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TITLE

The effect of 'lifestyle stigma' on public support for NHS-provisioned pre-exposure

prophylaxis (PrEP) and preventative interventions for HPV and type 2 diabetes: A

nationwide UK survey

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ABSTRACT

Objectives: This study examines how the perceived role of poor lifestyle and irresponsible behaviour in contracting HIV, HPV, and diabetes affects public support for government-provisioned prevention efforts in Britain. It assesses whether public attitudes on healthcare spending are broadly sensitive to 'lifestyle stigmas.'

Methods: We conducted an online survey of 738 respondents in Britain and embedded three separate survey experiments to measure support for government-provisioned interventions for HIV, HPV, and type 2 diabetes. In each experiment, we manipulated language used to describe the extent to which the diseases are caused by lifestyle choices. Most respondents participated in all three experiments, but assignment was randomized within each condition. Analysis compared support amongst respondents exposed to 'lifestyle' treatment (information emphasising the disease's lifestyle causes) versus control treatment. We estimated three separate t-tests in which support for government provision of interventions is the dependent variable.

Results: Support for government-provisioned prevention was high for all three diseases. There was no statistical difference between treatment and control conditions for HIV (treatment mean = 3.73, control mean = 3.86, p=0.38). But in both HPV (treatment mean = 3.96, control mean = 4.43, p<0.01) and type 2 diabetes (treatment mean = 3.53, control mean = 4.03, p<0.01) experiments, support for government-provisioned interventions was significantly lower under lifestyle treatment conditions.

Conclusions: Public opinion on healthcare expenditures in Britain is unexpected and uneven.

Consistent participant support for PrEP shows public attitudes are not always sensitive to lifestyle stigmas—but for other diseases, perceived relationships between individual behaviour and poor health can still shape public opinion about health expenditures.

Policymakers and practitioners should remain attentive to how health problems are framed and discussed to ensure broad public support, but also take advantage of policy windows like with PrEP as they may close.

Strengths and limitations of this study

- First-of-its-kind survey that measures public awareness and opinion on PrEP in Britain
- Comparison across multiple diseases to understand where lifestyle stigma does and does not operate
- Survey conducted at height of negative media coverage on PrEP
- Public opinion on matters related to the NHS can be unstable
- Online panels are not necessarily representative of the general population
- Lifestyle treatment in the HIV experiment works slightly differently than in the other experiments

INTRODUCTION

Despite trials demonstrating its effectiveness at preventing HIV and research showing its long-term cost savings, [1-3] in 2016 NHS England (NHSE) decided to not provide full universal access to pre-exposure prophylaxis (PrEP), a daily dose pill of antiretroviral drugs taken to lower risk of contracting HIV. While justified by the need for treatment rationing amidst broader fears of the National Health Service's (NHS) long-term sustainability,[4] the decision—and a subsequent High Court challenge—occurred in a charged media environment. Perceived beneficiaries were effectively put on trial; public provision of PrEP was suggested to be tantamount to government endorsement of irresponsible sexual behaviour. Most Britons had never heard of PrEP. Yet, media narratives were built upon the assumption that taxpayers are averse to giving public funds to those whose health problems are seen as resulting from 'irresponsible behaviour' and 'poor lifestyle choices.'[5, 6]

But does this assumption accurately reflect public attitudes in Britain? Rather than simply measuring and reporting public opinion about PrEP, we place it into a broader, comparative context. By exploring attitudes on the Human Papilloma Virus (HPV) and type 2 diabetes, this study aims to answer a larger question, one especially important in countries like Britain where publicly-funded healthcare makes health policy more susceptible to public opinion: are public attitudes on government expenditures broadly sensitive to a 'lifestyle stigma,' the belief that diseases are due to poor lifestyle or irresponsible behaviour?

Background

Beliefs that a lifestyle stigma can drive public opinion and affect government expenditure decisions are not unfounded. Responsibilisation attitudes[7]—the idea that individuals should take personal responsibility for their own well-being—frequently impact public opinion, especially on health matters and those which are newly-emerging [8, 9, 10-

12]; problems seen as resulting from irresponsible behaviour are less likely to garner support for government funding[13].

While the effect of public opinion on policymaking is the subject of debate, scholars estimate that it impacts policy three quarters of the time it is gauged, with substantial effect at least one-third of the time.[14]; its effect varies due to issue salience, public knowledge, degree of public attitudinal shifts, and political and institutional processes mediating the ability of policymakers to respond.[15-19] In liberal democracies, elected officials are incentivised to directly respond to public opinion through reform.[16, 20, 21, 22] But policymakers do not always have a good understanding of these attitudes. How policymakers *perceive* public opinion is thus especially pertinent and factored into how policy is developed.[15, 22, 23]

The popularity of Britain's publicly-funded National Health Service (NHS) has meant that public opinion is stronger and matters even more for policymakers. [23, 24, 25] With the introduction of market-based systems of provision in the 1990s and semi-privatisation in the last decade, public opinion is now effectively built into the NHS, bound by a legal requirement for 'public consultation-seeking' to better the 'consumer experience.' [25, 26] Increased emphasis on personal responsibility in healthcare provision is evident now as NHS's future has been seen dependent upon cost-cutting and rationing of care, [27, 28] featuring prominently in the EU Referendum. [29] It suggests that the treatment of certain diseases seen as the result of poor lifestyle choices and bad behaviour will lack public support and could factor into policymaking decisions. This was reflected in the recent case of PrEP in Britain. NHSE's decision to not fund the drug came amidst strong negative media coverage: a front-page story in the *Daily Mail* declared, 'NHS told to give out £5,000-a-year lifestyle drug to prevent HIV—as vital cataract surgery is rationed. What a skewed sense of

values.' Although the general public was not surveyed in advance of the decision, policymakers seemed to have been anticipating a negative response.[30-32]

We know very little about public perception of PrEP anywhere in the world, including Britain. Current literature has focused primarily on attitudes towards the drug amongst healthcare providers and potential beneficiaries.[33, 34] But even these studies point to a lifestyle stigma associated with PrEP use. A survey of healthcare providers in North America found moral concerns about 'bad behaviours' affects willingness of some providers to prescribe the drug.[35, p. 705] Even within gay communities, PrEP is often seen as an overly-expensive excuse for 'risk-taking' gay and bisexual men to continue engaging in 'irresponsible' risky sexual behaviour.[31, 36] Concerns that PrEP offers free license to be sexually promiscuous mirrors concerns over antiretroviral medicine in the mid-1990s for HIV/AIDS [31] and the oral contraceptive pill in the 1960s.[32]

While studies allude to a lifestyle stigma around PrEP use,[35] few have explored indepth how perceptions of lifestyle affect public support for PrEP provision and use.[37]

Limited research has examined how certain demographic groups—and prejudices and biases associated with them—might disproportionately experience lifestyle stigma in relation to PrEP.[30, 31, 34] And while stigmas on some lifestyle-related diseases have been compared previously,[38] no previous studies have included attitudes toward PrEP and HIV in such comparative analyses. Comparing public perceptions of PrEP and HIV with other lifestyle-related diseases can yield important insights about stigma and health policymaking more generally. Moreover, while a study of Britain is especially timely due to care rationing and growing attitudes of responsibilisation within the general public,[27, 28, 5] insights gleaned here could well travel to comparable political contexts facing similar issues.

The current study

This study compares public opinion of NHS-funded PrEP to prevent HIV with attitudes toward publicly-funded treatment for HPV and type 2 diabetes, focusing on how perceptions of lifestyle in their acquisition shapes opinion. While the majority of Britons believe in government responsibility for healthcare, the public increasingly feels the government's role should be weighed against personal responsibility.[5] The majority of respondents in a 2014 study disagreed that it should be the UK government's responsibility to influence individual behaviour by regulating and taxing high-calorie food and drink, and incentivising giving up heavy drinking and losing weight.[39] Lifestyle stigma can differ according to perceived causes of disease:[40] people are less likely to help victims of lung cancer resulting from smoking for 20 years than those who developed it from working in a mine for the same time[41] and less likely to donate money to lung cancer research (seen as the result of bad behaviour) than breast cancer research.[42]

Public attitudes toward health policies can also be influenced by pre-existing stigma against those seen as key beneficiaries. Support for policies varies depending on whether benefiting groups are perceived positively or negatively.[43, 44] During the AIDS epidemic in the US, public stigma towards gay men affected how policymakers subsequently framed policies that would entail social benefits to gay men with HIV.[45] Because HIV and HPV are both sexually transmitted, we expect this information to negatively affect public opinion of publicly provisioned PrEP and the HPV vaccine (currently offered to girls age 12 and 13, and soon to boys of the same age).

Previous studies on HPV suggest the presence of lifestyle stigma in public perceptions of the disease:[46, 47] adolescent girls with HPV feared they would be excluded if their condition was discovered by others;[48] when told it was an STD, university-aged female respondents in the US characterised those with HPV as being 'dirty, dishonest, and

unwise';[49] a study of British women found those who knew cervical cancer was linked to sexual activity were significantly more likely to blame the victims, as they viewed the cancer as thus the result of irresponsible behaviour.[47] As such, we expect that support for an NHS-funded vaccine will be highest when respondents are told that HPV can cause cancer; as it gets more closely linked to behaviour and lifestyle support will decrease.

Similarly, a study of adults with type 2 diabetes found a vast majority of participants perceived and experienced lifestyle stigma, feeling blamed for their condition through poor health habits.[6, 50] Responsibilisation attitudes are shown to underlie type 2 diabetes stigma, where the inability to adhere to healthy dietary habits, exercise, and regular professional supervision reflected 'moral failings';[6] similar attitudes toward obesity are present in Britain[47] and often associated with type 2 diabetes.[6] Other studies have explored how framing can affect support for diabetes prevention policies. When diabetes is discussed as a consequence of individual behaviour, Republican respondents in a US study were more likely to oppose government funding to address it.[51]

Against this backdrop, we therefore propose an overarching hypothesis: When respondents are prompted to think about lifestyle causes of diseases, they are less likely to support public provision of drugs to avoid or treat it. While we expect lifestyle stigma to be present in all three cases, there are important differences that could affect the strength of the stigma on attitudes.

METHODS

In order to test our expectations, we fielded a survey of 738 respondents in Britain using a panel from Prolific, a service that matches researchers with people willing to do short surveys, for small amounts of money. Participants (totally 170,000 as of September 2018) are recruited via social media, poster/flyer campaigns, and referrals; they must provide and

confirm a phone number and email address in order to participate. For any given study, a sample of eligible participants are contacted through the service. Prolific is comparable to Amazon's Mechanical Turk, though research shows it offers a more diverse sample that is more naïve and less dishonest. [52, 53]

Research ethics approval for the survey was granted in September 2016 by the first author's institution; all participants gave informed consent before beginning the survey.

While the research was done without direct patient or public involvement, the public was involved as survey respondents.

The sample has a distribution that is roughly analogous to that of the target population (adults in the UK), in terms of age (22.3% 18-24, 34.4% 25-34, 20.9% 35-44, 14.1% 45-54, 6.4% 55-64, 1.8% 65 or older), gender (40.7% male, 58.8% female, .6% other or prefer not to say), race and ethnicity (87.4% white, 2.4% mixed race, 6.4% Asian/Asian British, 2.8% Black/African Caribbean/Black British, 1.2% other ethnic group), and political ideology (24.5% conservative, 28.3% moderate, 47.2% liberal).

Within this survey, we embedded three separate survey experiments. Most respondents participated in each of the three experiments, but assignment was randomised (automatically through the survey software) within each condition. Therefore, assignment to one condition was independent of assignment to any other condition.

The first focused on attitudes towards PrEP, varying what group PrEP was described as targeting in a clinical trial. Participants were told, 'PrEP is a drug used to protect against exposure to the HIV virus. In a recent study of approximately 500 [target group], this drug was shown to be almost entirely effective at preventing HIV infection when used as directed. Based on this, would you approve or disapprove of the NHS covering the costs of PrEP?' The target group was either 'people' for the control condition (N = 115), or 'people

who have frequent sex with multiple partners' in the lifestyle condition (N = 105). In the full experiment, additional group targets were included: 'gay men,' 'gay men who have frequent sex with multiple partners,' 'high risk gay men,' 'pregnant women,' and 'non-UK born people.' For a cleaner comparison, we restrict our analyses here to only 'people' and 'people who have frequent sex with multiple partners,' in order to focus most clearly on the lifestyle element in which we are interested.

The second survey experiment focused on HPV. This experiment allows us to gauge whether elicitation of sympathy or perceptions of innocence change when prompted to think about sexual behaviour. Respondents therefore received one of two versions of the question, one where they are told that HPV is a sexually-transmitted disease (STD) that can cause cervical cancer, and a control where they are not told it is sexually transmitted. We asked participants, 'HPV, or "human papilloma virus", can cause cervical cancer in women. Do you approve of the NHS funding of the HPV vaccine for all girls age 12 to 13?' in the control condition (N = 241), and 'HPV, or, the "human papilloma virus," is a common sexually transmitted disease in women. Do you approve of the NHS covering the cost of the HPV vaccine for all girls age 12 to 13?' in the lifestyle condition (N = 255). Again, there was one omitted condition for this survey experiment, which combined the treatment and control, mentioning both cancer and that HPV is a sexually transmitted disease.

However, questions and experiments on HIV and HPV might also be affected by antigay biases or sexual moralising. Thus, to disentangle the conversation from sex and sexual identity we included a third survey experiment on type 2 diabetes. In the survey we ask about support for a hypothetical drug to prevent type 2 diabetes, while either including or excluding information about type 2 diabetes being associated with unhealthy lifestyle causes. We asked respondents 'Would you approve of NHS covering the cost of a drug that

could effectively prevent type 2 diabetes' in the control condition (N = 367), and 'Would you approve of NHS covering the cost of a drug that could effectively prevent type 2 diabetes, which is often associated with unhealthy eating and inactive lifestyles?' in the lifestyle condition (N = 356).

Our analysis compares respondents who are exposed to a 'lifestyle' treatment versus a control treatment. To consider these potential differences, we estimate three separate t-tests, with support for the funding of disease prevention as the dependent variable in each case. Each of these tests is reported in Table 1.

Patient and Public involvement

There was no patient or public involvement in this study.

RESULTS

Overall, support for prevention is high in each case. On a scale of 1 to 5 where 5 indicates greatest support, respondents in our sample across all conditions are well above the midpoint for support of HPV prevention (mean = 4.21, SD = 1.07), diabetes (mean = 3.78, SD = 1.11), and HIV (mean = 3.80, SD = 1.08) (see Figure 1). HPV prevention support is significantly higher than both support for HIV prevention (t= 8.22, p=0.01) and support for diabetes prevention (t= 10.33, p=0.01). Support for HIV prevention and for diabetes prevention is not statistically different (t= 0.42, p=0.68).

[FIGURE 1 ABOUT HERE]

Table 1: T-tests estimating support for funding prevention of PrEP, diabetes, and HPV

	HIV	Diabetes	HPV
Lifestyle	3.73 (1.09)	3.53 (1.08)	3.96 (1.18)
Control	3.86 (1.07)	4.03 (1.09)	4.43 (0.90)
T statistic	0.88 (0.38)	6.22 (0.01)*	4.80 (0.01)*
(significance)			
n	220	723	466

Means reported in first two rows, with standard deviation in parentheses. Note that n's are different for each test due to different numbers of conditions.

Overall, we find what we refer to as lifestyle stigma—effects of reminding participants of the lifestyle element of each of the three diseases we consider—for two of the three experiments (see Table 1 for test statistics).

In the case of diabetes, respondents are roughly half a point less supportive of funding prevention efforts when reminded of the lifestyle component of the disease ('unhealthy eating and inactive lifestyles') than when they are not (lifestyle mean = 3.53, control mean = 4.03, p<0.01).

When considering support of HPV prevention efforts, findings are similar, with respondents about half a point less supportive of funding prevention efforts when reminded that HPV is a sexually transmitted disease as compared to when that information is absent (lifestyle mean = 3.96, control mean = 4.43, p<0.01). Interestingly, we see an identical pattern, though at a lower level of support, when we ask about support for funding HPV prevention for boys. Mean support is lower compared to that of girls (4.08 versus 4.24, p<.01 when testing difference of means), and the pattern of support by condition mirrors that reported above – support is lower when sexual transmission is mentioned (p<.01).

When looking at support for HIV prevention, however, the pattern changes.

Specifically, we see no statistical difference between those who are reminded of lifestyle

^{*} p<0.01

factors related to contracting HIV ('people who have frequent sex with multiple partners') as compared to those who do not (lifestyle mean = 3.73, control mean = 3.86, p=0.38).

Notably, we have a lower n for this test (a total of 220 compared to 723 for diabetes and 466 for HPV) but should still have sufficient power to detect differences if they exist.

DISCUSSION

Results from the experiments suggest the relationship between lifestyle stigma and public attitudes on government healthcare expenditures is not clear-cut. Respondents who were asked about support for funding the HPV vaccine and told that it was a sexually transmitted disease were less likely to support it than those who were not. We found similar patterns with type 2 diabetes when respondents were given questions with additional information about its behavioural causes. But, surprisingly, we found no evidence of a lifestyle stigma in the experiment on HIV and PrEP. Thus, we do not have support across all three cases for our hypothesis that attitudes on public healthcare expenditures would sour when primed to think about the lifestyle causes of certain diseases. Therefore, we cannot say that public attitudes are broadly affected by the perception that those treatments are for diseases seen as being the result of poor lifestyle or irresponsible behaviour.

Our findings corroborate earlier research on British attitudes on care rationing, which similarly revealed diverse public preferences.[28] They further complicate and fill a major gap in earlier PrEP literature which found stigma towards PrEP use/provision in provider and some beneficiary communities,[31, 35, 36] but which—with few exceptions [30]—has so far not examined whether such lifestyle stigma affects general public support for PrEP (and specifically publicly-provisioned PrEP).

Given shifts toward responsibilisation in healthcare, diminished resources, and the strongly negative media narrative surrounding HIV and PrEP when the survey was

conducted, what might explain our divergent findings on lifestyle stigma? Specifically, what explanation can we offer for why we saw no 'lifestyle' priming difference for HIV? One possibility relates to knowledge. Perhaps people know enough about HIV to know that it is a sexually transmitted disease.[54, 55] For that reason, they are effectively thinking about it as a lifestyle disease whether the framing of the question prompts that or not. So even when we do not mention that HIV is sexually transmitted, that is a salient element of what people know about the disease, and therefore already top-of-mind.[56] This would explain why we see effects for HPV—where people are less knowledgeable about how the disease spreads [57]—but not for HIV.

Alternatively, drawing upon stigma literature, [40-42, 47, 58] we suggest an additional possible explanation: public attitudes of personal responsibility can be mitigated by perceptions of disease fatality and incurability, whether seen as the result of a one-time indiscretion or the long-term accumulation of bad behaviour. [58-60] Public perceptions of contracting HIV are often circumscribed by notions of blame and personal responsibility, [47, 55, 60] as the recent media coverage over NHS funding of PrEP suggested. [4] Yet, we found broad support for public-provisioned PrEP (and for public funding of prevention of HPV and diabetes). This echoes findings elsewhere [58] showing that because people perceive HIV to be life-threatening, they attach less importance to the stigma associated with how it was acquired. This could explain why support for PrEP was unaffected by lifestyle stigma; sympathy (or pity) for a 'fatal' illness could outweigh blame for how they contracted the disease via perceived 'risky' lifestyle behaviours.

The presence of a lifestyle stigma *was* statistically significant for public support of an NHS-funded HPV vaccine: we found that support was higher in the control condition where HPV was said to cause cervical cancer but no links to sexual lifestyle were mentioned. This is

consistent with previous research on HPV, which shows that knowledge of it being sexually transmitted can activate stigma against victims, and a tendency to blame the victim [46, 47].

However, it is possible that public support for PrEP and the HPV vaccine is also driven by fear. Diseases perceived as life-threatening can often cause healthy individuals to feel particularly vulnerable.[59, 58] Persistent beliefs that those infected lead 'lonely, hard, and isolated lives' cause some to take overly-cautious, even irrational measures to guard against HIV transmission.[55; 61] The incurability of HPV underlies public fear around it as well.[46] Thus, fears of communicability, concerns of their own vulnerability, and the drive for self-preservation could increase support for public provision of PrEP and the HPV vaccine regardless of personal prejudice.

By contrast, we found that type 2 diabetes received low support for publicly-funded interventions and demonstrated the strongest example of lifestyle stigma. This may be due to the prevalence of diabetes-related stigma, [6, 50] which is often linked with obesity-related stigma. [6] Whereas contracting HIV and HPV might be perceived as the result of a 'youthful indiscretion' or a single 'fateful mistake', type 2 diabetes is seen as the long-term accumulation of poor lifestyle choices. A chronic disease, type 2 diabetes is also widely understood to be manageable and potentially reversible with strict diet, exercise, and monitoring [62, 63]—the implication being that those who are unable to do so bear full responsibility for their disease. [6] Family support for people with diabetes has been found to decline over the long-term, while people with HIV experience greater family support than those with diabetes. [38] Recent US public attitudes research speaks to our lifestyle stigma finding around diabetes, showing worsening negative bias towards body weight/obesity, which the study authors note is a target of moral judgment due to perceived

controllability.[64] The strong lifestyle stigma could also be explained by race-based and class-based prejudice associated with type 2 diabetes.[6, 62]

Both where we see evidence of a lifestyle stigma in public support (HPV and type 2 diabetes) and where we do not (HIV), attitudes are likely shaped by many factors, including pre-existing perceptions and beliefs about disease fatality and acquisition (whether accurate or not). Studies on mass opinion show people are more likely to resist messages when those messages contradict their pre-existing worldviews.[56] Likewise, what we might be seeing in our study is the dominance of pre-existing worldviews on HIV, HPV, and type 2 diabetes and how they can affect public support for health policies.

LIMITATIONS

It is important to note that surveys do not always provide an accurate picture of public opinion. Results can vary by how, and when, public opinion is measured.[14, 25, 65-67] On matters concerning the NHS, public opinion can be volatile and unstable.[25] Because surveys are never conducted in a political vacuum, fast-changing media coverage can influence respondents, resulting in differing responses even when questions are identically worded.[25, 65] Moreover, respondents from online panels such as Prolific are not representative of a more general population, so results should be interpreted cautiously. While we employed survey experiments to minimise potential biases, some caution is still required when comparing the three experiments, particularly because the HIV experiment tests behaviour and lifestyle somewhat differently than those on HPV and type 2 diabetes. While these are weaknesses of our study, we also point out a key strength: The survey was conducted when the media narrative on HIV and PrEP was especially sustained and negative—'easy test' conditions wherein attitudes should have most strongly affected by

biases. Thus, we believe our findings of no lifestyle stigma in the PrEP experiment to be especially robust.

CONCLUSION

Despite finding broad participant support for PrEP in the case of HIV, results from the two experiments demonstrate that public opinion on health expenditures is not immune from lifestyle stigma. When framed in certain ways, Britons remain sensitive to the relationship between lifestyle behaviours and poor health. We explain this difference primarily by suggesting that pre-conceived (mis)understandings of the three diseases drive support up in some cases (HIV), and down in others (HPV, type 2 diabetes).

Regardless of how variation across the experiments is explained, our study contains important implications for health policymakers and practitioners. Support for publicly-provisioned treatments was quite high for all three diseases. But attitudes on healthcare expenditures are more complex than anticipated. Participant support for PrEP—where we had expected the greatest lifestyle stigma—is unlikely reflective of a broader shift in attitudes toward other diseases attributed to poor lifestyle. Yet, on the flip side, this presents a policy window[68] for PrEP: if policymakers seek to take advantage of an approving public, then this is all the more reason to do it urgently while public support for government-provisioned PrEP is still high.

However, the way health problems are discussed and framed continues to affect public attitudes on how—and if—the government should cover the costs to address them.

But this is also dependent on other factors, which makes the job of health policymakers and practitioners all the more difficult. This is particularly relevant in political contexts like

Britain where publicly-funded healthcare makes health policy more susceptible to public opinion—and simultaneously public opinion places a growing emphasis on the role of

personal responsibility in individual health.[23, 25-28, 5, 7] Ultimately—and challengingly—the unexpected and uneven pattern of public attitudes on healthcare expenditures requires greater savviness and attentiveness in responding to media narratives and taxpayers' views.

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FOOTNOTES

Contributors:

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FIGURE LEGEND

Figure 1: Mean support for public funding of disease prevention by experimental condition.

Data are shown from 2016 survey of 738 respondents in Britain that demonstrate mean

levels of support for publicly-funded preventions for HIV, type 2 diabetes, and HPV. Values

are on a scale of 1 to 5 where 1 is 'strongly disapprove' and 5 is 'strong approve'. The blue

bar indicates mean level of support for the lifestyle treatment in the survey experiment,

while the orange bar represents the mean level of support for the control

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