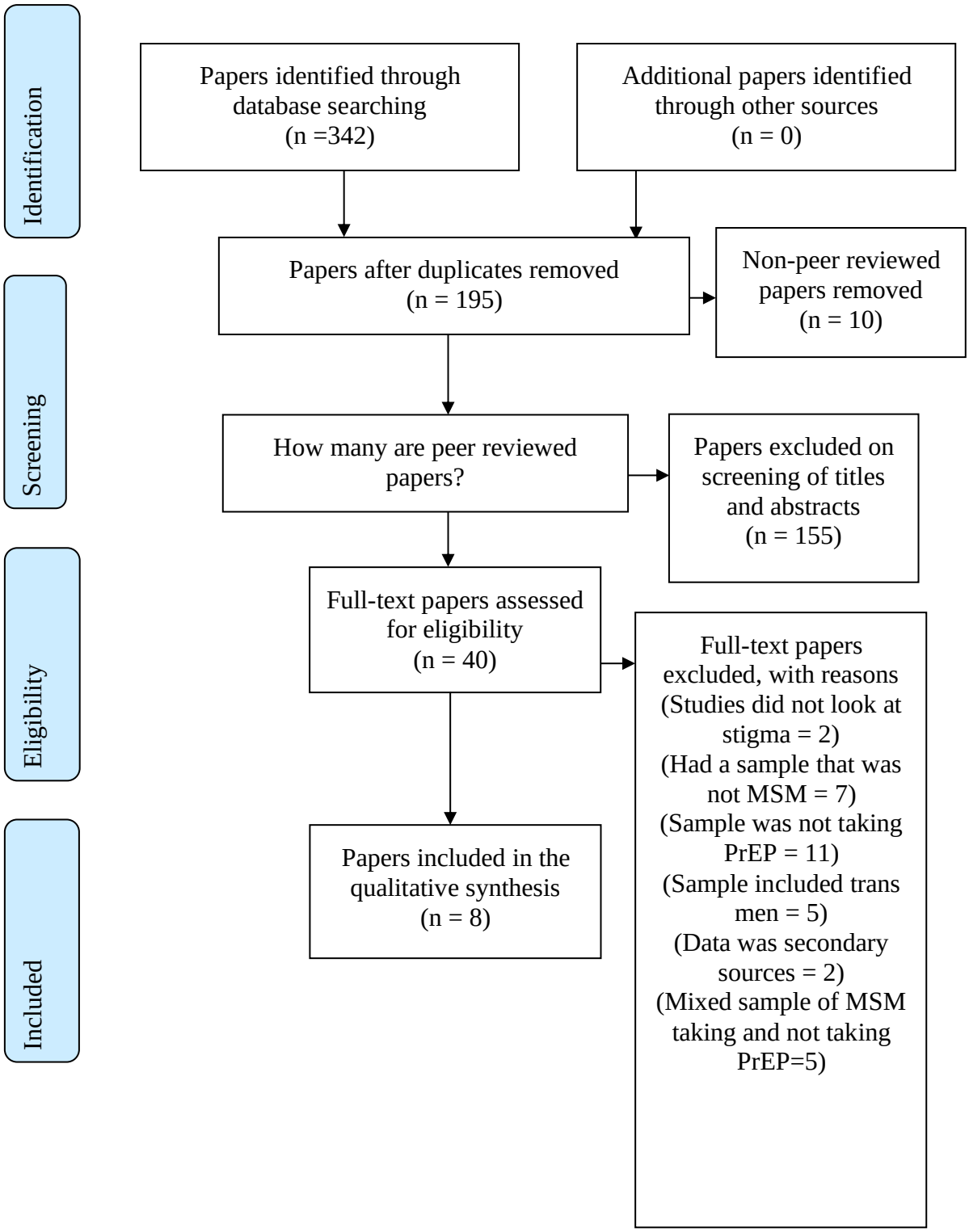
1. The study focused on gay, bisexual, or other MSM who were actively taking PrEP.
2. The study used a solely qualitative research method.

3. The study referred to PrEP-stigma or stigma.
4. Studies that contained a mixed sample of those contemplating pre-taking PrEP, those on a placebo and taking PrEP were excluded.

Sevelius et al. (2016) and Rowniak et al. (2011) highlight that trans communities can experience HIV and PrEP differently to cis-gendered groups. In order to maintain the purity of the phenomena explored it was therefore agreed by the research team to exclude studies which included trans participants.

Quantitative, mixed methods articles and articles utilising closed questions were omitted from the review. Articles included from the initial screen were then read by the lead author to ensure that they met the inclusion criteria as outlined in the PRISMA diagram below. The quality of included articles was assessed using the Critical Appraisal Skills Programme (CASP) tool for qualitative studies (Public Health Resource Unit, 2006). The assessment of an article's quality was not a reason to exclude an article that met the inclusion criteria.

Figure 1 PRISMA Diagram



Data Extraction

From the descriptive information from the articles included in the review, a table was drawn up (see Table 1) with the following parameters: author; year of publication; country; study population; sample size; method of analysis; data collection method and the number of CASP questions correctly answered in each article. A sample of two studies were coded by an independent reviewer to ensure the reliability of the CASP coding.

Table 1: Information on Included Studies and How Studies Met CASP

Studies	Sample size	Country	Population studied	Method of analysis	Data collection method	Was there a clear statement of the aims of the research?	Q 1*	Q 2*	Q 3*	Q 4*	Q 5*	Q 6*	Q 7*	Q 8 *	Q 9*	PrEP-Stigma reported	Study Aim
Grace et al. (2018)	16	Canada	Gay men from on an open trial	Grounded theory	Focus group interviews and one-to-one interviews	y	Y	y	y	y	n	y	y	y	y	y	To explore the everyday actualities of navigating one's sexuality and sexual partnerships in a shifting HIV prevention context.
Collins et al. (2017)	14	USA	Gay men through adverts	IPA	In-depth interviews	y	Y	y	y	y	y	y	y	y	y	y	To explore the perceptions and lived experiences of individual MSM who use PrEP, with the specific objective of describing the broader ways in which using PrEP impacts their sexual health, beyond its primary biomedical role in reducing HIV susceptibility.
Dubov et al. (2018)	43	USA & Ukraine **	Gay men from another study	Grounded theory	Online interviews and purposive sampling	y	Y	y	y	y	n	y	y	y	y	y	To explore PrEP- related stigma experiences of MSM living in the United States who use PrEP for HIV prevention.
Storholm et al. (2017)	30	USA	MSM, all of whom reported missed doses of PrEP and recent hazardous drinking or illicit drug use	Grounded theory & content analysis	Semi-structured interview	y	Y	y	y	y	n	y	y	y	n	y	To better elucidate 1) changes in risk perception and sexual behaviour, 2) adherence and its relationship to substance use, and the 3) psychosocial impact of taking PrEP among substance-using MSM prescribed PrEP as part of routine clinical practice.
Brooks et al. (2018)	29	USA	Latino MSM using PrEP purposive sample	Thematic analysis	Semi-structured interview	y	Y	y	y	y	y	y	y	y	y	y	To explore both the positive and negative perceptions of PrEP and PrEP users directly from the experiences of Latino MSM who are using PrEP.

Schwartz & Grimm, 2018	39	USA	MSM self-reported taking PrEP	Framework analysis	Focused interviews	y	Y	y	y	y	n	y	y	y	y	y	This study's purpose is to explore the experiences of gay men who have adopted PrEP, focusing on how they first learned about the treatment, their experiences talking with healthcare providers about PrEP, and to what extent they encountered stigma when discussing PrEP on their social networks.
Gilmore et al. (2013)	52	USA	Gay men from on an open trial	Deductive analysis	Focus group interviews and one-to-one interviews	y	Y	y	y	y	n	y	n	y	y	y	To better understand the individual and contextual factors influencing study participation and use of PrEP.
Franks et al. (2018)	37	USA	MSM taking prep	Thematic analysis	Interview and focus group	y	Y	y	y	y	n	y	y	y	y	y	To understand contextual factors influencing participants' use of PrEP, how participants fit PrEP into their established HIV prevention practices, and their preferences for dosing schedules.

*CASP questions please see Appendix 2.

** Study was a collaborative study across two countries.

Method of Synthesis

More conventional methods of qualitative systematic review could have been undertaken, such as narrative textual analysis or framework synthesis (Sandelowski & Barroso, 2006). However, a specialist synthesis approach was not adopted because the studies included lacked heterogeneity across samples and methods of analysis. The studies in this review are primarily descriptive in nature. Narrative synthesis is primarily used in systematic reviews of interventions. Wiles et al. (2008) note narrative synthesis can also be applied to qualitative research, which explores descriptions of lived experiences and for this reason, narrative synthesis is the adopted synthesis method. This approach does not use formal methods to either qualitatively or statistically pool data. The narrative synthesis approach can be used to describe and summarise the main features of the included studies to aggerate a description (Popay et al., 2006). Narrative synthesis allows for the investigation of similarities and differences between studies and exploration of relationships within the data and assessment of the strength of the evidence. It results in a summary of knowledge related to a specific review question that may be used to inform practice or policy. Key aspects of narrative synthesis were followed as outlined by Popay et al. (2006). Narrative synthesis is also most appropriate because the review question dictates that inclusion of heterogeneous studies that have a wide range of different MSM samples and qualitative methods of analysis be included which is inappropriate for other synthesis methods. The area explored aims to shape the understanding of how the experience reviewed is experienced (Sandelowski & Barroso, 2006; Popay et al., 2006). The aspects of narrative synthesis used in the review were tabulation (see Table 2) and thematic analysis (Popay et al., 2006).

Results

The thematic analysis of the articles yielded five themes: 1) Stigma directly associated with PrEP; 2) Imposed stigma from others; 3: Internalized stigma; 4) Acts to mitigate stigma; 5) Sex-related stigma.

Table 2: Tabulation of Themes from Studies

	PrEP and PrEP-stigma	*Internalised Stigma*	*Imposed PrEP-stigma from others*	*Acts to mitigate stigma*	*Sex and PrEP-stigma*
Collins et al. (2017)	✓	✓	✓	✓	✓
Dubov et al. (2018)	✓	✓	✓	✓	✓
Brooks et al. (2018)	✓	✓	✓	✓	✓
Schwartz & Grimm (2018)	✓	✓	✓	✓	✓
Gilmore et al. (2013)	✓	X	✓	✓	✓
Franks et al. (2018)	✓	✓	✓	✓	✓
Storholm et al. (2017)	✓	X	✓	✓	x
Grace et al. (2018)	✓	✓	✓	✓	✓

Key: ✓denotes theme present in the study. X denotes theme absent in the study.

PrEP and PrEP-Stigma

All the included studies reported that PrEP itself is associated with stigma. The reason for this is that PrEP acts as a label to communicate that the MSM taking PrEP are at higher risk of contracting HIV than others. The articles also explain that PrEP use can represent promiscuity, increased STI, or condom-less sex (Storholm et al., 2017; Grace et al., 2108; Collins et al., 2017; Dubov et al., 2018; Brooks et al., 2018; Schwartz & Grimm, 2018; Gilmore et al., 2013; Franks et al., 2018). As a result, PrEP and PrEP users may be described negatively by others and attract negative labels: 'PrEP whore', 'gay drug', 'bareback pill', 'slut pill', or 'recreational pill'. These labels have been reported to lead to acts of rejection from others towards PrEP users (Storholm et al., 2017; Grace et al., 2108; Collins et al., 2017; Dubov et al., 2018; Brooks et al., 2018; Schwartz & Grimm, 2018; Gilmore et al., 2013; Franks et al., 2018).

Grace et al. (2018) and Schwartz & Grimm (2018) argue that the act of taking medicine communicates illness to others, which can lead to stigmatisation due to the user becoming associated with illness. Dudov et al. (2018) adds that PrEP came from HARRT and this, therefore, brings a stigma that was associated with HIV positive individuals to PrEP as a method of HIV prevention and PrEP users. Furthermore, Brooks et al. (2018) and Grimm & Schwartz (2018) report that the clinical guidelines which determine if a person would be suitable for PrEP also adds to stigma, because it unintentionally labels the individual as a person who may partake in high-risk sexual behaviours. In turn, the criteria required to access PrEP mean MSM PrEP users are associated with risk and their reputation may be impacted.

In contrast, PrEP is not always associated with stigma. For example, Brooks et al. (2018) and Grace et al. (2018) noted that participants stated that PrEP has "changed the landscape" within the gay community, that it has eliminated a community-based fear of men who are HIV positive. Furthermore, it allows for others to engage in open relationships without fear of contracting HIV, suggesting that PrEP is allowing MSM to engage in new behaviours which were not previously seen as possible. Articles note that when PrEP is constructed in this way, it is perceived as a "magic pill" and "a miracle drug". In addition, the articles report how PrEP allows a person to communicate they are proactive in protecting themselves from HIV by taking PrEP (Brooks et al., 2018; Grace et al., 2018; Dudov et al., 2018).

Internalised Stigma

Six out of the eight studies reported either the absence or presence of internalised stigma associated with PrEP (Collins et al., 2017; Grace et al., 2018; Dudov et al., 2018, Franks et al., 2018; Schwartz & Grimm, 2018; Brooks et al., 2018).

Internalised Stigma Present

The studies report internalised PrEP-stigma can be explained in the following way: PrEP can create new forms of internalised shame and stigma associated with the PrEP users' sense of self. PrEP-stigma can also obstruct MSM's ability to alleviate these feelings (Collins et al., 2017; Grace et al., 2018; Dudov et al., 2018; Franks et al., 2018; Schwartz & Grimm, 2018; Brooks et al., 2018). For example, Dudov et al. (2018) explain that some users experience shame and guilt about how PrEP use has altered their perception of themselves and how others see them.

Dudov et al. (2018) and Grace et al. (2018) noted that participants often reported past trauma and/or internalised homophobia being associated with internalised PrEP-stigma. The reason for this was that it had left participants with feelings of shame about intimate relationships and so engaging in activities such as accessing PrEP or talking about taking PrEP evoked internalised stigma.

Additionally, Grace et al. (2018) and Collins et al. (2017) noted that individuals could see themselves as "sexual party animals". They note that this can be experienced as an internalised social-stigma about what PrEP use communicates to others. Internalised PrEP-stigma can create feelings of shame and regret for PrEP users alongside internalised conflict about the person's sexual behaviour. This perception of self can mean that when PrEP users are required to discuss PrEP use with others, they often pre-empt that they may be met with disapproval (Schwartz & Grimm, 2018).

Internalised PrEP-Stigma Not Present

The use of PrEP is largely reported, as a relief from internalised feelings of shame and anxiety around high-risk sexual behaviours. Some PrEP users do not internalise PrEP-stigma and see PrEP-stigma as an issue external to themselves. Furthermore, the experience of PrEP-stigma from others can mean MSM reflect on/challenge their own internal stigma that they may have towards MSM with HIV (Boorks et al., 2018; Grace et al., 2018;).

Imposed PrEP-Stigma from Others

All of the studies highlight that MSM experience PrEP-stigma from others. How the papers report this was either through PrEP-stigma from friends, family and sexual/romantic partners and/or PrEP-stigma from healthcare providers and other institutions.

PrEP-Stigma from Friends, Family and Sexual/Romantic Partners

All the articles reviewed recognised that others may hold negative preconceived views of PrEP and PrEP users within the gay community. They noted that PrEP users expressed upset and frustration about being labelled or judged by others as untrustworthy, irresponsible, and risky because of being identified as a PrEP user (Collins et al., 2018). All articles highlight that stigmatising behaviour is enacted through reducing social contact with the PrEP user, name-calling, shaming conversations and rejection. The papers show this can happen covertly or overtly and in both the real world and online settings.

The articles note that being identified as a PrEP user and the potential for others to stigmatise them for not conforming to perceived social norms was one of the main barriers to accessing PrEP or discussing PrEP use with staff (Grace et al., 2018; Dudov et al., 2018). Dudov et al. (2018) adds that PrEP-stigma is a cultural concept with gay men experiencing sexual shame associated with only those who are perceived as, ‘bad’, ‘dirty’ or ‘promiscuous’, contract HIV. The article adds perceived group thinking prevents MSM from engaging with PrEP.

All reviewed articles document that PrEP users often conceal their use of PrEP from others. Users report this experience as unusual because they were open about their sexuality even though stigma is present. However, the social-stigma attached to PrEP prevented them from disclosing to others about taking PrEP (Grace et al., 2018).

Brooks et al. (2018) and Grace et al. (2018) highlight the paradox within the social-stigma of PrEP. PrEP users are seen to engage in sexually high risk-related behaviors, yet the very act of taking PrEP also communicates to others that they are taking increased responsibility regarding their health. The social identity of a PrEP user is often associated with negative perceptions, which may conflict with one's personal identity; this may explain why some experience social-stigma but do not internalise it.

Romantic partners report that if others were aware that they were taking PrEP, they risk being stigmatised in their social groups. This may be due to infidelity and assumptions about couples' HIV status, which may come into question (Brooks et al., 2018). In contrast to these articles, Stolhom et al. (2017) note that PrEP is not always stigmatised but that friends, family and sexual/romantic partners can be supportive of MSM using PrEP.

PrEP-Stigma from Healthcare Providers and Other Institutions

Collin et al. (2017), Grace et al. (2018), Brooks et al. (2018), Dudov et al. (2018) and Schwartz & Grimm (2018) note MSM report perceiving their relationships with healthcare staff as "close and trusting". However, others report they can experience judgement and a negative relationship between them and healthcare staff for using or requesting PrEP. The way in which PrEP-stigma in healthcare settings may be

experienced by PrEP users is reported through avoiding talking about PrEP or through verbal and non-verbal communication as a means of enacting stigma. To protect their relationships with healthcare staff, PrEP users reported they may misrepresent condom use and other sexual behaviours whilst on PrEP to avoid being seen unfavourably.

In instances where PrEP-stigma was not present between PrEP users and healthcare staff, Grimm & Schwartz (2018) note PrEP users reported staff as: "non-judgmental; avoided communication perceived as lecturing; valued peer-type relationships with their patients; and inquired about their patients' personal lives" pp2. They also report that if PrEP users perceived staff as being LGBT or LGBT friendly, they were less likely to perceive PrEP-stigma.

In some cases, PrEP users are exposed to wider structural forms of stigma that go beyond the social, internal or interpersonal level. For example, Grace et al. (2018) note that PrEP acts as a tool to significantly reduce new infections resulting in a saving to health services. However, because of the cost and that PrEP is seen as an MSM related HIV treatment, stigma is linked to it. Grace et al. (2018) and Brooks et al., (2018) note that this feeds into how policy and social media explains PrEP to others, creating a stigmatising narrative. Moreover, these associations can prevent MSM from accessing PrEP because of the perceived level of judgement from the healthcare provider.

Dudov et al. (2018) suggest a way to overcome this narrative may be by public health messages normalising PrEP's use across all MSM, not just those who are seen as at risk. They add that by presenting PrEP as an added layer of protection against HIV, alongside conventional HIV prevention methods, it may challenge the existing perception that PrEP use and condom use are mutually exclusive.

Acts to Mitigate Stigma

All the studies highlight that MSM engage in activities to mitigate PrEP-stigma. This was reported in two ways; either through actions to avoid stigma or actions to challenge PrEP-stigma.

Action to Avoid PrEP-Stigma

The studies noted that MSM would avoid taking PrEP in front of others (Frank et al., 2018). Gilmore et al. (2018) builds upon this noting how PrEP is associated with LGBT and HIV positive people due to its origins. People would actively avoid taking PrEP if they knew they were around "homophobic or positive-phobic" people. However, Franks et al. (2018) and Dudov et al. (2018) show that even some PrEP users will not disclose to others that they take PrEP because of stigma. They will hide PrEP and take it in private spaces.

A further action used to avoid PrEP-stigma was for the individual to choose not to challenge the stigma, provided only a few people were stigmatising to the individual. The authors note that this way of avoiding PrEP-stigma was done as a means to prevent an escalation of stigma (Grace et al., 2018; Schwartz & Grimm, 2018).

Actions to Challenge PrEP-Stigma

MSM engage in activities which challenge PrEP-stigma. The studies explain this was achieved by educating others about PrEP and by challenging the language associated with PrEP-stigma.

Studies highlight that PrEP education amongst MSM and others is minimal and can create a miss-attribution of those using PrEP as 'risky' (Collins et al., 2017; Grace et al., 2018; Dudov et al., 2018; Schwartz & Grimm, 2018). By educating others when they experience PrEP-stigma, it is reported that imposed PrEP-stigma can be reduced/overcome. Furthermore, the studies argue it normalises the use of PrEP within the MSM community allowing for PrEP-stigma to be reduced (Brooks et al., 2018; Collins et al., 2017; Grace et al., 2018; Dudov et al., 2018; Storholm et al., 2017; Schwartz & Grimm, 2018).

A further way that individuals were able to overcome being associated with PrEP-stigma or internalising it was by re-framing the situation (Grace et al., 2018; Schwartz & Grimm, 2018). The studies were able to show how taking PrEP was an action which PrEP users could re-frame as protecting themselves and other MSM from HIV, which they were not able to do in the '80s and '90s. If access was possible in the '80s and '90s the studies report PrEP would have been embraced not stigmatised (Grace et al., 2018; Schwartz & Grimm, 2018; Dudov et al., 2018; Storholm et al., 2017).

Brooks et al. (2018) add that for some PrEP is an additional necessary form of protection for MSM HIV serodiscordant relationships. This was because PrEP users in this context can be seen as taking responsibility for protecting themselves from contracting HIV from their partners. PrEP reduced HIV anxiety in serodiscordant relationships. This awareness could reduce the stigma attached to both PrEP and MSM with HIV.

All studies note that PrEP-stigma was overcome in a majority of cases through participants feeling liberated or taking pride in using PrEP. For some, the studies note a

spoiled identity associated with being stigmatised was prevented. It also meant that when PrEP-stigma arose, they were able to address it and reclaim stigmatising language. An example was seeing the label "PrEP Whore" as a term of empowerment (Grace et al., 2018; Dudov et al., 2018; Storholm et al., 2017). Schwartz & Grimm (2018) and Collins et al. (2017) note that early adopters of PrEP take this stance and report seeing it as part of their role to challenge PrEP-stigma directly.

Sex and PrEP-Stigma

Seven out of the eight studies highlight that PrEP-stigma is closely related to sex (Franks et al., 2018; Collins et al., 2017; Dubov et al., 2018; Brooks et al., 2018; Schwartz & Grimm, 2018; Gilmore et al., 2013). Men in these studies described how PrEP related to assumptions being made about their sexual practice. The studies note how participants were seen as sexual risk takers because of being on PrEP. The articles noted that participants who are open about taking PrEP often experience stigma from sexual partners (Franks et al., 2018; Collins et al., 2017; Dubov et al., 2018; Brooks et al., 2018; Grimm & Schwartz, 2018; Gilmore et al., 2013). All of the studies highlighted that others assume that taking PrEP meant users engage in activities such as: unprotected sex, condom-less sex, drug-taking and promiscuity.

Gilmore et al. (2018) explain how PrEP parallels the stigmatisation of the contraceptive pill when it was first introduced and assumptions about the user's sexual immorality. Furthermore, participants noted that because of this type of stigma it was hard for them to initiate starting PrEP. The articles note that taking PrEP can be seen by

others as a clear communication that they are having unprotected sex and engaging in risky sexual behaviours even when this may not be the case.

A further factor which contributes to PrEP-stigma is that historically condoms were the only form of protection against HIV (Franks et al., 2018; Brooks et al., 2018). It is highlighted that now a “condom only” culture creates a barrier to using other forms of protection alongside condoms. Non-conformance to this cultural norm risks the person becoming stigmatised by others in their social group.

Articles discuss how MSM often reject disclosing aspects of sexual encounters which may give them pleasure, such as the exchange of bodily fluids and unprotected sex due to a fear of associated stigma. The articles note PrEP use exposes such activities, and so goes against this rejection leading to maintenance of PrEP-stigma (Franks et al., 2018; Collins et al., 2017; Dubov et al., 2018; Brooks et al., 2018; Schwartz & Grimm, 2018; Gilmore et al., 2013).

Grace et al., (2018) note, however, that PrEP does evoke stigma from the person’s sexual and social networks. It was also described as an action to remove stigma and fear related to HIV, sexual orientation, and sex with gay men living with HIV. Dudov et al. (2018) also note that the ability for MSM to take such proactive actions towards their sexual health and HIV prevention can mean stigma associated with MSM is overcome and instead of PrEP being seen as stigmatising it instead is empowering. Thus, it can be inconsistent as to whether a person will or won’t experience PrEP-stigma related to sex.

Discussion

Summary of Main Findings

The review shows that PrEP-stigma can impact MSM PrEP users. The review has shown how and why PrEP-stigma may have evolved. There are multiple levels at which PrEP-stigma may operate. The review also highlighted ways in which PrEP-stigma is addressed and overcome by PrEP users. Finally, the review noted that PrEP-stigma is not experienced by all users. There can be an inconsistency between PrEP users feeling/being stigmatised versus empowered because of their use of PrEP. Some PrEP users also have strategies to overcome PrEP-stigma (Storholm et al., 2017; Grace et al., 2108; Collins et al., 2017; Dubov et al., 2018; Brooks et al., 2018; Schwartz & Grimm, 2018; Gilmore et al., 2013; Franks et al., 2018).

The bringing together of the current articles has identified some of the underlying reasons PrEP-stigma is present. The analysis makes connections between PrEP-stigma and the interpersonal and social factors, which may sustain PrEP-stigma as highlighted in the analysis, for example, how PrEP-stigma parallels stigma associated with HIV and the labels that come with it (Storholm et al., 2017; Grace et al., 2018; Collins et al., 2017; Dubov et al., 2018; Brooks et al., 2018; Schwartz & Grimm, 2018; Gilmore et al., 2013 & Franks et al., 2018).

Strengths and Limitations of the Study

This is the first systematic review to synthesise studies on PrEP-stigma solely from the perspective of PrEP users. Studies in this area are recent due to PrEP only being accessible for HIV prevention since 2012 (Calabrese et al., 2018). The search strategy

was difficult to develop, due to PrEP-stigma being a recent phenomenon and no direct research tag being associated with the term PrEP-stigma. The use of search terms stated above, manual searches of literature and searching reference lists and citations of included papers did not yield any additional studies for review. Studies which did not fully meet the inclusion criteria were excluded from the study.

Whilst all studies included MSM PrEP users, the participants across the studies were not homogenous. Some studies recruited through research trials, others were recruited through naturalistic sampling and others were purpose recruited samples such as: early adopters, Latino MSM and substance misusers. It may be that if the sample consisted of a more homogenous group of MSM the findings may be different (Storholm et al., 2017; Grace et al., 2108; Collins et al., 2017; Dubov et al., 2018; Brooks et al., 2018; Schwartz & Grimm, 2018; Gilmore et al., 2013; Franks et al., 2018).

As can be seen from Table 1, the extent to which the studies explored PrEP-stigma varied, with some studies having the exploration of PrEP-stigma as the only focus of the study. In other studies, PrEP-stigma emerged as a theme as part of a wider study focusing on the experience of taking PrEP. This may impact the extent to which PrEP-stigma was explored and reported across the different studies.

A majority of the studies included in this review are primarily from the USA. Caveats must be voiced about the generalisability of the findings, as the studies were all conducted in developed countries. Notably, PrEP-stigma is reported across many different countries (Ayala et al., 2013; Tangmunkongvorakul et al., 2013). Studies from a broader range of countries were not included, due to the papers not meeting the inclusion

criteria. As a result, while PrEP-stigma is reported across different countries, it is hard to apply the findings of this review beyond the studies reported in this review.

The context of PrEP in the USA may have influenced the findings. Across the USA PrEP is accessed through: insurance, self-funding, charities or research trials (Amico & Bekker, 2019; CDC, 2017). By contrast, currently in the UK, PrEP is accessible freely in Wales and Scotland, whereas in England, PrEP is only accessible via self-funding or research trials (Paparini et al., 2018; Nandwani, 2017; Jones, 2017). In addition, the USA has an insurance-based healthcare system. This can mean that access to drugs differs from universal healthcare systems, such as the UK. Furthermore, it is noted that the way patients interact with healthcare systems varies across the two systems (Kotlikoff, 2007). The difference in the ways in which PrEP is accessed and the healthcare context in which it exists may have influenced the findings of the review. Further study of PrEP-Stigma should be undertaken within differing healthcare contexts before the findings are applied outside the USA context.

Table 1 shows that some studies did identify how participants accessed PrEP, however, other studies did not. Therefore, the ability to comment on how participants access PrEP and the influence this may have had on the findings of this review is limited. Furthermore, due to the nature of the review being aggregative, it is recommended that future studies into PrEP report on how MSM access PrEP, so this factor can be accounted for. As the research into the experience of taking PrEP and PrEP-stigma expands, it may be possible to do targeted reviews on the experience of taking PrEP and PrEP-stigma based on the way individuals access it. One of the few

studies of its kind by Paparini et al., (2018) does report experiential differences for MSM who self-fund PrEP in contrast to those who do not.

This study has delivered on some of the key components of a narrative synthesis. It has considered the main elements of: developing an understanding of a given phenomenon/intervention; developing an initial synthesis of findings from the articles included; exploring relationships in the data and assessing the robustness of the synthesis (Popay et al., 2006).

The credibility of the studies and review process is at the centre of this review. The use of the CASP allowed for the quality of the study's findings to be considered. Whilst, no study was excluded for not meeting the CASP criteria, it does give an indication as to the robustness of the studies that have been analysed. The reliability of the narrative synthesis and the CASP was enhanced by having a researcher independent of the review assess the face validity analysis and CASP scoring.

Narrative synthesis of qualitative studies is a new approach. No fully standardised methodology for its application has yet to be agreed upon within the literature. This means that narrative synthesis is a versatile method and can be used across a range of different papers. However, no consensus regarding either quality assessment, validity or appropriateness has been reached (Sandelowski and Barroso, 2006). Unlike other synthesis approaches, narrative synthesis allows for the different qualitative methods of analysis to be combined (see Table 2) (Popay et al., 2006). Whilst this is the case in this review, studies primarily consisted of methods which focus on the subjective viewpoints of participants drawing on a phenomenological approach (Flick, 2009). Further studies

should explore the area from alternative approaches looking at subjective experiences, such as ethnographic methodologies.

The findings examined in this review were predominately descriptive summaries. Narrative synthesis allows the researcher to thematically discern and group findings into themes or patterns (Vallido et al., 2010; Wiles, 2008). The analysis did not attempt to integrate data to develop new concepts or theories. Instead, it aimed to integrate the current literature so that a systematic description could be achieved. This is a recommended step that should be taken before an interpretive synthesis, such as meta-ethnography, is undertaken (Sandelowski & Barroso, 2006). As the body of literature in this area grows, it will be essential to use interpretive synthesis methods to develop models and theories of PrEP-stigma beyond the descriptive level.

It can be seen across the articles that PrEP-stigma fits with Parker and Aggleton's (2003) explanation of stigma in the broad HIV context. The studies also show that PrEP-stigma operates in a similar way to specific theories of HIV stigma (Kallings, 2008). The impact of stigma may result in MSM postponing HIV testing and/or coming forward to access PrEP; avoiding taking PrEP and assuming that only promiscuous gay men are at risk of HIV. The studies illustrate that PrEP-stigma operates though overt behaviours, perceived awareness of the stigma and internalisation of the stigma which is similar to Parker and Aggleton's (2003) and Kallings' (2008) theories.

Crucially the studies come from a range of different MSM groups (see Table 1). This may infer that PrEP-stigma occurs across different groups of MSM. However, due to the nature of qualitative research and the small number of studies in this analysis, this

can only be hypothesised (Atieno, 2009). It is recommended that further exploration of this is undertaken to establish if PrEP-stigma does cut across different groups.

The analysis also highlighted that MSM PrEP users do not always experience PrEP-stigma. The extent to which this is the case and the mechanisms which lead to this, cannot be entirely deduced from the studies explored. This is because the studies did not recruit samples of MSM PrEP users who had not reported experiencing PrEP-stigma. Studying these participants where they are either resilient to or report an absence of the phenomenon can lead to an understanding of factors, which prevent adversity from being experienced (Kobau et al., 2011). Future studies could be done to explore the phenomenon and so add to the understanding of PrEP-stigma and possible factors which may aid interventions to overcome PrEP-stigma.

Furthermore, the use of differing recruitment methodologies and differing primary focuses of the studies included may have influenced the findings of the review, as noted above. The findings of the review may show contradictions, because the samples and methods used across the studies are heterogeneous. In the case of the findings associated with the PrEP paradox, Popay et al. (2006) note that finding of paradox can be an artifact of combining studies which have different research aims and methods. This can be seen in Table 1. Consequently, the finding regarding the paradox may be an artifact of the included studies using different samples of MSM and different recruitment methodologies. It is therefore recommended if a further review were to be undertaken that this should be accounted for.

As stated previously, narrative synthesis is an aggregative review method which brings together studies, which are heterogeneous in method and sample to provide

description of a phenomenon. It does not seek to interpret or re-interpreted findings (Popay et al., 2006). As outlined in the method above, steps were taken to ensure this did not take place. This may suggest that the review findings of the reported paradox are consistent with the reported studies.

Across all included studies, PrEP-stigma was reported alongside PrEP being a protective positive/liberating act. From the findings in the review, it is hard to determine how the ability to hold a "both/and" position evolves (Real, 1990). However, it is not uncommon for MSM to feel both stigmatised and liberated in multiple different contexts at the same time (Cruikshank, 2014). Additionally, this finding can be found in HIV stigma research (Parker & Aggleton 2003) and in Goffman's (1963) original writing on stigma. The finding has also been reported in other systematic reviews of MSM contemplating taking PrEP (Peng et al., 2018; Hannaford et al., 2018; Sidebottom et al., 2018; Marcus, et al., 2014; Yi et al., 2017). It is recommended that further studies are undertaken exploring the PrEP paradox before a review on the specifics of the paradox is undertaken.

Consideration in future reviews should be given to how samples of MSM taking PrEP are recruited and how the methods used to analyse data in the included studies, impacts on the review findings. A decision should be made in further reviews about whether to include only studies that are specifically focused on PrEP-stigma, or studies which mention PrEP-stigma in the context of a wider study focus, as this may alter the review findings.

The transferability of the review is limited to the population described only in the original studies. With the limited descriptions from the studies, it is insufficient to get a clear picture of the full extent to which PrEP-stigma may or may not operate. To take the analysis further, the inclusion criteria for the current review could have been broadened.

Comparison with Existing Literature

In relation to the existing literature conducted on PrEP-stigma, this review is consistent with the findings of reviews into MSM who were contemplating taking PrEP (Peng et al., 2018). Golub's (2018) and Haire's (2015) narrative reviews of PrEP-stigma hypothesise that PrEP-stigma does impact a broad demographic of PrEP users. This review has been able to systematically document the way in which PrEP-stigma affects MSM specifically and the nuances within the phenomenon of MSM PrEP users.

As shown in Table 1, the sample in this review consists in the majority of early adopter MSM PrEP users. For this reason, samples could be likely to report a hopeful perspective on PrEP and PrEP-stigma (Grace et al., 2018). As PrEP becomes more established globally, it is possible that future users may not bring the same perspective to the one reported (Golub, 2018; Haire, 2015). However, it may be that as PrEP becomes more established in its use and message, it may become more normalised as studies report with the contraceptive pill, suggesting PrEP-stigma may reduce (Kitzinger, 2005).

All of the studies note more research into PrEP-stigma is needed across more diverse intersectional MSM groups. This may elicit different experiences of PrEP-stigma. Studies in this review primarily come from developed countries, research participants and those who met the criteria for PrEP. Further systematic reviews with a more flexible study

inclusion criterion, are required. This may allow for the experiences of other groups, such as those who are from developing countries, to be more fully understood.

The systematic review was limited in that it was restricted to papers published in English. This was due to the researchers only speaking English and not having access to translation services. Morrison et al. (2012) note this can lead to systematic review bias in the literature search and therefore influence the analysis. If a further review were to be conducted it would be recommended that the reviewer has access to support for reviewing literature of different languages so this bias can be mitigated.

Implications for Policy and Practice

HIV prevention is primarily understood from a biomedical perspective: PrEP is a new cost-effective tool to prevent HIV contraction (Adam, 2011; Nguyen et al., 2011; Sun et al., 2019). This review highlights how consideration needs to be given to psychosocial issues which impact on HIV prevention intervention across all levels of the system. In the context of this review, the sole focus was on the way in which PREP-stigma relates to PrEP users. It highlights how reducing the attribution of PrEP-stigma to PrEP users may improve uptake and engagement with PrEP.

The analysis shows that PrEP-stigma does not exist in isolation, but rather it is linked to social pressures associated with HIV stigma and dominating narratives around sexual identity, sex, condoms and how care should be provided. This highlights the role health promotion may have to alter the public discourse and so the barriers around accessing and using PrEP can be reduced. This may address some of the policy and practice level issues around PrEP-stigma. The analysis showed that there were also direct

strategies to challenge PrEP-stigma such as the importance of education for others. It may, therefore, be prudent to provide an intervention which educates the general public as has been done with other disease prevention campaigns to reduce stigma (Evans-Lacko, 2013). The implications that this study has for policy and practice will now be considered.

This review supports the view put forward by Golub (2018). This review highlights how the policy and clinical guidelines may set up a stigmatising environment for PrEP users to be exposed to. The analysis highlights how the language used around policy and clinical guidelines may be adapted to reduce the potential for stigma to occur. A change in the language may allow for a broader reach of PrEP and increase its use by those who need it. An example of where this has been done on a policy level can be seen in the American College of Obstetricians and Gynecologists (2016) in relation to contraception. This may also allow MSM who met criteria for PrEP to overcome barriers to accessing it and sustain their adherence. Framing policy and practice around a 'preventionist' identity for MSM, in contrast to the current high-risk identity, may reduce the level of stigma associated with PrEP (Golub, 2018). A drawback to this approach could be that it creates demand for PrEP by those who may not need to access it. However, Golub (2018) highlights that the benefits from PrEP are likely to offset the cost of its provision.

Policy change can be effectively supported by qualitative data (Greenhalgh et al., 2016). However, Hilliard et al. (2018) note that without quantification of the phenomena being explored, it is hard to justify change for large populations. Quantitative studies on

the topic of PrEP-stigma could triangulate the findings of this review and add more forceful argument to create policy change.

Conclusion

In conclusion, the review has highlighted that MSM taking PrEP experience PrEP-stigma on multiple different levels. PrEP-stigma can be imposed on the individual by others. It can also be internalised by PrEP users. The phenomenon of PrEP-stigma can create barriers to both the access and sustained use of PrEP. The studies also show that various strategies are used by PrEP users to overcome PrEP-stigma. These strategies could be developed to overcome PrEP-stigma experienced by MSM PrEP users at the different levels on the individual, interpersonal and policy level which add to PrEP-stigma being experienced by MSM PrEP users. It has been highlighted that studies are warranted with different populations. In particular, studies could explore broader groups of MSM taking PrEP, who both do and do not experience stigma, using both quantitative and qualitative methods. This may allow for any proposed intervention to be robustly defined, before the findings of this review can be applied.

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Paper Two: Empirical Study

Gay Men's Experiences of HIV Testing in a Post PrEP Landscape:

A Q study.

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Title

Gay Men's Experiences of HIV Testing in a Post PrEP Landscape: A Q study

[a]Richard Hobbs*, [a]Aimee Pudduck, [b]Austin Lockwood & [a]Dougal Julian Hare

[a]*Department of Psychology, Cardiff University, Cardiff, United Kingdom*

[b]*Division of Clinical Psychology, Manchester University, Manchester, United Kingdom*

Abstract

Gay men are identified as a group who are at higher risk of contracting HIV than the general population. As a result, in the UK, gay men are recommended to test for HIV either once a year or once every three months, depending on their level of risk. However, many do not meet this target. There are complex psychosocial barriers which can prevent gay men from testing. NHS Wales provides access to PrEP for gay men. No study has assessed the impact PrEP may have on gay men testing for HIV in Wales. This study is an exploratory Q study which aims to explore the viewpoints of gay men testing for HIV in Wales. In total, 25 HIV negative gay men from Wales completed a Q-sort. Principle component analysis with varimax rotation was performed on the 25 completed Q-sorts. The analysis yielded a 3-factor solution. The three factors were interpreted as: “Testing PrEP and shame/stigma”, "The psychological distress of testing and the search for certainty” and “HIV Testing a prosocial act and self-learning". The implications that the findings have for healthcare provision, policy and clinical practice will be considered.

Keywords: HIV; PrEP; Gay men; Q methodology; and HIV testing.

Introduction

This study aims to explore the viewpoints of gay men testing for HIV in Wales. Human Immunodeficiency Virus (HIV) is a blood-borne virus that damages the CD4 cells in the immune system, leaving a person more vulnerable to contracting serious illnesses that can be fatal (Phillips et al., 2008). With the introduction of Anti-Retroviral Therapy (ART), HIV is now a treatable medical condition with the majority of those living with HIV able to remain well with life-long treatment (Trickey et al., 2017).

To know if a person has HIV and to treat it effectively, they are required to test for it. The Joint United Nations Programme on HIV/AIDS (2014) set targets for 2020 to diagnose 90% of all HIV positive people, to provide ART for 90% of those diagnosed and to achieve viral suppression for 90% of those treated. In the most recent study of its kind, Levi et al. (2016) noted the UK had a 76% diagnosis rate and so did not meet the United Nations' 90% target. This view is supported by the British HIV Association (2008) who note that a significant number of people in the United Kingdom were unaware that they were infected with HIV, putting their health at risk and unknowingly putting others at risk of infection.

Beyrer et al.'s (2012) epidemiological study noted that men who have sex with men (MSM) are disproportionately affected by HIV infection globally, a finding echoed by Delpech et al. (2018) in the UK. As a result, it is recommended that MSM test for HIV either once a year or once every three months, depending on their level of risk. However, many do not meet this target (NICE, 2018; Frankis et al., 2014; British HIV Association, 2008). In addition, one in four MSM in England and Wales are known to

miss an opportunity to receive a diagnosis or early treatment (Chadborn et al., 2005). Whilst this figure is declining, Furegato et al. (2018) add that many MSM in the UK are missed or diagnosed with HIV later, leading to increased demand on services. A late diagnosis of HIV makes the individual ten times more likely to die within a year of contracting HIV (Flower & Davis, 2013; Cohen & Gay 2010). When HIV is detected early, it can be managed so that the individual leads a healthy life and achieves an average life expectancy (Dockrell, 2017).

Lui et al. (2018) highlights the need for identifying the diversity of viewpoints on HIV testing for MSM in the broader interpersonal, social and cultural environments so that further understanding of the social mechanisms and practices in relation to HIV testing can be understood and addressed in their own environment. The reason HIV testing needs to be understood in its own environment is that, over time, testing policies have varied considerably both within and between countries. This can be seen across the UK particularly regarding changes in HIV testing and HIV prevention in the UK (Fina et al., 2018; Adams, 2019; Mounier-Jack et al., 2008). In these instances, it is therefore essential to understand the decision-making process of testing within the person's respective environment.

Additionally, Lui et al.'s (2018) and Flower et al.'s (2003) findings suggest that an emphasis on the narrow biomedical rationale for HIV testing has led to overly simplistic models of HIV testing. This dominates the literature without taking account of the context in which the costs and benefits of testing occur. This may mean that the current theoretical frameworks for HIV testing are inadequate for taking into account gay men's motivations to engage in HIV-testing and also the barriers they may face.

HIV Testing in the Context of Behaviour Change.

Within the broader literature, health psychology theories have been developed regarding engagement with behaviours and behaviour change (Hatala, 2012). Long established models have been used to explain testing in a variety of contexts, such as the health belief model and theory of planned behaviour (Rosenstock, 1974; Rosenstock et al.,1994; Ajzen,1991; Rutter 2000; Ayodele, 2017). Although, such theories are useful to explain health behaviours and engagement with testing, they are criticised for being top-down generalist approaches. This can mean that issues pertinent to the population studies can be overlooked and the specificity of the theory/intervention developed may not map onto the needs of the population explored (Campbell & Murray, 2004). Furthermore, integrating bottom-up knowledge which is sensitive to the population studied and reflects the multiplicity of their experiences in top-down research is essential, if research in health behaviour change is to meet the needs of the population studied (Braithwaite et al., 2018).

This argument for exploring, describing and understanding the phenomena, before imposing generalist theories or interventions, has been made in the field of critical health psychology (Crossley, 2008). More recently this has been acknowledged in mainstream health psychology approaches with the development of the Behaviour Change Wheel (Michie et al., 2014). This theory argues that the first stage, and a central guiding principle of behaviour change, is to understand the behaviour and population before making changes. This then entails considering the framework, range of options and use of systemic methods required to make this change. Furthermore, the Behaviour Change Wheel argues that when new factors are introduced to an environment, the

phenomenon itself should be re-understood to account for the new factor which may influence a behaviour change. With the introduction of PrEP for MSM in the Welsh context it is therefore important to create an understanding of how this informs HIV testing for MSM in Wales before theory or interventions are applied. This study focuses on gay men testing for HIV in Wales. It aims to address the first stage of the Behaviour Change Wheel to inform further research, theory and intervention in this area.

Furthermore, many theories note that stigma is a central issue which impacts on men's engagement with testing for a chronic health condition. Behaviour change interventions have tried to address the role of stigma in screening for health conditions (Teo et al., 2016; Scott et al, 2015; Chesney 1999). There has been little description of how PrEP or PrEP-stigma may be related to MSM testing for HIV (Golul 2018; Haire 2015). This study takes place within a context where PrEP is freely accessible to MSM. Accessing the viewpoints within this context may provide a description of PrEP-stigma and stigma more broadly, to inform behaviour change theory as recommended by (Michie et al., 2014).

Barriers to Testing for HIV

There are various barriers which prevent MSM from testing for HIV (Deblonde et al., 2010; Lui et al., 2018). The main barriers are argued to be the administration of tests, the attitudes and practices of healthcare providers, and perceptions of patients. Further barriers are that if the individual perceives themselves to be at risk but stigmatised or shamed for testing, they are less likely to test. A review by Bolsewicz et al. (2015) suggests that the effect of interventions focusing on barriers to HIV testing

are limited by the degree to which the barriers outlined are addressed. Furthermore, for HIV testing interventions to be effective, further research is needed to understand the barriers to testing within the target population's social and geographic environment. This current study focuses on a Welsh population.

Flower et al. (2003) note that before taking an HIV test, uncertainty plays a key role as to whether MSM will engage with the testing process or not. They add that the decision to test may be seen as a decision for the individual between living with uncertainty and the predicted impact of knowing one's HIV status will have. However, Flowers et al. (2013) add that the decision to test is not only determined by the level of uncertainty. Instead, it involves numerous multifaceted medical, environmental, psychological and social factors which can make the decision to test complex. They note that as testing evolves, the factors impacting on the decision to test may alter and these should be explored as they occur.

No Barrier Present

Clifton et al. (2016), Flowers, et al. (2013) and Desai, (2019) identify that HIV testing has become a partially normalised process for gay men. This may mean that some gay men may be unaffected by perceived barriers reported to testing. However, all authors state that some barriers specific to the person's environment remain. They add that it is important to understand gay men who report no barriers and are engaged with the testing process alongside those who report barriers to testing. They suggest that in order for effective design and evaluation of biomedical and psychosocial interventions,

it is important to understand the populations who do not experience barriers in their specific environment.

The Environmental Factors

In order to understand Lesbian, Gay, Bisexual and Trans (LGBT) phenomena, it is essential to look at it from within the social and cultural environment (Plummer, 2005). This argument is supported by researchers who note that there are many contextual and environmental factors, which could contribute to gay men delaying HIV testing. It is essential to understand these factors in their own environment (Flower et al., 2003; Lui et al., 2017; Kimmel & Levine, 1998). For example, research highlights that further studies need to identify if these processes are present in other demographic contexts, particularly as the majority of HIV testing research has been conducted in Scotland and England (Flower et al., 2003). No recent study has assessed whether the viewpoints of testing for HIV differ in Wales. Therefore, this study will describe gay men's experience of testing for HIV in the Welsh context in relation to current research.

A key factor, which may make the experience of uncertainty and testing for HIV different in the Welsh context is the provision of Pre-Exposure Prophylaxis (PrEP). PrEP is a drug that is highly effective at preventing HIV contraction (McCormack et al., 2016). In Wales, unlike in England, PrEP is available to all HIV negative MSM deemed at risk of contracting HIV (Adams, 2019; NHS Wales, 2017). However, MSM are required to test for HIV before accessing treatment. It may be that the long-term gain of accessing PrEP allows for short-term uncertainty to be managed and so a person, who would not normally test, will test. However, this has not been explored in the Welsh

context. The key aim of this study is to identify viewpoints regarding HIV testing as reported by gay men in Wales.

The Application of Q Methodology to the Study

Flower et al. (2003) note that further studies are required before generalisations about testing can be made to gay men from wider geographical and social environments. Q methodology has been noted as a user-friendly technique to assess attitudes and perceptions on issues surrounding HIV (Goto et al., 2008). It is noted that Q method can operationalise and integrate complex subjective viewpoints to provide objective data for analysis (Watts and Stenner, 2005).

To date, studies into HIV testing have relied primarily on face-to-face approaches (Liu et al., 2017). Whilst providing an understanding of how various factors may impact on HIV testing, direct interviewing methods do not always allow participants to express their own viewpoints, because of factors such as social desirability. One way to overcome this is to use online methods of research where the information provided is anonymous (Denzin & Lincoln, 2011).

The impact of social desirability can be mitigated to some extent by Q because it presents a broad array of viewpoints to the participant and asks them to sort amongst them (Watts & Stenner, 2005). This means a participant may be more able to reflect their viewpoint and allow for pertinent factors to be represented in a way that has not been done in previous studies.

Methodology

Several approaches have been developed in order to measure various aspects of testing for chronic conditions, such as HIV (Galdas et al., 2005). The main investigations have employed questionnaires or interview-based methods. Questionnaire methods usually address isolated components of HIV testing rather than looking at the holistic overview. It has been observed that this unitary representation of HIV testing might be artificial, and so to disentangle various components at clinical, policy, social or academic levels is inappropriate. Moreover, there is a clear distinction between knowledge concerning various aspects of HIV testing and the attitudes related to its consequences (Knussen, C. et al., 2004; Winn & Skelton, 1992). Therefore, some studies have employed more ecological, qualitative and phenomenological approaches in order to identify community reactions to HIV testing, for example: the experience of healthcare professionals, or person living or testing for HIV (Lorenc et al., 2011; Lui et al., 2018). This study proposes a novel approach in order to investigate the mental representation of gay men testing for HIV, known as the Q method. Q is an iterative process which explores the subjective gestalt of a topic through scientific means (Stephenson, 1953).

The present study used Q methodology: a robust technique for the 'scientific study of the subjective'. Q methodology is iterative and explores individual viewpoints to highlight shared understanding. It allows diverse subjective phenomena to be studied systematically and empirically, without the imposition of predetermined epistemologies or assumptions. Thus, researcher bias is reduced because data used in Q methodology is developed and structured by the participants, in contrast to investigators (Stephenson, 1953).

The distinguishing feature of Q, in comparison to classical research methods in social sciences, is its method of analysis which correlates people instead of variables and so builds typologies (Stephenson,1953). In addition, Q is qualitative because of its assumptions and research logic. However, it is also quantitative because of its statistical apparatus sustaining data analysis through Q-factor analysis (Brown, 1993).

Epistemology of Q Method

As discussed by Watts and Sterner (2012), Q is an adaptable research methodology that is, to a large degree, epistemologically neutral. Brown (1980) proposes that given that the ontological position underpinning Q methodology is that subjectivity is observable through behaviour, Q involves a minimal epistemology. This assumes that objective measurement of subjectivity requires data to be collected under operant conditions in order to develop a scientific study of subjectivity.

Moreover, the voice and stance of the researcher in Q is purposefully minimised and inherently secondary to the those of the participants. Hence, any epistemological stances that may be perceived in Q studies are essentially those of the participants as reflected through their Q sorts. Because of this, Q can bring together contradictory epistemologies and research practices for comparison. Q is designed to identify diverse and often incompatible perspectives on any given topic, rather than to construct an average opinion for a large population. Therefore, conventional notions of bias are largely incongruent with Q methodology (Stephenson, 1953; Brown 1980; Watts & Stenner, 2012).

Ethical approval was gained from Cardiff University School of Psychology Ethics Committee [Appendix 3].

Participants' Demographics

Participants interviewed for the concourse and Q-Sort participants were recruited via snowballing recruitment techniques as outlined by Streeton, Cooke & Campbell (2004). This used the first author's existing links with the LGBT community in Wales, social media and participants then referring others to the study. Participants were asked only to take part if they were HIV negative, from Wales, MSM and were aged 18 or over. The recruited sample consisted of an opportunity sample of MSM who identified as gay men.

Demographics of Concourse Informants

Concourse informants took part in stages one and two of the procedure only as outlined below.

All five health professionals interviewed lived in Wales, were HIV negative, white males who reported testing for HIV within the past four-six months. Two were aged 25-34, two were aged 35-44 and one was aged 45-54. One was married and four were single. Two were sexual health nurses, one was a General Practitioner and two were HIV consultants. Two were educated to an undergraduate level and three were educated to postgraduate level. One reported taking PrEP and four reported not taking PrEP.

All eight non-health professionals interviewed reported being HIV negative gay men living in Wales. Two were aged 18-24, three were aged 25-34, two were aged 35-44 and one was aged 45-54. Two reported being BME and six

reported being white. Six reported being single and two reported being in a closed relationship. One was educated to A level, four were educated to undergraduate level and three were educated to postgraduate level. Five reported taking PrEP and three reported not taking PrEP. Five reported testing for HIV between 0-3 months, and three reported testing for HIV between 4-6 months.

Demographics of Q-sort Participants

Participants who completed stage three and informed stage four.

All 25 participants reported being HIV negative gay men living in Wales. Ten were aged 18-24, six were aged 25-34, six were aged 34-44, one was aged 45-54, one was aged 55-65 and one was 65+. Twenty-one were single, one was in a closed relationship and two were in an open relationship. Seven were educated to A level, ten to undergraduate level and eight to postgraduate level. Twelve reported not taking PrEP and 13 reported taking PrEP. Fifteen reported testing for HIV every 0-3 months, six every 4-6 months, two every 7-9 months and two every 10-12 months.

Procedure

Stage One: Developing the Q-Concourse

Following Watts and Stenner's (2012) guidance, the initial Q-concourse was developed from a range of sources, which explored HIV testing. This included: grey literature, policy documents, public health advice, art, websites and academic literature. Concourse informants including five health professionals and eight gay men were also interviewed on their experience of HIV testing in Wales.

Interviews took place with the lead researcher at a convenient location for the interviewees. All participants were given an information sheet and written consent was received prior to the study. Participants were debriefed after the interviews and a semi-structured interview schedule was used to guide the interview. Interviews were audio recorded and transcribed. All data was anonymised during the transcription process. No further interviews were undertaken after completion of the interviews; the research team agreed that theoretical sufficiency had been met, due to no new content emerging.

Stage Two: Developing a Q-set

The Q-set was then developed from the concourse. The concourse consisted of 826 statements and was reduced to create a Q-set of 70, as advised by Watts and Stenner (2005) (see Appendix 1 for list of statements). This was done by the researchers [RH & DJH] reviewing statements for repetition, duplication, relevance, accuracy and content of statements that reflected HIV testing. The concourse was then reviewed by six of the initial concourse informants (three health professionals and three gay men) to ensure validity. As advised by Perz et al. (2013), if two or more members of the initial interviewees agreed on a statement being relevant to the topic, it was then included in the Q-set.

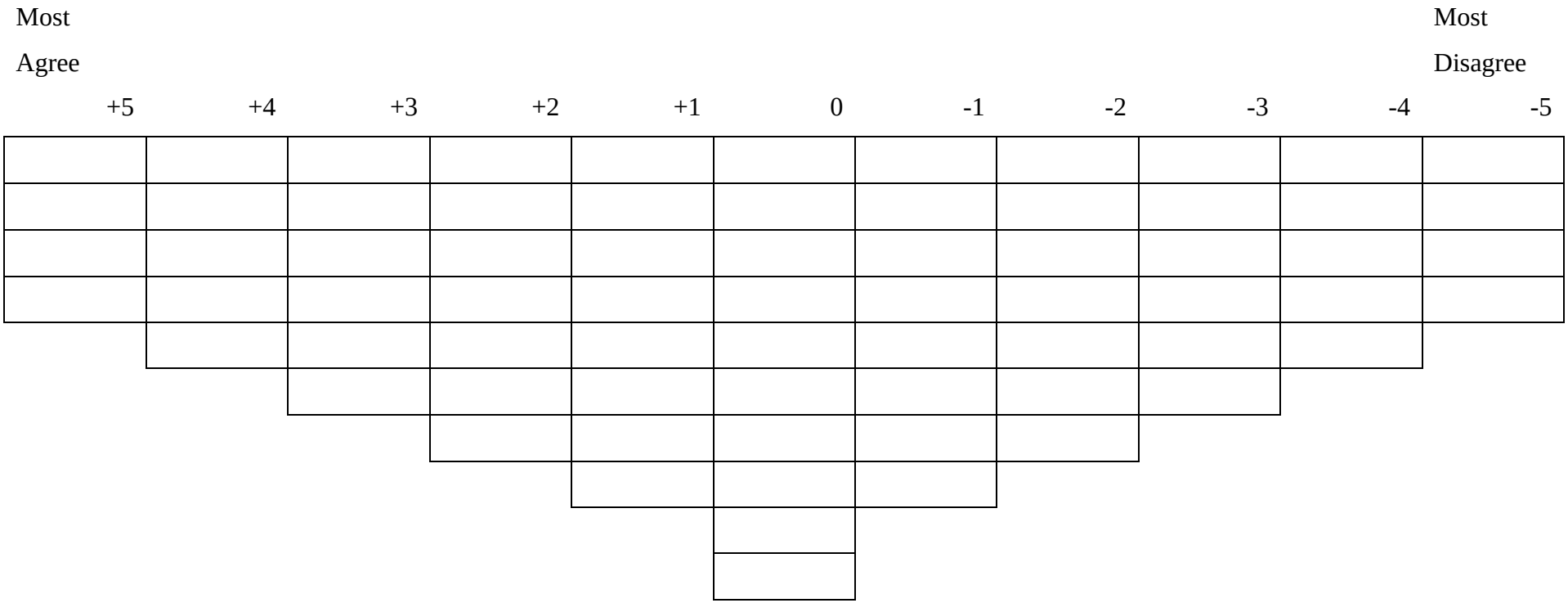
Stage Three: Q-sort

It is ideal to recruit one participant per three statements within the Q-sort (Watts & Stenner 2012). Therefore, a minimum of 23 participants should be included in the Q-sort. Q-sort participants were invited to take part in an online Q-sort and asked to sort the Q-set statements according to the following instructions:

“Testing for HIV in Wales makes me think …”. To aid the sort participants are required first to sort the cards into three piles (i.e. agree, disagree or neutral) (Watts & Stenner, 2005). Participants were then invited to sort the statements into ranked positions on an online Q board. This was made up of an 11-point scale reflecting a fixed quasi-normal distribution curve (see Figure 1).

Figure 1. A Fixed Quasi-Normal Distribution Curve

Testing for HIV in Wales makes me think …



Possible ranking values ranged from +5 for statements that were considered by the participant to be ‘most agreeable’, through to zero for neutral statements, to -5 for statements that were considered ‘most disagreeable’ (Watts & Stenner, 2005). Once all items were ranked on the board, participants were given a chance to make any changes. To ensure their responses reflected their subjective opinion accurately, post Q-sort, participants were asked to write their reasons for ranking their four highest and lowest cards, along with any other information (Watts & Stenner, 2005).

Stage Four: Q-Sort Analysis

The 25 completed Q-sorts were analysed in PQ Method 2.33 (Schmolck & Atkinson, 2002). PQMethod inverts conventional factor analysis techniques by representing participants in columns and the items represented in rows. This makes the participant the variable, rather than the item. A correlation matrix is produced, which correlates each participant’s Q-sort with the other participants’ Q-sorts in the study. It highlights how similar or dissimilar one participant’s Q-sort is from another. The data was then subjected to principal components analysis with varimax rotation. This provided the extracted factors for interpretation alongside the ‘exemplar’ participants’ qualitative feedback on the items placed at the ends of the quasi-normal distribution grid. ‘Exemplar’ participants are those who loaded most strongly on to a given factor. The principal components analysis initially produced an eight-factor solution, with only four having an eigenvalue > 1 leading to a four-factor solution. However, four participants did not load onto the four-factor solutions (Watts & Stenner, 2012). This was reduced down to two at a three-factor solution with more participants represented at a three-factor solution. The data was analysed using a three-factor solution with varimax rotation.

Interpretation

Q method analysis resulted in a three-factor solution accounting for 59% of the variance. The factor matrix (Table 1) shows: participant loadings, factor exemplars, eigenvalues and the percentage variance explained for each factor. Two participants (21 and 24) had mixed loadings meaning that they had very similar scores across all factors.

Table 1: Exemplar Factors

Participant Number	Factor 1	Factor 2	Factor 3
1	-0.1310	**0.5338X**	0.4646
2	**0.7501X**	0.0492	0.1040
3	**0.6918X**	0.2025	0.0061
4	0.2182	0.2995	**0.4677X**
5	**0.6746X**	-0.0128	0.3135
6	**0.6978X**	-0.1715	-0.0499
7	0.1511	**0.7807X**	0.0578
8	**0.5732X**	0.1370	0.4214
9	-0.0137	0.3412	**0.5974X**
10	**0.5362X**	0.4232	-0.0999
11	**0.5960X**	0.0245	0.5943
12	0.0707	0.1073	**0.7436X**
13	0.0949	-0.0041	**0.8644X**
14	0.2658	**0.4457X**	0.1372
15	-0.1322	**0.7495X**	0.0659
16	**0.7114X**	0.1916	0.4727
17	0.2044	**0.8337X**	0.0937
18	**0.6445X**	0.1014	0.4462
19	0.4581	0.1239	**0.6058X**
20	0.5406	0.1017	**0.6241X**
21	0.5109	0.3998	0.4281
22	0.2925	-0.0469	**0.6564X**
23	**0.6880X**	0.1948	0.3537
24	0.5940	0.1840	0.6115
25	**0.6598X**	0.1836	0.5429
Eigen value	6.25	3.25	5.25
Percentage Variance Explained	25	13	21

Note: Factor exemplars are in bold and marked with an **X**.

Factor One: Testing, PrEP and Shame/Stigma

Eleven participants exemplified factor one (100% reported taking PrEP, 100 % report testing every 0-3 months). This factor places importance on the proactive role PrEP can play in allowing individuals to test for HIV and maintain a negative HIV status. However, at the same time, the factor acknowledges that testing and taking PrEP can be a stigmatising and shaming experience. This factor also distinctively rejects being unconfident and uncertain around HIV testing.

In factor one there was a distinctive agreement with statement 69 (+5) "*I take PrEP so I have long-term certainty when I test*", alongside exemplar participant statements such as "*the long-term certainty means I can manage the uncertainty about testing for HIV and the risks of getting HIV in a proactive way*" (P3). Similarly to other exemplar factors, participants in this factor implied that PrEP provides a sense of certainty around HIV status, which would not otherwise be possible. This allows them to engage proactively with the HIV testing and prevention processes.

An alternative reason why exemplar participants in factor one test frequently is shown with the distinctive agreement with statement 70 (+5) "I *have to test regularly to get access to PrEP*". Additionally, an exemplar participant's comment highlights that testing for HIV, for some, is part of an exchange that the individual undertakes with health services to get access to a sustained HIV negative status: "*Without being forced to test by the NHS to get access to PrEP I would not do it. PrEP gives me the confidence to know that when I have sex*

I will remain negative. If I did not have this incentive to test regularly I wouldn't." (P2). This may also explain why there is agreement with statement 1 (+5) "*regular testing is part of my normal routine*". This is in contrast to the pro-social viewpoint put forward in factor three.

The other distinguishing statements in factor one that participants agreed with are: 13 (4+) "*Society will reject me if I don't test*", and 12 (4+) "*Stigma prevents me from testing*". These were positioned alongside the non-distinguishing features of statement 16 (+5) and 17 (+ 4), suggesting there is a level of shame associated with testing. "*I think lots of gay men find it shaming. I think HIV is still a taboo for gay men so doing something that can confirm that is shaming. I also think people get slut-shamed when they find out you go to the clinic for tests or PrEP. I think also the process of testing for HIV is a bit shaming*." (P 16). PrEP and testing are seen as protective strategies for the individual. However, what this communicates to others also creates a perception that peers and society will stigmatise/shame the individual for engaging with protective strategies. Finally, there was distinctive agreement statement 60 (+4) "*When I test I feel like a robot and don't connect with myself*." This factor may indicate that there are strategies which individuals engage with to overcome negative aspects they associate with testing and PrEP.

Statement 32 (-5) "*It's better to be uncertain than test positive*" is a distinguishing statement of disagreement in this factor. P8 builds on this noting, "*I remember when this used to be an idea but now I would say with PrEP and treatments for HIV this is not the case*." This is placed alongside statements 46 (-5) and 59 (-5) inferring that historical ideas and perception of HIV testing do not relate to people within this factor. This is a perception which is supported by exemplar participant comment "*HIV is treatable so I would rather test and*

know what I am facing than die. I think if you were living in the '80s you may have seen this differently." (P3).

The agreement with statement 11 (+4) "*The benefits of a negative result drives me to test*" suggests there is also a perceived benefit in accessing a negative HIV status, which acts as a motivating factor for this group to test. Exemplar participants highlight that the benefits are: increased social status and access to sexual partners. P5 "*I find having a negative status increases my social status*", and P25 "*A negative test result means I can have more sexual partners.*"

A distinguishing statement rejected by participants in this factor was 41(-4) "*I don't feel confident enough to test*", which fits with statement 69 (+5) above, that certainty, confidence and knowledge over their HIV status allows individuals to test, which is in contrast to this statement. Looking at statement 1 (+5), alongside the distinguishing statement 45 (-4) "*It's not clear what will happen when I test*" participants are clear on what the testing process will involve, due to it being a regular routine.

Factor Two: The psychological distress of testing and the search for certainty

Five participants exemplified factor two accounting for 13% variance (100% were not taking PrEP, 40% reported testing every 4-6 months, 20% reported testing every 0-3 months, 20% reported testing every 9-12 months and 20% reported testing every 6-9 months). This factor conceptualises the psychological impact of testing for HIV and the role certainty or uncertainty plays for individuals in the process of testing for HIV.

In factor two, the distinguishing item 64 (+5) "*Testing for HIV causes me distress*", notes that testing is a distressing experience for individuals. Further distinguishing items in this factor highlight how emotions may lead to participants acting in certain ways. For example, 68 (+4) "*I try to keep my feelings about testing to myself*", highlights how participants in the group see emotions associated with testing as private. In the case of emotions such as anxiety and uncertainty, agreement with the following statements: 50 (+5) "*The anxiety of testing puts me off regular testing*", 65 (+5) "*Uncertainty gets me to test*", illustrate how testing may motivate or prevent individuals from testing.

Notably disagreement with 63 (-4) "*I'm mentally resilient enough to test*" implies that testing is a distressing experience for the individual. It also denotes they do not view themselves as having the psychological resilience to engage with the testing process. This may explain why, in contrast to factors 1 and 3, statement 1 (-4), "*Regular testing is part of my normal routine*", is distinctively rejected.

A further distinguishing statement is 39 (+5) "*The testing process is intrusive*", which alongside exemplar P17's comments on statement 39, "*I don't like having to answer all the questions about sex. I find it embarrassing. I am okay with being gay but having to tell others about all the sex can make you feel dirty*", highlights that whilst he may be comfortable with his sexuality, the process of testing and talking about sex can create a sense of embarrassment and perception of the self as being "*dirty*". The statement 48 (+5) "*I just block testing out of my mind*" indicates a level of cognitive avoidance around testing. This is supported by P5's comment that "*Once it's done, I try to forget about it*". However, testing in this factor also has a shared perception of being a shaming experience with statement 16 (+4) being placed in a similar position as was found in factor one.

Statement 7 (+4) "*You are only as certain as your last test*" had similar agreement to factor three. However, when positioned with these statements 65 (+5) and 59 (-4) "*I like the thrill of having sex and not knowing my status*", demonstrates it is uncomfortable for participants to be in a position of uncertainty regarding their HIV status. When certainty regarding their HIV status is absent, they test, as reported by exemplar P 22 "I *test only when I become uncertain about my HIV status*." Furthermore, the rejection of statement 46 (-5) "*I don't test because the test won't pick up on my HIV*" and statement 33 (-4) "*I can predict if I have HIV*", shows participants are aware that it is not possible to tell if they have contracted HIV and believe that testing for HIV can do this.

There is the same positioning of statement 47 (-5) "*There is no point in testing for HIV because there is no cure*", in factors two and three. However, along with exemplar P4's comment "*You test to keep well*", it shows participants are able to see the benefit of testing with regard to their health. In factor two, statement 21 (-4) "*Testing is the cost of being a gay man*", is distinctively rejected. When this placement was reported on by exemplar P17, he stated, "*I think everyone has to test, not just gay men*". This implies that in this factor testing is not seen as important for gay men but for all.

Factor Three: HIV testing a prosocial act and self-learning

Seven participants exemplified factor three accounting for 21% variance (43% were taking PrEP, 57% were not taking PrEP, 50% reported testing every 4-6 months and 50% reported testing every 0-3 months). This factor highlights how HIV testing may be

conceptualised as primarily a prosocial act. However, it also notes the lived exposure to possibly becoming HIV positive or knowing people with HIV, act as motivators to test.

Participants distinctively agreed with statements: 6 (+5) "*I test because I am responsible for my own health*", 5 (+5) "*Testing benefits others*", 63 (+5) "*I'm mentally resilient enough to test*", 43 (+5) "*I'm proactive in testing and know the issues around testing*" and 9 (+ 4) "*If more people had an HIV test there would be fewer HIV infections*", along with statements (1,+5) suggest that people associated with this factor see themselves as routinely testing for HIV and being proactively engaged in HIV prevention. They may perceive HIV testing as a prosocial act that they are psychologically resilient enough to undertake, in order to protect themselves and others from HIV.

This idea is further supported by participants distinctively rejecting statements: 55 (-4) "*I only need to test if I've been at risk of HIV*", 35 (-4) "*Fear of a positive result puts me off testing*" and 30 (-4) "*My life won't be the same after testing*". P13 adds "*Everyone has a duty to test regardless*". This further demonstrates the prosocial aspects of testing. However, in relation to statement 30 (-4), P20 adds "*Nothing will change when I test now I'm on PrEP I know I will remain neg*", implying that for those using PrEP in this factor there is perceived knowledge that their life will remain the same after testing. 55 (-4), this position may suggest that the sense of personal responsibility influences some to test. The most rejected statements in factor 3 are: 3 (+5), 51(+5), 47 (+5) and 31 (+5). This is in keeping with the perception that individuals in this factor see value in testing for HIV.

Whilst factor three shows that gay men report testing for HIV as a prosocial act, it also notes that a level of self-knowledge associated with HIV testing is a distinguishing feature. This is seen by agreement with the distinctive factor 8 (+4) "*Past life experiences get*

me to test". P19 and P13 expand on this in the quotes below explaining how both have lived experience of exposure to HIV and interacting with people who live with HIV increases their motivation to test. "*I have had HIV scares in the past and since then I make sure I test often*" (P19), "*Having friends who are HIV+ has made me more aware of the topic and has driven me to be more proactive in my testing*" (P13).

Consensus Statements

The Q-analysis noted three statements had significantly similar ranked positions across the factors. 51 (-5), 52 (-4, -5, -4) and 37 (+4). This is indicative of commonly shared opinions (Watts and Stenner, 2012). All participants strongly rejected the statement 51 (+5) "*I'm better off dead than testing for HIV*". They also strongly rejected statement 52 (-4, -5, -4) "*If you think you are positive, then you'll act to get HIV*". This could be taken as indicating that participants do not actively seek an HIV infection before testing and that they value knowing their status rather than avoiding it. This is in contrast to historical views reported about testing (Kelly et al., 1998; Gauthier et al., 1999). Statement 37 (+4) "*When you have decided to test its easy, you just want it all done there and then*", may show how across all the factors, once the decision has been made to test there is a preference for a swift process.

Discussion

This study set out to explore the viewpoints of gay men deciding to test for HIV in Wales. Research to date had not considered how access to PrEP could affect gay men's viewpoints regarding testing for HIV in Wales. The Q-analysis identified a three-factor solution, revealing three distinct viewpoints. The first viewpoint placed emphasis on PrEP as

a motivator for sustaining an HIV negative status and this was done in exchange for regularly testing for HIV with the health service. For this group, there was a perception of judgement and/or stigma from others regarding testing. The second viewpoint emphasised the psychological distress that testing for HIV represents for some, and that uncertainty plays an important role in the decision to test or not. Finally, factor three noted HIV testing may be seen as a prosocial act toward the self and others and that lived experience supports this.

The findings support the idea that there is a plethora of viewpoints regarding HIV testing (Siegel et al., 1989; Flowers et al., 2013; Myers, 1993; Lui et al., 2017; Lupton et al., 1995). Factor two, places significant emphasis on psychological distress testing for HIV and was only loaded onto by non-PrEP users. This is in line with previous reviews by Lui et al. (2018) and Lorenc et al. (2011). However, there is also a group of participants who load onto factor three, who do not report the associated distress or uncertainty of testing and are not accessing PrEP. In this group, testing seems to be constructed as a normalised pro-social act.

This study adds to the literature addressing a gap that was identified by Lui et al. (2018) that little is known about the impacts of PrEP on HIV testing. This study notes that in factor one, made up of solely PrEP users, engagement with HIV testing on a regular basis is done to sustain access to PrEP. Moreover, PrEP gives them the ability to manage uncertainty in the long-term regarding their HIV status. This allows them to engage with on-going testing. This factor also reports a perceived level of stigma associated with testing from others alongside shame. It is also notable that the other factor, which PrEP users loaded onto is factor three, which conceptualises HIV testing as a pro-social act, and concepts such as stigma and shame had neutral positions.

All factors had consensus on what they disagreed with, as highlighted in the findings above. This may infer a wider cultural shift in perspective around HIV testing. Since the context of HIV has become more biomedical with the condition being treatable, the perspective around what it means to test and the extent to which an individual avoids testing, has altered (Flowers et al., 2013). However, as factors one and two note, there are still psychosocial issues associated with testing.

Furthermore, factor three highlights that there are a group of people for whom testing for HIV is no longer conceptualised as a distressing experience. Instead, it is seen as a routine and prosocial act (Young et al., 2016). Some gay men in the UK still do not test for HIV or access a late HIV diagnosis (Furegato et al., 2018). Therefore, it is important to understand how gay men who reported a positive testing experience can engage with the process successfully (Lewthwaite & Melhuish, 2018).

Strengths and Limitations of the Research Method

An alternative methodological approach could have been to use a qualitative method to explore this area. Given the lead researcher identified as a gay man and the participants were recruited through snowballing, this would have required the use of reflexive practices used to mitigate for biases which may occur within the research process. However, Finlay & Gough (2008) note that no qualitative study even when reflexive practices are used can truly be free of the researcher epistemology and bias. Smith et al. (1995) and Watts and Stenner (2005) note that Q can be used as an alternative way to explore the subjective, which can uncover diverse viewpoints. As discussed above, the epistemology of Q mitigates for bias because of its: scientific approach to the subjective; use of statistical analysis and giving power over to the

participants rather than the researcher. In addition, Q allows for a reflection of diverse viewpoints that remain close to the data, which can be hard to obtain when using more typical social science-based methodologies (Watts & Stenner, 2012).

The Q method is a recommended approach to explore attitudes and subjective opinions on a range of topics (Corr, 2001; Watts & Stenner, 2005). Q's advantages stem from its inherently robust mixed methods (Ramlo & Newman, 2011). Yet, there are also concerns, for example: Daniel (2000) suggests that the selection of statements for the sort can be influenced by the researcher and limit the participant's sort. This view is supported by Robbins & Krueger (2000), who note that the researcher's own viewpoint may influence the development of the concourse and Q-sort. A further criticism is that participants often object to being forced to choose between statements and having to categorise every statement, particularly when individuals hold ambiguous opinions on a topic (Simons, 2013). The study attempted to limit the impact of these criticisms by the utilisation of external reviewers in the development of the Q-sort. Furthermore, participants were invited to provide feedback on any aspects they thought were missing. The comments provided brought lucidity and depth to the analysis in the interpretation stage.

Q can create the possibility for participant bias because the participants may respond in a way that is seen a socially desirable rather than reporting their true subjective view (Jackson-Blott et al., 2019). In the context of HIV testing, participants are known not to report viewpoints that do not conform with conventional norms (Ford et al., 2013). Furthermore, confidentiality and privacy around HIV testing are seen as key to ensuring test engagement (Fehrs et al., 1988). In order to try to mitigate for this, the Q study was completed online with the researchers having no identifiable information regarding

participants. Concerns have been raised about the validity of completing Q-sorts online (Jeffares & Dickinson, 2016). However, Q-sorts online are deemed valid and reliable (Davis & Michelle, 2011).

A strength of Q is in its application of quantitative methods to identify factors (Dune et al., 2018). Cross (2004) notes that this aspect of Q minimises interpretation bias on the part of the researcher which can be found in other methods which explore the subjective. In addition to this, Q sorting gives participants meaningful control in determining what is and is not important to them regarding the explored phenomena (McHugh et al., 2019). This means that new configurations of viewpoints may be uncovered, which are not traditionally possible in other methods such as thematic analysis (McKenzie et al., 2011). This is a notable advantage in this study as Lui et al. (2017) note a large amount of research has been done in a thematic tradition. Alongside this strength, Q method allows individual responses to be gathered and correlated, so that the extracted factor provides an 'idealised' form of discourse latent within the data provided by the individuals involved in the study (Barry & Proops, 1999). This means that implicit discourse associated with the various factors can be made explicit. It also means that no one viewpoint of a participant is privileged over another.

The generalisability of the findings may be limited due to the sample size and demographics of the population studied. However, the study's aim to recruit participants only from Wales and address the contextual issues surrounding this group should be acknowledged. Consideration as to how the findings relate to other contexts should be held with caution before they are applied. All the participants in the study identified as openly gay men. It is known that MSM who do not identify as gay and trans-men have different behaviours and cognitions regarding HIV testing (Young et al., 2016). Further research

would be needed to explore how the findings of this study apply to groups outside the population studied. Whilst the participants were asked to provide feedback on their sorts and their +5 and -5 scores, due to the online nature of the sorts, they were not interviewed after the sort. This means it is difficult to fully know the relational and gestalt components of the sort (Watts & Stenner, 2012). Thus, the interpretations of the findings are limited and hypothetical.

Further consideration should be given to the concourse informants who were identified through a snowballing methodology of the lead researcher's links with the LGBT community in Wales. A high amount of LGBT research is carried out by non-LGBT researchers. This creates a heteronormative bias within the research carried out and, in turn, creates a bias in policy and service provision for LGBT people (Meezan & Martin, 2012; Enson, 2015). Within Q-method, steps can be taken to mitigate this bias such as the researcher identifying as being a member of the community explored and Q-sort informants being from the community explored (Boros et al., 2007). In the context of this study, the lead researcher identified as a gay man and the recruitment of MSM individuals was used to inform the concourse and Q-sort statement development.

Furthermore, Q states that concourse informants should be representative of the community to which the phenomenon relates (Watts & Stenner, 2012). In acknowledgement of this, all concourse informants identified as gay men. This may lead to a homonormative bias within the research findings. It could be argued that this bias privileges the LGBT community over expert perspectives. Steps were taken to mitigate this bias by the inclusion of statements related to HIV testing from the existing literature alongside the concourse informant's statements (Watts & Stenner 2012). If further Q-sorts were to be developed in

this area, research may benefit from interviewing a wider range of individuals within this topic area, such as sexual health policy makers and adherence specialists. However, the impact of this on biasing the findings and concourse toward an expert or heteronormative informed concourse and Q-sort should be considered.

Furthermore, when Q-sort participants complete the Q-sort they are not told where each individual statement comes from. This is done in order to minimise the impact that any one statement would have on the Q-sort as a whole. Stephenson (1953) also notes that the statistical nature of the interpretation which assess each Q-sort's intercorrelates with another also reduces the bias that may be imposed by the initial concourse informants on the findings.

Clinical, Policy and Service Implications

The study is consistent with other studies into HIV testing amongst gay men in the UK, which report that there is no one homogenous group as identified in this study. Factors two and three are also consistent with recent descriptions of gay men testing for HIV in the UK (McAloney-Kocaman et al., 2016).

The findings have implications for HIV testing, that are important for clinicians and public health professionals working in the area, and to engage and support gay men when they come forward to test. For instance, gay men consistently agreed that testing is important, and for most, testing was preferable to being uncertain of their HIV status or acting in ways to access a positive result. Public health strategies have focused on recommending the frequency of HIV testing and the need for increased access to HIV tests for gay men (British

HIV Association, 2008). This finding supports the argument for promoting the psychosocial benefits of testing, alongside the biomedical as highlighted by DeWit & Adam (2008).

The study found that similarly to previous research, for some gay men, despite the normalisation of HIV testing, there are still significant psychosocial issues surrounding testing (Lui et al., 2018). Primarily in factor two, this was expressed as distress/uncertainty regarding testing, as recommended strategies, such as pre-test counselling are shown to be effective at supporting gay men when they come forward to test. However, with significant steps having been taken to normalise the testing process intensive pre-test counselling may hinder this initiative (Anand et al., 2015). Recently, Chippindale & French (2018) state that when HIV test counselling is used it needs to proactively acknowledge and support gay men with psychosocial issues surrounding testing. It has been highlighted that there are novel methods which may prove useful in engaging and supporting gay men in the testing process outside traditional pre-test counselling models through the effective utilisation of online technologies as noted by Anand et al. (2015). This could allow clinicians to provide targeted support to individuals who need it, rather than taking a whole cohort approach, meaning that the normalisation of testing can be sustained. Brief coping interventions, such as those used for individuals waiting for fertility results, may apply to this cohort (Lancastle & Boivin, 2008).

Lui et al. (2018) reported that PrEP might shift the viewpoint of some gay men who test for HIV. The study found that for some, taking PrEP creates a new viewpoint in testing as outlined above. For health professionals and policy, it is important to note how PrEP increases testing. However, the testing process for these individuals was conceptualised as both a positive thing but also a stigmatising and shaming activity. This may align to Golub

(2018) and van Wijngaarden et al.'s (2018) views that policy in this area constructs the individual as sexually risky. However, this study notes there is possible utility in promoting the positives associated with taking PrEP such as sustaining certainty of an HIV negative status and pro-social acts, to engage others with the testing process and reduce the experience of shame as reported in factors one and two. Furthermore, Hutchinson & Dhairyawan (2018) add that addressing shame related to HIV testing through public health may aid HIV prevention work. However, strategies to address this have yet to be robustly developed.

The implications for factor three are two-fold: firstly, HIV testing for some gay men has become normalised and secondly, some feel able to engage with the testing process. This may be reflective of current HIV policy in the UK which aims to normalise testing (Clifton et al., 2016). Additionally, factor three views HIV testing as a prosocial act. Mahajan et al. (2008) note that when HIV testing is perceived as a prosocial act the level of psychological distress and stigma experienced by the individual is reduced. Further research may be advantageous in exploring how both PrEP using and non-PrEP using participants in factor three make this distinction. Once this is done, it may be possible to develop an intervention to support individuals who experience distress/shame/stigma in the testing process.

The findings of this study are limited for the following reasons. Q seeks out "those who have something to say on a given topic". This means that it does not access the viewpoints of all people represented within the community explored (Watts and Stenner, 2012). This means that the findings of Q are biased towards the views of the participants that take part in the study rather than those of a wider general population. Q is an iterative approach which uses small samples to collate and describe viewpoints of a given phenomenon. Therefore, the findings should be explored further using alternative methods

before any generalisation is made to a wider population. However, what Q has provided is a robust description of the gestalt of HIV testing for gay men in Wales. Whilst, it does not penetrate one specific viewpoint to its full depth, it provides researchers with an area from which to explore. The findings are also from a self-selecting snowballed sample. It may be that more naturalistic samples may view the topic explored differently. A further limit of the findings is that all those sampled were reported as being engaged in testing for HIV. It may be that those who do not test for HIV view testing differently.

Finally, it should be noted that the study is cross sectional in design. Therefore, the study's findings are limited to providing a description of HIV testing for gay men in the Welsh context at a specific moment in time. This study alone is not enough to infer a suggestion that PrEP has shifted the experience of HIV testing in Wales for MSM. In order to explore if this is the case, it is recommended that as PrEP becomes more established, longitudinal studies are undertaken to see if a shift in the subjective viewpoints on HIV testing Wales has occurred.

Conclusion

Gay men's views regarding testing for HIV have both commonality and variance. It is important to consider this when developing interventions, services and policy to engage gay men in testing for HIV. This understanding may inform health professionals in terms of how HIV testing may impact on individuals who come forward to test for HIV. It also shows that, for some, HIV testing is a normal prosocial act and viewed positively. However, in order to support people with the testing process, psychosocial factors alongside the biomedical factors need to be considered and addressed.

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Paper Three: A Critical and reflective account

Total word count: 5724

(excluding tables, figures, references and appendices)

Introduction

This paper is a critical and reflective account of the two papers provided. It will consider the rationale for exploring HIV testing in gay men in Wales and associated PrEP-stigma. It evaluates the empirical study and systematic review process. The paper will consider: the research process; plans for dissemination; strengths and weaknesses of the papers; specific implications for theory; clinical practice and policy and further research.

Decision to Explore the Research Area

Research projects were presented to trainees at a research fair. I selected a topic with a supervisor who allowed for the creation of a project within their scope of knowledge. The ability to undertake novel research autonomously is a core part of clinical psychology training (BPS, 2019).

Before clinical training, I worked therapeutically in physical health settings. I noticed how testing for a physical health condition evoked distress in individuals. In my MSc, I developed an interest in gay men's health, undertaking a research project in the area. At the research fair, a researcher advertised a project to consider the psychological processes involved in deciding to test for a health condition.

When I came to Wales, Pre-Exposure Prophylaxis (PrEP) had recently been introduced, as an additional form of HIV prevention for Men who have Sex with Men (MSM) who meet criteria (Fina et al., 2018). I discussed the possibility of looking at the

impact this introduction would have on MSM in Wales with regard to testing for HIV. My supervisor agreed that because of the potential impact PrEP could have on the psychosocial processes involved in HIV testing for MSM, further exploration would be warranted.

Paper One: Systematic Review

An initial scoping exercise of the literature was conducted. The initial plan was to review uncertainty regarding HIV testing in MSM. Whilst conducting initial searches, an updated review assessed studies on the psychosocial barriers to testing for HIV in MSM. This included the role of uncertainty in HIV testing (Lui et al., 2018). The possibility of assessing quantitative studies was then considered; however, this review had also been undertaken (Deblonde et al., 2010; Evangeli 2016). The researcher returned to the Welsh context and considered what factors might be pertinent from this perspective. As noted earlier, PrEP had recently been introduced to Wales. The literature on PrEP was explored. Several reviews were identified that assessed PrEP either on adherence interventions, or the perspectives of those contemplating taking PrEP (Hannaford et al., 2018; Sidebottom et al., 2018; Marcus, et al., 2014; Yi et al., 2017). However, no specific review considered what it means for individuals taking it exclusively. Two broad literature reviews considered the experience of stigma in taking PrEP across all populations (Golub, 2018; Haire, 2015). However, neither of these used a systematic approach or looked at an exclusively MSM population. It is known that systematic review findings often differ from literature reviews and therefore a systematic review would be warranted (Mulrow, 1994).

In Wales PrEP is targeted specifically at MSM considered to be at risk of contracting HIV (Fina et al., 2018). It is important to consider the target cohort for intervention to be effective (Ogden, 2012). For the project to be applied to the Welsh context, the review needed to focus on MSM only. This also allowed for the study to be different from past reviews which focused on PrEP-stigma in general populations.

Aim of the Review

The review aimed to systematically review the qualitative literature on the experience of PrEP-stigma for those taking PrEP through aggregative description of the phenomena.

Search Strategy

University librarian services and supervisors ensured the search terms were comprehensive enough to identify all the relevant articles related to the review. To allow for broad coverage, search terms were entered into three key databases: one related to health (Medline); one related to social science (Psychinfo) and one multidisciplinary (Web of Science). PrEP-stigma is a recent phenomenon (Golub, 2018; Haire, 2015). The initial database search yielded only 45 studies. However, when stigma and PrEP-stigma were excluded as search terms and a manual search was conducted 342 articles were identified. This highlighted the importance of ensuring search terms are sensitive enough to pick up the relevant studies whilst not limiting the number of studies identified. Excel was used to record, manage and screen articles. Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) was used to ensure the search process was transparent (Boland et al., 2017). PRISMA is not a quality assessment instrument to gauge the quality of a systematic review, but rather a way of showing process (Stovold et al., 2014). A manual search of reference lists was undertaken to identify additional studies.

For studies to be included in the review, they needed to report on the experience of stigma in relation to PrEP, be purely qualitative and only include MSM taking PrEP. Studies which did not meet this criterion were excluded. As noted in paper one, men who identified as trans-men were excluded from the review.

Grey literature and journals not in English were excluded creating a bias towards peer-reviewed journals written in English.

Quality Assessment

The search yielded eight studies with diverse groups of MSM and research designs. The Critical Appraisal Skills Programme (CASP) developed for qualitative methods has good reliability and validity for assessing such studies. The lead researcher watched Sheffield University's (2013) guide to using the CASP and proceeded to assess the articles accordingly. The CASP highlighted that reflexivity was often not reported in the studies. This is a common finding in qualitative research and is linked to tight word limits in many journals (Newton et al., 2012). To mitigate bias when assessing the papers, an independent reviewer reviewed a random selection of two papers in order to ensure that the rating was appropriate. The reviewer found similar findings to the researcher, and it was agreed that there was consensus between the ratings. NICE (2012) recommends that a minimum of ten percent of all papers identified are randomly reviewed in this way.

The CASP showed that a majority of studies were of high quality. The integrity of the review is fundamentally reliant on the quality of the included studies. However, it is noted that in qualitative reviews, no study is excluded for poor methodology when using aggregative approaches (Boland et al., 2017). However, it is important to be aware that the

limitation of the studies should be considered if further research is to be improved (Thomas & Harden, 2008).

Data Synthesis

When undertaking the data synthesis, it is important to consider the expertise of the research team alongside the research aim (Boland et al., 2017). The aim was to systematically review qualitative studies exploring PrEP related stigma in MSM. The review aimed to be aggregative, meaning that it looks for commonality across studies (Boland et al., 2017).

The method of synthesis was then selected. Boland et al. (2017) identify that the research needs to consider: the research question; the time available; expertise of the researcher and type of data being reviewed. Initially, it had been considered that a meta-ethnography of the data would be suitable. However, meta-ethnography requires supervision from an individual who has expertise in the method, and this was not available to the researcher (Boland et al., 2017; Morse, 2016).

Meta-ethnography is a dominating approach in qualitative systematic reviews (Boland et al., 2017). It is important to consider the functions of the selected method and not to defer to a dominant approach (Gough et al., 2012). Additional methods such as framework synthesis and narrative textual analysis were considered. |However, these were considered inappropriate given that the reviews focused on aggregative description (Barnett-Page & Thomas, 2009). Additionally, the review studies were not homogenous enough for such approaches. It was therefore agreed to undertake a narrative synthesis of the studies which takes into account heterogeneity (Popay et al., 2006).

Freeman (1984) defined the process of narrative work as “ordering landscape”. A narrative approach can strengthen a review, both by adapting to the expansion in qualitative systematic review approaches and as a tool for consensus-building with current bodies of literature (Jones, 2004). One of the criticisms of narrative synthesis is that it is a generic term for a broad set of approaches to reviewing literature (Sandelowski & Barroso, 2006). However, this is a criticism that has been applied to many qualitative synthesis approaches (Barnett-Page & Thomas, 2009). Popay et al. (2006) have noted this issue and have outlined processes that can make the review more transparent.

One of the advantages of using narrative synthesis in this review is that it allows for studies which include different MSM populations and qualitative methods to be combined. This is because the unstructured nature of narrative synthesis allows for the research to be flexible when considering working across studies. The approach acknowledges that there will be heterogeneity when exploring the data (Popay et al., 2006).

The components of narrative synthesis which the review used were tabulation and thematic analysis. Tabulation is a common approach used in systematic reviews to represent data visually and adds transparency to the synthesis. It is useful for developing an initial synthesis of findings across studies and helps the researcher to begin to identify themes, which provide the foundation for later steps of the synthesis (Popay et al., 2014).

The second part of the synthesis was to use thematic analysis. It is a technique often used in the analysis of primary qualitative data. However, it can be used systematically to identify the main concepts across studies on lived experience. Thematic analysis allowed for the organising and summarising of the findings across the studies. The analysis was

conducted inductively. Thematic analysis allowed the researcher to directly reflect the main themes and conclusions that were present across the studies, rather than develop a new knowledge base (Popay et al., 2014).

There are caveats to using this thematic analysis at a systematic review level. It can be hard for readers to trace back the development of a theme (Popay et al., 2014). In this study, the reviewer read and re-read the findings and discussions of the studies. They then clustered the findings under a set of initial hypothesised themes that arose from the process. Direct quotations have not been used in the body of the review, in line with similar descriptive narrative-based systematic reviews (Wiles et al., 2008; Vallido et al., 2010; Schoeb & Bürge, 2012; Jacques-Aviñó et al., 2019; Lui et al., 2018; Barclay et al., 2011; Badrakalimuthu & Barclay, 2013). The researcher coded each article to ensure they were reflective of the themes. Tabulation was used to ensure that the themes were transparently reflected in the main body of the review (Popay et al., 2014).

Notably, the results of the review may appear different if a deductive or theory-driven approach is used in comparison with an inductive approach (Morse & Mitcham, 2002).
It is also known that the research can have an impact on the analysis and so reflexive practices were adopted to reduce this (Finlay & Gough, 2008). In order to mitigate bias and help to ensure validity of the analysis, the reviewer invited a peer to review the study for face validity and to assess if the findings reported could be traced back to the original articles. This was completed, and consensus was agreed.

Implications of the Findings

The review describes how PrEP-stigma is experienced across multiple levels. As HIV prevention methods become more diverse, the issues surrounding HIV prevention must go beyond the current biomedical approach adopted for understanding HIV prevention and its associated behaviours (Girard et al., 2019). The review highlights how, across studies, PrEP-stigma exists on multiple levels and as such needs to be addressed through a systemic approach which addresses the multi-level experiences of stigma at the: policy, service, community and individual levels. Therefore, theories and interventions which operate in this way, such as the biopsychosocial model of HIV, may be of value.

The findings are consistent with research in the policy surrounding PrEP, which highlights that although PrEP is an effective form of HIV prevention, in some settings PrEP's rollout has slowed due to policy framing PrEP as a drug for "risky" individuals. This has created a selective provision of PrEP across different groups of people (Amico & Bekker, 2019). The review highlights that the way in which PrEP is endorsed and marketed to MSM impacts on their perception of PrEP and the degree to which they will experience PrEP-stigma. In turn, this can have an impact on how MSM engage with PrEP as an intervention. As PrEP becomes established, HIV prevention policy needs to consider how issues, such as PrEP-stigma, can be addressed if long-term HIV prevention is to be successful for MSM (Amico & Bekker, 2019).

The studies on the impact of PrEP-stigma are taken further by the review findings through the provision of an aggregative description of the phenomenon. Unlike previous

reviews on PrEP-stigma, this review focused exclusively on a specific cohort: MSM taking PrEP who report PrEP-stigma. This has not been done in other reviews of PrEP-stigma or individuals taking PrEP. This review has similar findings to narrative reviews by Golub (2018) and Haire (2015). However, the strength of this review is its systematic search and analysis of the literature.

This review supports the assertion that rather than having a one level intervention for addressing PrEP-stigma, a multi-level approach is needed in order to address the multiple levels on which PrEP-stigma occurs (Girard et al., 2019). However, it should also be noted that the review found that in each layer, there were examples where PrEP-stigma was not present. It is important to understand how PrEP is conceptualised and what factors allow PrEP-stigma to be absent at each level (Liu et al., 2014; Grace et al., 2018). In doing this, it may allow for an effective intervention to be developed for MSM who experience PrEP-stigma.

Furthermore, the exact prevalence rate of those who experience PrEP-stigma has yet to be assessed. The level of impact it has on cohorts of MSM has yet to be fully calculated. Therefore, this should be assessed before developing an intervention to address PrEP-stigma in order to ensure any intervention is feasible.

Paper Two: Empirical Study

The research question was developed through considering the practicalities of conducting a research project in this area. The researcher was keen to ensure that the study had application to the Welsh context. On scoping the literature, limited research into how

testing for HIV was viewed from the perspective of Welsh gay men was identified. Notably, PrEP is currently accessible to MSM in Wales who meet criteria, unlike in other parts of the UK (Fina et al., 2018). Broader research has shown that PrEP has changed the field of HIV prevention in the UK (McCormack et al., 2016). In Wales, gay men are required to test for HIV in order to get access to PrEP (Public Health Wales, 2017). The researcher hypothesised that this might alter the role of uncertainty, motivators and barriers for gay men testing for HIV in Wales. However, no study had been undertaken in Wales. Therefore, this study aimed to explore the current viewpoints of MSM testing for HIV in Wales.

Rationale for Q Methodology and Ethical Approval

A qualitative approach was considered for exploring the research question. An exploration of the subjective experience of testing for HIV amongst gay men needed to be achieved. This would have required an interview-based approach followed by a deductive thematic analysis (Braun & Clarke, 2006). However, after being introduced to Q methodology through supervision and reading Stephenson (1953), Q was identified as a more appropriate approach. The reasoning behind this will now be discussed.

Q intends to systematically explore the individual's own subjective viewpoint in relation to others and is ideal for research questions which explore subjectivity (Brown, 1995). Q achieves this by systematically incorporating qualitative and quantitative approaches. Q is a method which allows researchers to explore complex and sensitive subject matter (Davis & Michelle, 2011). HIV testing is identified as a highly private and sensitive area of research. Q is well placed to explore this (Ringheim, 1995; Watts & Sternner, 2012). Q has been applied to the area of health research across many studies (Brown, 1996; Cross, 2004; Goto et al., 2008; Akhtar-Danesh, Baumann & Cordingley, 2008). It has been found to

yield results that are different from conventional approaches, which explore subjective viewpoints (Watts & Stenner, 2012).

Q was considered relevant to this study because it can uncover participants' own subjective perspectives, instead of measuring participants' understandings in relation to the researcher's pre-determined definitions (Kitzinger, 1999). Participants in HIV research often act in a socially desirable way (Van de Mortel, 2008; Ross, Tikkanen & Månsson, 2000). Q is argued to overcome this challenge by requiring the participants to sort across a range of viewpoints (Cross, 2004).

Once it was agreed that Q would be a suitable approach, an application was made to Cardiff University's Ethics Committee. Ethical approval was granted by the university (Appendix 3).

A concern about using Q was how it fitted with the researcher's own epistemological stance. However, a feature of Q is its adaptability to epistemological stances (Ramlo & Newman, 2011). Furthermore, due to the robust nature of the analysis, Q reduces bias from the researcher imposing an epistemological assumption on the data (Watts & Stenner, 2005).

Recruitment

Snowballing was used as the recruitment method and is utilised in LGBT research (Martin & Dean, 1993). Recruitment in this way is not considered random but is inclusive of the diversity of the LGBT community. Furthermore, snowballing is appropriate to use when the focus of the research is exploration and analysis, instead of testing of predetermined hypotheses (Biernacki & Waldorf, 1981). Snowballing has been used in previous Q studies and is also in keeping with Q's explorative line of enquiry (Stenner, Cooper & Skevington,

2003). Additionally, snowballing is a valid recruitment method where the area of exploration is sensitive, such as in HIV research (Streeton, Cooke & Campbell, 2004). However, the generalisability of the finding is limited because the sample is self-selecting (David, 2002).

Online recruitment methods are effective in MSM HIV research (Chiasson et al., 2006). It increases access for the majority of participants to engage in such studies. However, it limits the findings to populations who have access to online technologies (Riggle, Rostosky & Reedy, 2005). Notably, Q has been found to give sustained reliable findings when conducted online (Davis & Michelle, 2011).

Creating a Concourse and Q-Set

Q has predefined steps that the researcher undertakes. The first step is to create a concourse; this involves collecting a broad range of statements related to the area. Statements are then refined to a Q-set. Each statement in the Q-set represents a unique viewpoint in relation to the area explored (Stephenson, 1953).

The concourse is required to represent a wide range of subjective viewpoints in relation to the subject area. As recommended, the researcher undertook interviews with various key stakeholders alongside outcome measures, academic and non-academic literature in the area explored (Stephenson, 1986). It was notable that as the process of statement development developed, the emphasis on the role of uncertainty reduced. It is not uncommon for researchers undertaking Q studies to have such findings when developing the concourse. Rather than the researcher imposing their pre-imposed ideas on the concourse, it is argued they should broaden the area explored (Watts & Stenner, 2012). In trying to represent a broad range of statements on the subject area, the lead researcher became aware of their own

viewpoint and was keen to ensure this did not impact on the study. This was discussed in supervision and interviewees were involved in Q-set development (Watts & Stenner, 2012).

The Q-set imposes limits on how the participants can respond. Interviewees reviewed the preliminary Q-set for reliability and validity. This ensured a wide range of viewpoints were represented within the concourse, researcher bias was reduced and the included statements made sense (Watts & Stenner, 2005).

Q-Sort and Analysis

To ensure participants had as much anonymity as possible, the Q-sort was put online. This removes the requirement for participants to meet the researcher and reduces pressure for socially desirable responses (Joinson, 1999). However, participants are unable to engage in post-sort interviews to aid the researcher's analysis. To mitigate this, participants were asked to provide qualitative feedback on items they most agreed and disagreed with.

The data was analysed using PQMethod 2.33 (Schmolck & Atkinson, 2012). The research supervisor supported the analysis of the Q-sort data. A principal components analysis with a varimax rotation was completed. Initially, an eight-factor solution was yielded. However, six participants did not load onto any factor, and several eigenvalues were below one (Stephenson, 1953). Through Watts and Stenner's (2012) outlined process, consensus was reached on a three-factor solution with only two participants not loading onto any factor and all eigenvalues above one. This explained 59 % of the variance suggesting that there were three unique viewpoints. After this point, the analysis was written up alongside the Q-sort feedback. This allowed for coherence both between and within each distinctive factor to be achieved.

Implications of the Findings

The study yielded three distinct viewpoints regarding HIV testing for gay men in Wales. These were: *"Testing, PrEP and shame/stigma"*, *"the psychological distress of testing and the search for certainty*" and *"HIV Testing a prosocial act and self-learning"*. The findings are explorative in nature. They add to the current body of literature and have potential implications for policy and clinical practice.

Factor three is supportive of the premise that HIV testing has become partially normalised for gay men (Flower et al., 2013; Persson, 2013). One aspect that sets this group apart is either that they had exposure to those living currently with HIV or had experience of being exposed to HIV. The impact of this was not fully explored in this study, nor were the specific factors that created the ability to view HIV testing as a prosocial act. Further exploration of this group may allow for interventions to be developed to help those who either do not test for HIV, or find HIV testing to be distressing.

Factor two is consistent with findings that HIV testing can be a distressing experience for gay men (Smit et al., 2012; Jacobsen et al., 1990; Miller & Green, 2002). This also fits with models related to HIV testing, such as the health belief model (Rosenstock et al., 1994). Distress can prompt individuals to test and therefore is beneficial from a public health perspective (Hilliard et al., 2018). However, the impact on the individual is not fully considered. Before developing interventions to support this group, consideration needs to be given to avoid pathologising the HIV testing process for wider groups of individuals (Meunier & Siegel, 2019).

Factor one highlighted how PrEP creates a new environment for individuals to test. It is notable that those in this group perceive testing as a social exchange. PrEP does provide certainty regarding HIV status for those in this factor. However, accessing PrEP is done in exchange for regular testing and possibly a level of imposed/experienced stigma or shame. When levels of stigma or shame are high, adherence to drug-related interventions reduces (Marcus et al., 2014). This study highlights that in order for PrEP to be sustained as an effective intervention, theories and interventions need to incorporate and address the psychosocial factors raised.

This study does not assess the prevalence rate of people within each viewpoint. The ability to identify the prevalence rate of each viewpoint is important. Establishing this would allow for the provision of clinical resources and interventions to be targeted in line with prudent healthcare (Bradley et al., 2014; Weinstein et al., 1996; Boerma & Stansfield, 2007).

A limit of this study is that all the participants come from cohorts of men who reported testing for HIV. It is important to understand the drivers for those who do not test for HIV, in order to reduce the prevalence of HIV (Lorenc et al., 2010; Zablotska et al., 2012). Furthermore, the sample consisted of only MSM who identified as gay. It may be that MSM who do not define as gay experience the testing process differently. If an intervention were to be applied to the Welsh context, based on these findings, it should only be applied to gay men. Other populations of MSM would need to be studied further before the findings are generalised.

Theoretical implications are consistent with wider research into HIV testing amongst MSM. Unlike biomedical models, which may see gay men who test for HIV as a homogenous group, this study highlights that there is heterogeneity within this group of

people. Thus, strengthening the broader argument that it is important to understand the psychosocial environment for people who test for HIV (Deblonde et al., 2010; Lui et al., 2018; Fee & Krieger, 1993; Halkitis et al., 2013).

An additional implication is that the study of biomedical factors, such as the provision of PrEP, can alter the subjective viewpoints of gay men testing for HIV. As new viewpoints develop, the theory behind HIV prevention will have to evolve along with these developments.

The role of Stigma and Prejudice within the Thesis as a Whole

The thesis in part discusses the experiences of stigma and prejudice for MSM taking PrEP and testing for HIV. The conceptualisation of this and issues related to this will now be discussed.

Goffman (1963) first drew attention to the area of stigma research and since then there has been a vast array of research into the area looking at the nature, impact and sources of stigma. However, a significant amount of this work has been undertaken from social psychology, where stigma is understood in the context of people creating cognitive categories that link to archetypal beliefs. This has led to stigma being vaguely defined and individually focused without recognition of the social world and context in which a person lives (Link & Phelan, 2001,). Fox et al. (2009) add that in order to move beyond this criticism, research should explore stigma across the levels it presents or within in its own context. Fox et al. (2009) and Link and Phelan (2001) also recommend returning to Goffman's (1963) explanation of stigma as the starting point for conceptualising this.

Goffman (1963) describes stigma as a phenomenon where the individual presents with a feature or characteristic which is rejected by their society as a result of the feature or characteristic. He notes that the feature or characteristic acts as a “tattoo”/ “mark” which is hard for the person to remove. This process creates a reaction from others, which spoils identity and creates stigma. Goffman (1963) notes that, in turn, the meaning of the “tattoo” / “mark” is bound within the context in which the individual lives. This is enacted and created through the use of language and structures within the society. This thesis utilised this approach to conceptualise stigma. Paper one looked at the multiple levels of PrEP-stigma and paper two took a context-focused approach.

Cultural norms can create and prevent stigma. When stigma is imposed on a group or individual it creates an out-group status which in turn, can create prejudice towards the social group or individual (Creighton et al., 2015). LGBT individuals were perceived as out-group members in the UK. However, it is suggested that this has shifted so that LGBT individuals are considered as in-group members (Alldred & Fox, 2015). When a shift occurs, it can mean that individuals amplify practices which will enhance their in-group acceptance and minimise, avoid or self-stigmatise practices that may risk their in-group status or cause them to experience prejudice (Branscombe et al., 1993). Stigma operating through this conceptualisation can be seen in papers one and two.

However, there are key conceptual challenges as to how stigma has been researched (Link & Phelan, 2001). Many social scientists who explore stigma do not belong to the group explored and so from this perspective, many of the theories of stigma are uninformed by the lived experience of the people they study. This can lead to priority being given to the researcher’s scientific theories and research techniques rather than to the words and

perceptions of the people they study. This can result in misunderstandings and assumptions about the individuals who experience the stigma (Link & Phelan, 2001; Hayfield & Huxley, 2015; Schneider, 1988). In order to allow for this conceptual issue, the lead researcher identifies as being a member of the community explored. Furthermore, Q method as an approach is argued to account for this by giving power over to the participants placing emphasis on their words and perceptions rather than pre-existing theory (Stephenson, 1953).

Another key conceptual challenge is that research on stigma has primarily been individualistic. This creates key issues in the research literature, which is that the main emphasis is placed on both the micro level and individual level. Little emphasis is placed on the multiple levels at which stigma can occur. The effect of this is that wider social structures which create stigma and prejudice are less well understood (Hatzenbuehler et al., 2013). Moreover, Goffman (1963) argues that the language of relationships surrounding the attribute, not innate to the attribute itself, needs to be understood. This can mean research often focuses on the "mark" or attribute within the individual, rather than acknowledging the language that surrounds it and creates that stigma around the attribute itself (Rosenthal, 2016). This conceptualisation links to paper one which acknowledges this by highlighting the multiple levels at which PrEP-stigma can occur. It looks at the various structures which can create PrEP-stigma whilst, acknowledging the impact PrEP-stigma has on the individual level. In paper two, this understanding has led to stigma not being placed at the centre of the study, but rather it is understood within a gestalt of a range of issues.

Thesis as a Whole

The thesis set out to consider the role of uncertainty in HIV testing for gay men. However, as noted above, Lui et al.'s (2018) systematic review addressed this question. Therefore, the review question changed as noted above to explore the role of PrEP-stigma for MSM. As the Q study developed, the role of uncertainty was less prominent. The study included uncertainty as part of concourse development and the Q-sort in a wider range of statements. The role of uncertainty has therefore been explored as part of the aim to assess viewpoints on HIV testing in Wales for MSM, post introduction of PrEP.

The main strength of the thesis lies in the ability of each paper to explore different aspects of HIV prevention. Each paper's area of enquiry was selected to explore a gap in the literature on HIV prevention. The ability to explore PrEP and HIV testing in this way allowed for reflection on the wider issues in the area. A summary critique of the strengths and limitations of the studies undertaken will now be provided.

The systematic review yielded a limited number of studies, which were heterogeneous in method and sample. This meant a narrative synthesis was undertaken as outlined above. Although no causal conclusions can be taken from the paper, the synthesis does provide a rich description of PrEP-stigma. A suitable appraisal tool, CASP, was used to determine the studies' quality. Despite the review's limits, it does indicate where further study may be warranted.

The Q study explored the area of HIV testing for gay men in Wales and is reported in paper two. Q is a mixed methodological approach, which allows for reliable and valid conversion of the subjective into an objective understanding (Ramlo & Newman, 2011). Research bias and social desirability cannot be eliminated totally. Steps were taken at each point of the process to reduce this (Robbins & Krueger, 2000). Q still has limits, such as its

explorative iterative nature, meaning that firm conclusions cannot be assumed to apply to the broader population.

The thesis shows that concepts, such as HIV prevention, can be understood across system levels. However, the way in which it is explored will alter depending on the level at which the researcher is seeking to explore it. This fits with arguments made in systemic work and critical health psychology research (Burnham, 1992; Crossley, 2008; Rogers, 1996). Paper one aimed to provide an aggregative description of the broader experience of PrEP-stigma for MSM PrEP users so that the multiple levels within this specific area could be understood. In contrast, paper two described the subjective viewpoints of gay men who test for HIV in Wales since the introduction of PrEP.

This study did not address the plethora of psychosocial issues and all of the current developments in HIV prevention (Lui et al., 2018). It does explain how service provision needs to go beyond the biomedical models of understanding HIV prevention to incorporate the psychosocial factors, for medical advances to be effective. It provides an understanding of how PrEP relates to the context of HIV testing and the implications this may have for HIV testing and prevention as the field develops.

Whilst both papers have limitations, the methods have been employed in academic studies. The possibility of disseminating the studies both at conference and in publication format will extend the influence of the findings for both academic and non-academic individuals. A strength of the thesis as a whole is its ability to enrich the discussion on both the research process and findings.

Dissemination

Paper one has been accepted for poster presentation at the *British Association of Sexual Health and HIV* conference (Appendix 8). Paper two has been accepted for presentation at the *BPS Psychology of Sexualities* conference (Appendix 7). Both papers will be submitted to the *Journal of Sex Research*, which aims to promote a broad understanding of topics in sexual science.

Conclusion

The thesis demonstrates how HIV prevention is an evolving field. Paper two shows that as HIV testing becomes normalised and new methods of HIV prevention become available, HIV testing still raises psychosocial issues for MSM. This can impact on the testing process. Paper one highlights that PrEP, as a biomedical method of HIV prevention, becomes accessible to MSM, the impact of associated PrEP-stigma needs to be considered and addressed at multiple levels. The thesis considers the implications for policy, clinical practice and the need for further psychosocial research regarding HIV prevention, alongside biomedical research, if new methods of prevention are to be effective.

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Appendices

Appendix 1: The Journal of Sex Research Author Guidelines

This journal

- Aims and scope
- Instructions for authors
- Society information
- Journal information
- Editorial board
- News & offers

Aims and scope

The Journal of Sex Research (JSR) is a scholarly journal devoted to the publication of articles relevant to the variety of disciplines involved in the scientific study of sexuality. JSR is designed to stimulate research and promote an interdisciplinary understanding of the diverse topics in contemporary sexual science. JSR publishes empirical reports, brief reports, theoretical essays, review articles, methodological articles, commentaries, and letters to the editor. We do not accept personal narratives or case reports. Each year we publish the Annual Review of Sex Research, an issue devoted to comprehensive reviews of current topics in sexual science. JSR actively seeks submissions from researchers outside of North America.

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The Journal of Sex Research is an international, peer-reviewed journal publishing high-quality, original research. Please see the journal's Aims & Scope for information about its focus and peer-review policy.

Please note that this journal only publishes manuscripts in English.

The Journal of Sex Research accepts the following types of article: original articles, brief reports.

The Journal of Sex Research (JSR) is a scholarly journal devoted to the publication of articles relevant to the variety of disciplines involved in the scientific study of sexuality. JSR is designed to stimulate research and promote an interdisciplinary understanding of the diverse topics in contemporary sexual science. JSR publishes empirical reports, brief reports, theoretical essays, review articles, methodological articles, commentaries, and letters to the editor. We do not accept personal narratives or case reports. Each year we publish the Annual Review of Sex Research, an issue devoted to comprehensive reviews of current topics in sexual science. JSR actively seeks submissions from researchers outside of North America.

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Updated 10-01-2019

Appendix 2: CASP Qualitative Checklist

CASP
Critical Appraisal
Skills Programme

www.casp-uk.net
info@casp-uk.net
Summertown Pavilion, Middle Way Oxford OX2 7LG

CASP Checklist: 10 questions to help you make sense of a Qualitative research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

CASP
Critical Appraisal Skills Programme

Paper for appraisal and reference:

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- what was the goal of the research
- why it was thought important
- its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
- Is qualitative research the right methodology for addressing the research goal

Comments:

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:

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4. Was the recruitment strategy appropriate to the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments:

5. Was the data collected in a way that addressed the research issue?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Comments:

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6. Has the relationship between researcher and participants been adequately considered?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:

CASP
Critical Appraisal Skills Programme

8. Was the data analysis sufficiently rigorous?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement of findings?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider whether
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:

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Section C: Will the results help locally?	
10. How valuable is the research?	HINT: Consider • If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature • If they identify new areas where research is necessary • If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:

Appendix 3: Ethical Approval

Ethics Feedback - EC.18.04.10.5284R2A

P psychethics [redacted]

Reply all

Inbox

[redacted]

Dear Richard,

The Ethics Committee has considered the amendment to your PG project proposal: The role of uncertainty on decision-making about uptake of HIV testing in wales amongst gay men: A Q study (EC.18.04.10.5284R2A).

The project has been approved.

Please note that if any changes are made to the above project then you must notify the Ethics Committee.

Best wishes,
[redacted]

School of Psychology Research Ethics Committee

Cardiff University
[redacted]
Cardiff
[redacted]
[redacted]
Email: psychethics@cardiff.ac.uk
http://psych.cf.ac.uk/aboutus/ethics.html

[redacted]

Appendix 4: Interview Schedules

Semi-structured Interview Schedule for healthcare professionals

Demographics: Age, Profession , Sexual identity, Level of education, Are they taking PrEP , HIV Status, Relationship Status, Ethnicity, When did they last test for HIV.

Interview:

1. Can you tell me about experiences of supporting gay men to come forward for an HIV test?

2. Can you tell me about what may make gay men uncertain when they come for a HIV test?

   Probe:
   c. Why is this ?

3. Are there any barriers there any barrier to them coming for to test?
   Probe:
   a. How do you think they overcome these ?

4. What things make it more or less easy for them to come forward?

5. When gay men come forward to test for HIV how do they act and behave ?
   Probe:
   a. What does that look like ?
   b. In what ways is that similar or different to other people who come forward to test?

6. When waiting for a test result what do you hear people do?

7. What do they tell you they've done to help them cope with the uncertainty of a HIV test result?

Semi-structured Interview for gay men Schedule for Part 1

Demographic questions :

Age, Profession , Sexual identity, Level of education, Are they taking PrEP , HIV Status, Relationship Status, Ethnicity, When did they last test for HIV.

Interview:

1. How do you think gay men view sexual health?

2. What does it mean to you to complete a HIV test?

Pre testing :

3. Before having an HIV test what goes through your mind?
   a. How did/do you manage these thoughts?
   b. What might others say puts gay men off of HIV testing regularly?

4. What might it be like for someone to be uncertain about their HIV status?
   a. What might people do to manage this uncertainty?
   b. How would this activity help or not help them?

5. Can you tell me about your experience testing for HIV?
   Probes:
   a. What were your thoughts and feelings about HIV testing?
   b. What might others say about HIV testing?
   c. If you were to talk to a friend about HIV testing what might they say?

Post test

6. What was it like waiting for test results?
   Probe:
   a. How did you find this?

7. Were there things you did when you were waiting that you would not normally do?
   a. What did these things do for you?

8. Could uncertainty about HIV status play a role in HIV testing?
   a. Can you explain why?
   b. What might others say about the role of uncertainty?

9. What might it be like for someone to be uncertain about their HIV test results?
   a. How might they manage this?
   b. How would this activity help or not help them?

Appendix 5: Q-Set

1. Regular testing is part of my normal routine.
2. Testing does not bother me.
3. I don't need to test because HIV is not a terminal illness.
4. The time between testing is really hard.
5. Testing benefits others.
6. I test because I am responsible for my own health.
7. You are only as certain as your last test.
8. Past life experiences gets me to test.
9. If more people had an HIV test there would be fewer HIV infections.
10. I need to test when my relationship status changes.
11. The benefits of a negative result drives me to test.
12. Stigma prevents me from testing.
13. Society will reject me if I don't test.
14. Testing is disgusting experience.
15. Testing for HIV shows weakness.
16. Testing is shaming.
17. Others will assume I am promiscuous if I test.
18. If my test is positive I will just be living up to the stereotype of a gay man.
19. I need to test because gay men are more prone to contracting HIV.
20. I test to fit in with others.
21. Testing is the cost of being a gay man.
22. Testing is a form of oppression imposed on the gay community.
23. I can predict when I need to test.
24. I use condoms with occasional lapses. I test to keep on top of things.

25. People who want control test.

26. Testing means I lose control.

27. What I see in the media makes me test.

28. Testing affects how I am seen on dating apps.

29. Without being reminded to test I wouldn't.

30. My life won't be the same after testing.

31. I think I have HIV so why bother.

32. It's better to be uncertain than test positive.

33. I can predict if I have HIV.

34. I'm certain they will not find anything wrong with me.

35. Fear of a positive result puts me off testing.

36. I'm too busy to test.

37. When you have decided to test its easy, you just want it all done there and then.

38. I test because policy recommends I go for regular tests.

39. The testing process is intrusive.

40. I don't know if testing will be confidential.

41. I don't feel confident enough to test.

42. Testing is a lonely process.

43. I'm proactive in testing and know the issues around testing.

44. It's unclear how testing will help me.

45. It's not clear what will happen when I test.

46. I don't test because the test won't pick up on my HIV.

47. There is no point in testing for HIV because there is no cure.

48. I just block testing out of my mind.

49. There are pros and cons to testing.

50. The anxiety of testing puts me off regular testing.

51. I'm better off dead than testing for HIV.

52. If you think you're positive, then you'll act to get HIV to ensure a positive result.

53. Everyone else tests so I don't have to.

54. PEP is always available, so there's no point in testing.

55. I only need to test if I've been at risk of HIV.

56. I test so I can have unsafe sex.

57. My sexual role determines how often I need to test.

58. I practice safe sex so why bother

59. I like the thrill of having sex and not knowing my status.

60. When I test I feel like a robot and don't connect with myself.

61. I can't think about anything else other than testing.

62. I have ways of coping which help me manage testing.

63. I'm mentally resilient enough to test.

64. Testing for HIV causes me distress.

65. Uncertainty gets me to test.

66. Testing allows me to manage psychological distress.

67. I think I'm clean therefore I don't need to test.

68. I try to keep my feelings about testing to myself.

69. I take PrEP so I have long-term certainty when I test.

70. I have to test regularly to get access to PrEP.

Appendix 6: Exemplar Factor Array

Factor 1			
Most Strongly agree	Q-Sort Value	Most Strongly disagree	Q-Sort Value
I have to test regularly to get access to PREP.	+5	I'm better off dead than testing for HIV.	-5
I take PREP so I have long-term certainty when I test.	+5	I like the thrill of having sex and not knowing my status.	-5
Regular testing is part of my normal routine.	+5	It's better to be uncertain than test positive.	-5
Testing is shaming.	+5	I don't test because the test won't pick up on my HIV.	-5
Others will assume I am promiscuous if I test.	+4	I think I have HIV so why bother.	-4
Stigma prevents me from testing.	+4	It's unclear how testing will help me.	-4
When I test I feel like a robot and don't connect with myself.	+4	I don't feel confident enough to test.	-4
The benefits of a negative result drives me to test.	+4	It's not clear what will happen when I test.	-4
Society will reject me if I don't test.	+4	If you think you're positive, then you'll act to get HIV to ensure a positive result.	-4

Factor 2			
Most Strongly agree	Q-Sort Value	Most Strongly disagree	Q-Sort Value
Testing for HIV causes me distress.	+5	I'm better off dead than testing for HIV.	-5
The anxiety of testing puts me off regular testing.	+5	There is no point in testing for HIV because there is no cure.	-5
The testing process is intrusive.	+5	I don't test because the test won't pick up on my HIV.	-5
Uncertainty gets me to test.	+5	If you think you're positive, then you'll act to get HIV to ensure a positive result.	-5
I try to keep my feelings about testing to myself.	+4	I can predict if I have HIV.	-4
I just block testing out of my mind.	+4	I'm mentally resilient enough to test.	-4
When you have decided to test its easy, you just want it all.	+4	Regular testing is part of my normal routine.	-4
Testing is shaming.	+4	I like the thrill of having sex and not knowing my status.	-4
You are only as certain as your last test.	+4	Testing is the cost of being a gay man.	-4

Factor 3			
Most Strongly agree	Q-Sort Value	Most Strongly disagree	Q-Sort Value
I test because I am responsible for my own health.	+5	I think I have HIV so why bother.	-5
Regular testing is part of my normal routine.	+5	here is no point in testing for HIV because there is no cure.	-5
Testing benefits others.	+5	I'm better off dead than testing for HIV.	-5
You are only as certain as your last test.	+5	I don't need to test because HIV is not a terminal illness.	-5
I'm mentally resilient enough to test.	+4	Testing means I lose control.	-4
I'm proactive in testing and know the issues around testing.	+4	If you think you're positive, then you'll act to get HIV to ensure a positive result.	-4
If more people had an HIV test there would be fewer HIV infections	+4	My life won't be the same after testing.	-4
When you have decided to test its easy, you just want it all done there and then.	+4	Fear of a positive result puts me off testing.	-4
Past life experiences gets me to test.	+4	I only need to test if I've been at risk of HIV.	-4

Appendix 7: Confirmation of Presenting at the BPS Psychology of Sexualities Conference

Dear Richard,
I'm pleased to tell you that the review committee has now considered all the abstracts that were submitted for the BPS Psychology of Sexualities Conference 2019 and that yours was received very favourably.
We would like to invite you to to present your work in a 5 minute oral presentation format
Congratulations!
There are four things for you to do now:

1) Check your details

   Please look at the attached document and check that I have all the correct information for your presentation. This is what I will use to generate the abstract booklet and it's what will be published in a subsequent issue of the Psychology of Sexualities Review.

2) Register for the event

   Please register for the conference via Eventbrite, the address is https://www.eventbrite.co.uk/e/british-psychological-society-psychology-of-sexualities-section-annual-conference-2019-tickets-56403173410

   Read the instructions on the first page and then click the big green "tickets" button to make your purchase.

3) Prepare your presentation

   Your presentation slot is 5 minutes long with a few spare minutes for change over (and possibly some questions, depending on whether your session chair thinks it's doable). The schedule is very tight as there will be four of you presenting in your thirty minute session. If you talk for longer than five minutes the chair of the session will have to stop you, so please do practice your timing in advance and prepare your presentation so that the slides auto-advance and finish before your time is up.

   Short presentations like this are great for getting over the main points of your research in a catchy engaging way. If you haven't presented in this format previously it might be worth looking at this video to get an idea of how Petcha Kutchas (which is a similar type of short presentation with auto-advancing slides) work https://www.youtube.com/watch?v=I9zxNTpNMLo. We recommend a "five slides, five minutes" format, with one slide every minute, but you are free to use your time however you want. You could go completely wild and maybe have just one slide in the background while you talk. We would definitely advise against trying to cover twenty minutes worth of material in five minutes by speaking quickly – it doesn't work! Maybe take inspiration from these people who can condense a whole PhD thesis into three minutes! https://threeminutethesis.uq.edu.au/

Because the schedule is so packed we're asking people to email us in advance with their slides which we can then have ready loaded up on the computers. Please email your presentation as an attachment to me by Friday June 21st.

4) See who else is coming

   As well as your information the document attached also shows who else will be presenting their work during the same session as you, so that you can see where you might be able to make connections and contacts. The full programme will be going live on the conference webpage in the next couple of days https://www.bps.org.uk/events/psychology-sexualities-annual-conference-2019. Be sure to follow #PoSConf19 on Twitter.

We're really looking forward to the conference and to hearing more about your research. If you have any questions in the meantime please don't hesitate to ask, I'm very happy to help.

Appendix 8: Confirmation of Presenting at the British Association of Sexual Health and HIV Conference

Dear Mr richard hobbs,

The BASHH Conference abstract review meeting took place on the 10th April, I am delighted to inform you that your abstract A systematic review into PrEP-stigma amongst MSM taking PrEP a narrative synthesis. reference 177, has been accepted for Poster presentation at BASHH Annual Conference 2019.

Your abstract has been given a new reference number P067 please use this code going forward for any correspondence. If your abstract has been presented or published elsewhere please inform the admin team with the details as soon as possible.

Guidelines for posters will follow. To take advantage of the reduced rates, ensure that you register before the early bird deadline, midnight on 29th April 2019. Registration should be done through the BASHH website, www.bashh.org.

We look forward to seeing you

Event Organiser

British Association for Sexual Health & HIV (BASHH)
BASHH Secretariat
Registered Office:

Website: www.bashh.org
A company limited by guarantee and not having a share capital
Registered in England and Wales No: 07863350
Registered Charity No: 1148196

Appendix 9: Participants Interviewed for the Q-Sort Information, Consent and Debrief Form
To be printed on headed paper

Information Sheet

Title of Project: The role of uncertainty on decision-making about uptake of HIV testing in wales amongst gay men: A Q study

Details of Project

We are interested gay men's views of testing for HIV in Wales. Gay men's experience of uncertainty and other aspects about HIV testing may be influential in the way decisions to test for HIV are made in Wales. The presence of issues such as uncertainty could influence views of testing for HIV. Little is known about gay men's viewpoints on testing for HIV in Wales. This study seeks to look at view around uncertainty of HIV testing and how this may relate to other issues linked to testing.

Project aims

This project aims to gauge your perception/ thoughts on HIV testing.

Who is undertaking this project?

This research will be undertaken by Richard Hobbs Trainee Clinical Psychologist. This project is part of a Doctorate in Clinical Psychology thesis. The project is supervised by Dr. Dougal Hare and Dr Aimee Pudduck at Cardiff University.

Why am I being invited to participate?

You are an individual who could provide some valuable input into understanding the different perceptions/ thoughts on HIV testing.

What will I be asked to do?

You will be required to complete a 45-60 minute interview. The Interview will be used to generate statements about HIV testing and uncertainty that will be combined with staff working in sexual health, other gay men and those found in the academic literature. This list of statements will ensure that we have a comprehensive set of viewpoints about uncertainty and the HIV testing context. The statement will then be used in the second stage of the study, where gay men will be asked to sort a series of statement generated from the interview into what is most and least like them. The reason for doing the research in this way is to avoid bias in research and ensures that we encompass and represent all possible perspectives.

Can I withdraw from the project?

Participation in this project is on a voluntary basis and therefore you will be able to withdraw from the project at any time prior to the completion of the Q-set.

What will happen to my information?

The study will be conducted anonymously and therefore no personal data will be collected/ divulged. All data will be collected and stored in accordance with the Data Protection Act 1998 (UK).

Ethical considerations and project risks

This study has been approved by Cardiff University School of Psychology Ethics Committee. Aside from the time required to undertake the sorting of statements, there are no foreseeable risk associated with the project. However, if you have any questions or problems relating to your participation, or if you wish to raise a concern or complaint about the project, please contact Richard Hobbs in the first instance.

Contact Details

Researcher: Richard Hobbs: [redacted]

Supervisor: Dr Amiee Pudduck: [redacted] or Dr Dougal Hare: [redacted]

Please discuss the information above with others if you wish or ask us if there is anything that is not clear or if you would like more information.

If you know others who may be keen to partake in the study please invite them to contact Richard Hobbs at [redacted]

It is up to you to decide whether to take part or not; choosing not to take part will not disadvantage you in any way. If you do decide to take part you are still free to withdraw at any time and without giving a reason.

All data will be collected and stored in accordance with the Data Protection Act 1998. Thank you for reading this information sheet and for considering take part in this research.

Interview Consent Form

TO be printed on headed paper

The role of uncertainty on decision-making about uptake of HIV testing in wales amongst gay men: A Q study

Research investigator:

Richard Hobbs: Trainee Clinical Psychologist

Research Participants ID:

…….

The interview will take approximately 1 hour. We don't anticipate that there are any risks associated with your participation, but you have the right to stop the interview or withdraw from the research at any time.

Thank you for agreeing to be interviewed as part of the above research project. Ethical procedures for academic research undertaken from UK institutions require that interviewees explicitly agree to being interviewed and how the information contained in their interview will be used. Please could you read the accompanying information sheet and then sign this form to certify that you approve the following:

- The interview will be recorded and a transcript will be produced
- The transcript of the interview will be analysed by Richard Hobbs as research investigator.
- Access to the anonymised interview transcript will be limited to Richard Hobbs and academic colleagues and researchers with whom he might collaborate as part of the research process
- Any summary interview content, or direct quotations from the interview, that are made available through academic publication or other academic outlets will be anonymised so that you cannot be identified, and care will be taken to ensure that other information in the interview that could identify yourself is not revealed .
- The actual recording will be destroyed after transcription and the transcript destroyed after the creation of the Q-Set.
- Any variation of the conditions above will only occur with your further explicit approval.

I also understand that my words may be quoted directly. With regards to being quoted, please initial next to any of the statements that you agree with:

	I wish to review the notes, transcripts, or other data collected during the research pertaining to my participation.
	I agree to be quoted directly.
	I agree to be quoted directly if my name is not published and a made-up name (pseudonym) is used.
	I agree that the researchers may publish documents that contain quotations by me.

All or part of the content of your interview may be used:

- In academic papers, policy papers or news articles
- On websites and in other media that we may produce such as spoken presentations.
- Some quotes may also form part of a card sort for a further study asking people to rate how much they agreed with the quote.

By signing this form, I agree that;

1. I am voluntarily taking part in this project. I understand that I don't have to take part, and I can stop the interview at any time;
2. The transcribed interview or extracts from it may be used as described above;
3. I have read the Information sheet;
4. I don't expect to receive any benefit or payment for my participation;
5. I can request a copy of the transcript of my interview and may make edits I feel necessary to ensure the effectiveness of any agreement made about confidentiality;
6. I have been able to ask any questions I might have, and I understand that I am free to contact the researcher with any questions I may have in the future.

_____ Printed Name

_____
Participants Signature Date

_____
Researchers Signature Date

This research has been reviewed and approved by the Cardiff University School of Psychology Ethics Committee. If you have any further questions or concerns about this study, please contact:

Richard Hobbs researcher: [redacted]

You can also contact my supervisors:

Dougal Hare: [redacted]

Amiee Pudduck: [redacted]

School of Psychology, Cardiff University

Debrief:

Thank you for taking part in the study. If you wish to seek support about emotional support or discuss your own sexual health after completing the study you can contact the below services.

The Terence Higgins Trust Direct hour which offers advice and support at on 0808 802 1221

Or the Samaritans on 116 123 or 0808 164 0123 for Welsh Language Line.

If you have any questions regarding the study please contact. Researcher: Richard Hobbs: [redacted] or Supervisors: Dr Dougal Hare: [redacted] or Dr Amiee Pudduck: [redacted]

Appendix 10: Q-Sort Participant Information, Consent and Debrief Form

The role of uncertainty on decision-making about uptake of HIV testing in Wales amongst gay men: A Q study

Please make sure you are completing that study at a PC or Laptop. If you decide to complete take part in the study please make sure you click continue at each screen and select submit data at the end.

Details of Project

We are interested gay men's views of testing for HIV in Wales.

Gay men's experience of uncertainty and other aspects about HIV testing may be influential in the way decisions to test for HIV are made in Wales. The presence of issues such as uncertainty could influence views of testing for HIV. Little is known about gay men's viewpoints on testing for HIV in Wales. This study seeks to look at view around uncertainty of HIV testing and how this may relate to other issues linked to testing.

Project Aims

This project aims to gauge your perception/ thoughts on HIV testing.

How will this be done?

This will be achieved through sorting of a number of pre-set statements on the subject matter online. The information provided will facilitate an understanding of the different areas deemed as important or less important to the topic area.

Who is undertaking this project?

This research will be undertaken by Richard Hobbs Trainee Clinical Psychologist. This project is part of a Doctorate in Clinical Psychology thesis. The project is supervised by Dr. Dougal Hare and Dr Amiee Pudduck at Cardiff University.

Why am I being invited to participate?

You have been identified as an individual who could provide some valuable input into understanding the different perceptions/ thoughts on HIV testing.

What will I be asked to do?

You will be required to complete a q-sort of pre-set statements on the subject of HIV testing based on your current personal understanding of the subject matter. You would also be

required to provide your feedback on how/ why you sorted those statements the way you did to provide the researcher with some data for analysis purposes.

Can I withdraw from the project?

Participation in this project is on a voluntary basis and therefore you will be able to withdraw from the project at any time prior to submission of your q-sort or 2 weeks after submission by submitting the data and time of completing the study to the researcher.

What will happen to my information?

The study will be conducted anonymously and therefore no personal data will be collected/ divulged. All data will be collected and stored in accordance with the Data Protection Act 1998 (UK).

Ethical Considerations and Project Risks?

This study has been approved by Cardiff University School of Psychology Ethics Committee. Aside from the time require undertaking the sorting of statements, there are no foreseeable risk associated with the project. However, if you have any questions or problems relating to your participation, or if you wish to raise a concern or complaint about the project, please contact Richard Hobbs in the first instance.

Contact Details

Researcher: Richard Hobbs: [redacted]

Supervisor: Dr Dougal Hare: [redacted] or Dr Amiee Pudduck: [redacted]

Please discuss the information above with others if you wish or ask us if there is anything that is not clear or if you would like more information.

If you know others who may be keen to partake in the study please share the website link with them: [redacted]

It is up to you to decide whether to take part or not; choosing not to take part will not disadvantage you in any way. If you do decide to take part you are still free to withdraw at any time and without giving a reason.

All data will be collected and stored in accordance with the Data Protection Act 1998. Thank you for reading this information sheet and for considering take part in this research.

Submitting Data

If you wish to submit your data at the end of the study please make sure you press the submit data button at the end of the study.

Consent Form

Please read and complete this form carefully. If you are willing to participate in this study, ring the appropriate responses and sign and date the declaration at the end. If you do not understand anything and would like more information, please ask.

1. I have had the research satisfactorily explained to me in verbal and / or written form by the researcher.

2. I understand that the research will involve: *a sort of statements related to HIV testing and will be asked to give feedback after completing the sort.*

3. I understand that I may withdraw from this study at any time without having to give an explanation.

   Yes No

4. I understand that all information about me will be treated in strict confidence and that I will not be named in any written work arising from this study.

   Yes No

5. I understand that should I wish to withdraw from the study I can do this at any point up to the point of analysis when data are anonymised and I can do this by quoting the date and time I completed the study.

   Yes No

6. I freely give my consent to participate in this research study and have been given a copy of this form for my own information.

   Yes No

7. I have read the information and above and consent to take part in the study that has been outlined above.

   Yes No

This project has been approved by Cardiff School of Psychology Ethics Committee **(EC.18.04.10.5284R2.)**

Psychology Ethics Committee

Cardiff University

School of Psychology

[redacted]

Demographic Questions

What gender do you identify as?

Male
Female
Other

What is your current relationship status?

Single
Married
Widowed
Divorced
Separated
Open relationship
Close relationship
Prefer not to say

What is your age?

18-24
25-34
35-44
45-54
55-64
65 +
Prefer not to say

What is your current occupation?

What was your highest level when you finished education?

Primary education
Secondary education no qualifications
Secondary education GCSE's
Secondary education/ Sixth form college (A levels / BTEC)
Undergraduate degree

Masters
Doctorate
Post doctorate
Prefer not to say

What sexual orientation do you identify with?

Gay
Bisexual
Men who has sex with men
Straight
Other

Do you currently take Pre-Exposure-Prophylaxis (PREP)?

Yes
No

Do you test for HIV?

Yes
No
Prefer not to say

How often do you test for HIV?

0-3 months
4-6 months
7-9 months
10-11 months
Every 1-2 years
Never

HIV Status

HIV Positive
HIV Negative
Unknown
Prefer not to say

What area of wales do you live in?

Please give the first 3 digits of your post code

Please choose one option that best describes your ethnic group or background

English / Welsh / Scottish / Northern Irish / British
Irish
Gypsy or Irish Traveller
Any other White background
Please describe
White and Black Caribbean
White and Black African
White and Asian
Any other Mixed / Multiple ethnic background

Please describe
Indian
Pakistani
Bangladeshi
Chinese
Any other Asian background
Please describe
African
Caribbean
Any other Black / African / Caribbean background
Please describe
Arab
Any other ethnic group
Please describe
Prefer not to say

We are interested gay men's experiences of testing for HIV. The views listed here come from practitioners, other gay men and research findings.

We would like you to think about testing for HIV in Wales. We would like to know how much you agree or disagree with the views that others have shared.

Please maximize your browser window and click on the 'Continue' button to start the survey.

STEP 1
Please read the following statements carefully and split them up into three groups: a group of statements you tend to **disagree** with, a group of statements you tend to **agree** with, and a group for the ones you feel **neutral** about.

You can either drag the statements into one of the three columns, or press '1', '2' or '3' on your keyboard. You will be able to make changes later.

If you want to read this instruction a second time, press the 'Help me!' button in the bottom right corner.

STEP 2
Look at the statements from the 'Agree' column at the bottom right-hand side and read them again. You can scroll through the statements using the scroll bar.

Select the three statements you most agree with and place them on the far right side of the response grid below the '+5'.

Then read the statements in the 'Disagree' column at the bottom left-hand side.

Select the three statements you most disagree with and place them on the far left side of the response grid below the '-5'.

Then select the four statements you next most agree with and place them under the '+4' column.

Next select the four statements you next most disagree with and place them under the '-4' column.

Follow this procedure for all the statements in the 'Agree' and 'Disagree' column'

Finally, read the 'Neutral' statements again and drag them into the remaining open boxes in the middle of the response grid.

Please sort according to the following statement Testing for HIV in Wales makes me think ….

If you've sorted all the statements but it's not showing 100% and a 'Continue' button hasn't appeared, see if you can spot if one of the statements is lying on top of another and slot it into the missing gap on the grid.

If you want to re-read these instructions, click the 'Help me!' button in the bottom right corner.

STEP3

Now you have placed all the statements on the response grid, are you happy with how they are distributed?

If you want, you can make changes by shifting the statements around.

By hovering the mouse over the box you can read the full statement.

STEP 4

Please explain why you most agree or most disagree with the following statements you placed below '+5' and '-5'

Submit Data

Please now **press the 'Submit data' button**.

Pressing this button will save your responses.

Once you have pressed the button you have completed the survey.
Submit data

Debrief

Thank you for taking part in the study. If you wish to seek support about emotional support or discuss your own sexual health after completing the study you can contact the below services.

The Terence Higgins Trust Direct hour which offers advice and support at on 0808 802 1221

Or the Samaritans on 116 123 or 0808 164 0123 for Welsh Language Line.

If you have any questions or feedback regarding the study please contact email [redacted] or Researcher: Richard Hobbs: [redacted] or Supervisors: Dr Dougal Hare: [redacted] or Dr Amiee Pudduck: [redacted]