Questions from the Quality Management Summit
October 20, 2021

Stigma

- Q for @Dr. EARNSHAW. Please share any evidence/research on how routine HIV testing contributes to destigmatizing HIV (or STI testing) or in support of "normalizing" routine HIV testing.

Dr. Earnshaw: I know of research suggesting that less HIV stigma leads to more HIV testing, but I'm not familiar with research suggesting that HIV testing leads to lower HIV stigma. Theoretically, it makes sense (especially because HIV testing often involves some education about HIV) but I haven't seen that study. Here's one study that observed that people who tested for HIV had lower HIV stigma. But given the design of the study, it's not clear whether low levels of stigma led people to get HIV tests (i.e., low stigma caused more HIV testing) or whether HIV testing led to lower levels of stigma (i.e., HIV testing caused lower stigma). [see attached article]

PrEP

- Danielle Warren-Dias: Can we hear more about linkage to online PrEP prescriber?
- Daniel Davidson: It would be great to hear from APNH about how the online PrEP service has been going. We might need to give them a bit longer to get more clients linked but could be a CHPC presentation in the future?

Will Kenny: I'd suggest following up with Barry about APNH's online PrEP prescription process. It's something we started this summer.

Health Equity

- Links to additional research

Scott Braithwaite: See attached article as a good introduction to inequality-aversion approach to cost-effectiveness analyses.

Changing patterns in HIV/AIDS stigma and uptake of voluntary counselling and testing services: The results of two consecutive community surveys conducted in the Western Cape, South Africa

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Changing patterns in HIV/AIDS stigma and uptake of voluntary counselling and testing services: The results of two consecutive community surveys conducted in the Western Cape, South Africa

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Voluntary counselling and HIV testing (VCT) has been associated with decreased human immunodeficiency virus (HIV) risk behaviour, but in South Africa, which has the largest HIV/acquired immune deficiency syndrome (AIDS) epidemic in the world, uptake of VCT remains low. HIV/AIDS-associated stigma has been identified as a barrier to HIV testing. This study explored changes in stigma, and VCT access in a peri-urban South African community with high HIV prevalence, following education and research interventions, as well as the introduction of a wide-scale antiretroviral therapy (ART) programme. Two cross-sectional community surveys assessing HIV knowledge, attitudes and uptake of VCT services were conducted. The first survey was performed in 2004 prior to the implementation of a community-based HIV awareness and education campaign, HIV prevention research studies and the introduction of an ART programme. The second survey was performed in 2008 after a three-year education programme, the implementation of HIV-related research studies and following the scale-up of the ART programme. The same study design was used in both the 2004 and 2008 surveys: 10% of households were randomly selected and all residents aged ≥ 14 years were invited to complete a self-administered questionnaire. Overall basic knowledge of HIV/AIDS increased from 2004 to 2008 ($p = 0.04$) and stigmatisation towards HIV-positive individuals decreased over the same time period ($p < 0.001$). Increasing knowledge score was significantly associated with a lower stigma score ($p < 0.001$). Decreasing stigma score was associated with knowing someone who was HIV infected ($p < 0.001$), or who had died from HIV/AIDS ($p = 0.04$). The proportion of participants who had undergone HIV testing increased from 2004 to 2008 (40 vs. 70%, respectively) and, in particular, VCT increased from 26 to 43%. In adjusted analysis, participants who had undergone HIV testing were more likely to have a higher HIV knowledge score ($p = 0.02$) and a lower stigma score ($p = 0.09$). A reduction in levels of HIV/AIDS-associated stigma was noted in a community burdened with high HIV prevalence, as was an increase in reported VCT. These findings may be the result of a number of interventions including a wide-spread and targeted education campaign, and the "normalisation" of HIV through the availability of ART. Given the role of HIV/AIDS-associated stigma in influencing choices to access HIV testing, and the benefits associated with HIV testing, interventions to reduce stigma in communities affected by this disease should be encouraged.

Keywords: community; knowledge; HIV testing; VCT; stigma

Introduction

South Africa has the world's largest human immuno-deficiency virus (HIV)/acquired immune deficiency syndrome (AIDS) epidemic (UNAIDS & World Health Organisation, 2009), yet recent studies point to persistent inadequacies in HIV transmission knowledge (Griessel et al., 2010; Ragnarrsson, Onya, & Aaro, 2009). Effective strategies to increase knowledge and reduce risk behaviour are urgently needed. Voluntary counselling and testing (VCT) provides the opportunity to educate and promote behaviour change (Authors not listed, 2000). However, uptake of testing services remains low (Pettifor, Macphail, Suchindran, & Delaney-Moretlwe, 2008) and research in developed and developing countries has highlighted a number of barriers to accessing VCT, including

HIV/AIDS-associated stigma (Bond, Chase, & Aggelton, 2002; Chesney & Smith, 1999; Herek, 1999). Several definitions of stigma are reported in the literature, but in this context, the term stigma refers to "a social process through which individuals are devalued on the basis of particular negatively perceived characteristics or status" (Maughan-Brown, 2010). Simbayi et al. (2007) define internalised stigma as "a socially constructed view of AIDS that is assimilated and internalised by infected persons (themselves)" (p. 1824). Both internalised stigma and fear of stigmatisation (discrimination by others) serve as barriers to VCT. Individuals who expressed or ascribed greater shame, guilt, and social disapproval towards people living with HIV/AIDS (PLWHA) are less likely to test for HIV/AIDS (Pettifor et al., 2008). Among individuals who considered HIV testing, fear

of stigmatisation due to a positive result was reported as a key reason for not testing (Meiberg et al., 2008; Solomon, Venkatesh, Srikirishnan, & Mayer, 2008).

Several studies in South Africa have attempted to quantify HIV/AIDS-associated stigma (Maughan-Brown, 2010; Shisana & Simbayi, 2002). In 2002, a national population-based household survey showed measurable levels of stigma: 26% of respondents would not be willing to share a meal with a PLWHA, 18% would be unwilling to sleep in the same room with someone with AIDS and 6% would not talk to a person they knew to have AIDS (Shisana & Simbayi, 2002).

Maughan-Brown (2010) reports on changes in different dimensions of HIV-associated stigma by assessing data from two surveys conducted in 2003 and 2006 among a cohort of young adults in Cape Town, South Africa. This study reported that HIV-associated stigma had increased and, more specifically, that knowing someone who had died of HIV-related diseases increased both instrumental (negative judgement based on inflated fears) and symbolic stigma (negative moral judgement). Increased personal contact with PLWHA was not significantly associated with changes in stigma.

There is a paucity of research in sub-Saharan Africa exploring changes in stigma over time and the impact of these changes on VCT access. We used data from two consecutive community based, cross-sectional surveys, performed 4 years apart, to describe the changes in stigma, HIV knowledge and VCT access over time in a community with high HIV prevalence.

Methods

Two cross-sectional community surveys assessing HIV knowledge, attitudes and uptake of VCT services were conducted 4 years apart in a peri-urban township in the Western Cape, South Africa. The community is described elsewhere (Middelkoop, Bekker, Myer, Whitelaw, Grant, Kaplan, 2010), but in brief is a well-demarcated township of predominantly low socio-economic status. The community population grew from 12,801 residents in 2004 to 14,592 in 2008 and HIV prevalence among residents ≥ 15 years of age was 23% in 2004 and 26% in 2008 (Middelkoop et al., 2010; Wood et al., 2007). Antiretroviral therapy (ART) became available in this community in 2004, with 21% of HIV-infected population receiving treatment by 2008.

The first survey was performed in 2004 prior to the implementation of a community-based HIV awareness and education campaign, HIV prevention research studies and the introduction of an ART programme. The second survey was performed in 2008 following a three-year education programme, the implementation of HIV-related research studies and the scale-up of the ART programme. The education campaign (described elsewhere [Middelkoop, Myer, Smit, Wood, & Bekker, 2006]) included both drama sketches and didactic teaching, and focused on addressing key HIV knowledge issues, correcting myths and misconceptions, promoting VCT and explaining HIV-related research projects in the community.

The same study design was used in both the 2004 and 2008 surveys (Smit et al., 2006). Following a random selection of 10% of plots (in formal sector) and 10% of households (in informal sectors) in the community, all residents in these households aged 14 years and older were invited to participate in the study. Up to three attempts were made to contact eligible participants. Participants completed a self-administered questionnaire, which was available in the two dominant languages of the community, such as English and Xhosa. The same questionnaire was used in both surveys, with additional questions exploring participants' exposure to research and the community-based education campaign included in the 2008 survey. The questions on HIV/AIDS stigma were a combination of behavioural intentions towards PLWHA and instrumental stigma (negative judgement).

All participants provided written informed consent and these studies were approved by the Human Research Ethics committee of the University of Cape Town.

Data were analysed using STATA 10.0 (Stata-Corp, College Station, TX). Bivariate analyses employed Wilcoxon sum rank and χ^2 tests, as appropriate for comparison of variables between the two surveys. Cronbach's alpha reliability coefficients of 0.74 and 0.73 were obtained for knowledge and stigma variables, respectively, showing acceptable internal consistency of these measures. Therefore, a general HIV knowledge score was calculated as the number of correct answers to 17 questions pertaining to basic HIV concepts. Participants who answered "unsure" or "refuse to answer" were grouped with incorrectly answered for this analysis. The HIV stigma score was calculated by summing the answers to eight questions positively indicating stigma towards HIV positive individuals. High stigma scores indicate high levels of stigma. Answers to stigma questions were compared across both surveys, and participants who answered "unsure" or "refuse to answer" to these questions where grouped with those who gave a stigmatising answer. A multivariate linear

regression model was developed to examine changes knowledge and stigma scores between the two surveys, after adjusting for potential confounders. Collinearity between education level and knowledge score was assessed using a variance inflation factor. Univariate linear regression models assessed the association between stigma scores and knowing someone who was infected with HIV or who had died from HIV/AIDS-related illnesses. A multivariate logistic regression model was developed to examine factors associated with VCT in 2008.

Results

In 2004, 200 (10%) plots or households were randomly selected, comprising 1127 eligible residents. Of those eligible, 725 (64%) completed the study questionnaire; 85 questionnaires were discarded due to substantial missing data (Smit et al., 2006). In 2008, using the same 10% sampling technique, there were 1318 eligible residents on the 316 randomly selected plots or households. Of these, 1281 (97%) completed the questionnaire. In 2008, the non-responders either could not be contacted by fieldworkers ($n = 19$) or refused participation ($n = 18$). No questionnaires from the 2008 survey were discarded due to substantial missing data. The demographic characteristics of the two samples are shown in Table 1. While the samples were comparable in terms of age and gender, participants in 2008 reported higher levels of education, although proportionally fewer were employed, compared with participants in 2004.

HIV/AIDS knowledge

Reported access to HIV/AIDS information was higher in 2008 compared with 2004. In 2008, more participants reported access to HIV/AIDS information through newspapers (21% compared with 11% in 2004; $p < 0.001$), at the local clinic (34% in 2004 vs. 63% in 2008; $p < 0.001$) and at a hospital (13% in 2004 vs. 21% in 2008; $p < 0.001$). Access to HIV/AIDS information from family or schools remained relatively constant across the two surveys. In both surveys, 16% of participants reported receiving information from their family ($p = 0.84$). In 2004, 24% reported receiving HIV/AIDS information from school versus 28% in 2008 ($p = 0.07$). The additional questions in 2008 regarding educational and research activities showed that 27% of participants received HIV information from talks in the community and 11% received information from a research study.

Table 2 compares responses to individual HIV knowledge questions and the overall composite knowledge score between the two surveys. The overall knowledge score was significantly higher in the second survey, compared to the first survey ($p < 0.001$), and this finding persisted after adjusting for age, gender, education and employment ($p = 0.04$). In this regression model, education was the only significant predictor of knowledge score. The linear regression model is reported in Table 3.

HIV/AIDS stigma

In 2008 compared with 2004, more people reported knowing someone who was HIV-positive (56 vs. 44%, respectively, $p < 0.001$), having an HIV-positive

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Table 1. Demographic characteristics in the survey 2004 and 2008.

Demographic characteristic	2004 (Survey 1) Total $n = 640$[a] n (%)	2008 (Survey 2) Total $n = 1281$[a] n (%)	p-value
Age: median (interquartile range [IQR])	27 years (IQR: 21–36)	27 years (IQR: 22–33)	0.07
Gender			
Male	251 (41%)	552 (44%)	0.40
Female	354 (59%)	715 (56%)	
Education (school)			
Primary	150 (26%)	159 (14%)	<0.001
Secondary	370 (63%)	834 (72%)	
Tertiary	64 (11%)	165 (14%)	
Employed			
Yes	260 (47%)	386 (31%)	<0.001
No	294 (53%)	840 (69%)	

[a]While there were no substantial sections of missing data, some questions were skipped by participants. Therefore, the n for each variable may not be equal to the total n for the survey.

Table 2. Correctly answered HIV/AIDS knowledge questions.

Knowledge questions	2004 (Survey 1) Total $n = 640$[a]	2008 (Survey 2) Total $n = 1281$[a]	p-value[b]
Is HIV a curse from god?	413 (72%)	838 (67%)	0.03
Is HIV a curse from the ancestors?	466 (84%)	929 (75%)	<0.001
Is HIV a bewitching?	384 (70%)	891 (73%)	0.28
Can a person become infected with HIV from insects or pets?	420 (74%)	955 (77%)	0.29
Can a person become infected with HIV from drinking dirty water?	498 (87%)	1087 (87%)	0.87
Can a person become infected with HIV from sharing cups or cutlery?	520 (90%)	1148 (91%)	0.53
Can a person become infected with HIV from hugging?	529 (93%)	1131 (92%)	0.50
Can a person become infected with HIV through sex?	425 (71%)	1113 (89%)	<0.001
Can a person become infected with HIV from sharing food with someone who is infected with HIV?	494 (85%)	1083 (87%)	0.47
Can a person who is infected with HIV look healthy?	361 (63%)	891 (72%)	<0.001
Do you think HIV causes AIDS?	534 (92%)	1115 (92%)	0.97
Do you think you can die from AIDS?	555 (94%)	1082 (89%)	<0.001
Can a pregnant woman infected with HIV or AIDS pass the illness to her unborn child?	470 (83%)	871 (71%)	<0.001
Can a pregnant woman infected with HIV or AIDS prevent her baby from becoming infected by taking medication?	388 (70%)	930 (76%)	0.01
You can protect yourself from getting HIV by using a condom when you have sex?	520 (81%)	1080 (84%)	0.09
You can protect yourself from getting HIV by knowing if you or your partner is infected with HIV?	54 (8%)	164 (13%)	0.004
You can protect yourself from getting HIV by not having sex?	306 (48%)	620 (48%)	0.81
Composite knowledge score[c]: median (IQR)	13 (10–14)	13 (11–15)	<0.001[d]

[a]While there were no substantial sections of missing data, some questions were skipped by participants. Therefore, the n for each variable may not be equal to the total n for the survey.
[b]Chi-square test of proportions.
[c]Compiled based on correct answers from 17 HIV knowledge questions.
[d]Wilcoxon sum rank test of comparison of medians.

family member (36 vs. 9%, respectively, $p < 0.001$), as well as reporting the death of a family member due to HIV/AIDS (30 vs. 12%, respectively; $p < 0.001$).

Answers to questions exploring attitudes and stigma towards HIV-positive individuals are reported in Table 4. The composite stigma score was significantly lower in 2008 compared with 2004 (median score 2 vs. 3, respectively; $p < 0.001$). The multivariate linear regression model assessing factors associated with stigma score is shown in Table 5. The difference in composite stigma scores between survey years persisted after adjusting for age, gender, education, employment and composite knowledge score ($p < 0.001$). In the model, increasing knowledge score was significantly associated with a lower stigma score (stigma score decreasing by 0.1 point for every point increase in knowledge score (95% CI: -0.15 to -0.09). There was no evidence of collinearity between education and knowledge score in this model (VIF $= 1.23$).

In univariate regression analysis across both surveys (2004 and 2008 data combined), a lower stigma score was associated with knowing someone who is HIV infected (stigma score 0.35 points lower if participant knew an HIV-infected individual; $p < 0.001$). This association was greatest if the infected individual was a family member (0.53 drop in stigma score; $p < 0.001$), a friend (0.40 drop in stigma score; $p = 0.003$), or a sexual partner (0.40 drop in stigma score; $p = 0.09$) compared to an acquaintance (0.15 drop in stigma score; $p = 0.24$). Similarly, a lower stigma score was associated with knowing someone who had died from HIV/AIDS (stigma score 0.20 points lower if participant knew someone who had died; $p = 0.04$). This association was also greatest if the deceased was a family member (0.41 drop in stigma score; $p = 0.002$) or a friend (0.59 drop in stigma score; $p < 0.001$), compared to a sexual partner (0.18 drop in stigma score; $p = 0.52$) or an acquaintance (0.07 drop in stigma score; $p = 0.55$).

HIV testing

Uptake of HIV testing was significantly higher in 2008 compared with 2004 (in 2008 70% reported

Table 3. Multivariate linear regression model assessing factors associated with knowledge score.

	Adjusted coefficient	95% Confidence interval	*p*-value
Survey year	0.35	0.01–0.68	0.04
Age	−0.003	−0.02 to 0.01	0.74
Gender	0.16	−0.15 to 0.47	0.33
Education (school)			
Primary	Reference		
Secondary	0.75	0.32–1.18	0.001
Tertiary	1.51	0.93–2.09	<0.001
Employment	0.02	−0.17 to 0.21	0.81

having "ever been tested for HIV/AIDS" versus 40% in 2004; *p* <0.001). Table 6 shows the reasons for HIV testing and Table 7 shows reasons for never testing for HIV/AIDS. We distinguished between patient-initiated HIV testing (i.e. VCT) and provider-initiated HIV testing. As shown in Table 6, reported uptake of VCT was significantly higher in 2008 compared with 2004 (43 vs. 26%, respectively; *p* <0.001). Table 8 reported the multivariate logistic regression model assessing factors associated with VCT in 2008.

In 2008, participants who had undergone VCT compared to those who either underwent HIV testing due to a medical indication or who had not tested for HIV were less likely to be female (OR: 0.43, 95% CI: 0.32–0.58), to have a higher education (secondary school: OR: 1.92, 95% CI: 1.15–3.22; tertiary education: OR: 2.71; 95% CI: 1.47–5.00), a higher HIV knowledge score (OR: 1.07, 95% CI: 1.01–1.13) and a lower stigma score (OR: 0.92, 95% CI: 0.84–1.01).

Discussion

This paper is among the first to compare two HIV knowledge and stigma surveys conducted in the same community, before and after the implementation of a community-wide HIV education campaign and implementation of an ART programme, and to relate these findings to reported HIV testing uptake in the same community. Furthermore, this paper reports on the community-level benefits obtained from community-based research projects, in terms of both increased levels of HIV knowledge and testing.

There was an increase in reported access to HIV/AIDS information from 2004 to 2008. Access to HIV/AIDS information at the local clinic increased significantly and this may be a consequence of increased uptake of VCT services, as well as the education campaigns run in the clinic waiting rooms. However, it should be noted that access also increased at the local hospital, which offers VCT but was not a targeted education campaign venue. In addition, 27% of the 2008 survey sample reported receiving HIV information from HIV/AIDS talks in the community, and a

Table 4. Assessment of HIV stigma across the two surveys.

Stigma questions	2004 (Survey 1) *n* = 537	2008 (Survey 2) *n* = 1143	*p*-value[b]
Would you be willing to share a meal with a person you knew had HIV/AIDS? (answered "yes")	347 (63%)	949 (76%)	<0.001
If a teacher has HIV/AIDS but is not sick should he or she be allowed to continue teaching? (answered "yes")	389 (70%)	1077 (86%)	<0.001
If a student has HIV/AIDS but is not sick should he or she be allowed to attend school? (answered "yes")	401 (73%)	1106 (88%)	<0.001
If you knew a shop keeper with HIV/AIDS would you buy food from him or her? (answered "yes")	337 (61%)	978 (78%)	<0.001
If a male relative of yours became ill with AIDS would you be willing to care for him in your household? (answered "yes")	415 (76%)	1058 (86%)	<0.001
If a female relative of yours became ill with HIV/AIDS would you be willing to care for her in your household? (answered "yes")	430 (78%)	1099 (89%)	<0.001
If a family member became ill with HIV/AIDS would you want it to remain a secret? (answered "no")	133 (24%)	369 (30%)	0.02
If you became infected with HIV, would you want it to remain a secret? (answered "no")	147 (27%)	656 (54%)	<0.001
Composite stigma score[c] median (IQR)	3 (2–5)	2 (1–2)	<0.001[d]

[a]While there were no substantial sections of missing data, some questions were skipped by participants. Therefore, the *n* for each variable may not be equal to the total *n* for the survey.
[b]Chi-square test of proportions.
[c]Compiled based on stigmatised answers to eight questions assessing attitudes towards HIV-infected persons.
[d]Wilcoxon sum rank test of comparison of medians.

Table 5. Multivariate linear regression model assessing factors associated with stigma score.

	Adjusted coefficient	95% Confidence interval	p-value
Survey year	−1.08	−1.29 to −0.88	<0.001
Age	0.004	−0.005 to 0.01	0.32
Gender	−0.04	−0.23 to 0.15	0.69
Education (school)			
Primary	Reference		
Secondary	−0.21	−0.48 to 0.05	0.11
Tertiary	−0.30	−0.65 to 0.05	0.10
Employment	0.08	−0.03 to 0.19	0.16
Knowledge score	−0.12	−0.15 to −0.09	<0.001

further 11% received information from participating in HIV/AIDS research studies, reflecting an additional benefit of the research projects in this community.

The overall increase in the knowledge score across the two surveys was statistically significant but, given the small difference in median scores, may not be practically significant. While some increase in knowledge is expected given the wide-scale community education programme and the numerous research studies performed in this community over the years, the small increase noted may also reflect the relatively good HIV knowledge levels found in 2004. While most significant changes in answers to specific questions were in the direction of improved knowledge, it is interesting to note that fewer people thought one could die from HIV infection in 2008 compared with 2004. This may be due to changing perceptions of HIV disease given the increased availability of ART in this community, and its associated increased survival (Egger et al., 2002).

Table 6. Uptake of HIV testing and reasons reported for testing.

	2004 (Survey 1) n = 630[a]	2008 (Survey 2) n = 965[a]
Ever tested for HIV	203 (40%)	762 (70%)
Reasons for HIV testing		
VCT	51 (26%)	334 (43%)
Pregnancy	57 (29%)	230 (29%)
Tuberculosis	29 (15%)	108 (14%)
Sexually transmitted Infections	33 (17%)	71 (9%)
Partner dies of HIV	3 (2%)	14 (2%)
Other reasons	17 (9%)	21 (3%)

[a]While there were no substantial sections of missing data, some questions were skipped by participants. Therefore, the n for each variable may not be equal to the total n for the survey.

Table 7. Reasons reported for not undergoing HIV testing.

	2004 (Survey 1) n = 630[a]	2008 (Survey 2) n = 965[a]
Never tested	304 (60%)	326 (30%)
Reasons for not undergoing HIV testing		
Never thought about having an HIV test	42 (14%)	44 (14%)
Do not think I am at risk for HIV	38 (13%)	31 (10%)
Concern about confidentiality	23 (8%)	25 (8%)
Concern about a positive result	45 (15%)	23 (8%)
Scared of needles	241 (80%)	13 (4%)
No advantage to knowing your HIV status	24 (8%)	14 (5%)

[a]While there were no substantial sections of missing data, some questions were skipped by participants. Therefore, the n for each variable may not be equal to the total n for the survey.

The composite stigma score shows a significant reduction in stigma between the two surveys and a low stigma score was significantly associated with knowledge and having tested for HIV. Knowing a family member or friend who is HIV infected or died from HIV-AIDS was also associated with a lower stigma score. This underscores the importance of encouraging patients to disclose their HIV status to a trusted family member or friend. In 2008, there was an increase in the number of participants who knew someone who was HIV-positive. Furthermore, the substantially higher participation rate in the second survey may also reflect decreased stigma in the community, with community members more willing to take part in an HIV-related study compared to 2004. Similarly, reported HIV testing increased between the two surveys and there was a significant increase in VCT as opposed to provider-initiated testing for medical reasons, suggesting that this increase in testing was predominantly client driven. The finding of self-reported increased uptake of VCT was consistent with other studies assessing VCT rates in this community (April et al., 2009; Middelkoop et al., 2006).

It is not possible to determine from this study whether the increased VCT uptake was due to decreased stigma, or vice versa, especially as HIV testing was associated with both increased knowledge and decreased stigma scores. Studies in South Africa have shown both that decreased stigma resulted in increased uptake of VCT (Kalichman & Simbayi, 2003) and that HIV/AIDS-related stigma was decreased amongst those who had undergone VCT (Pettifor et al., 2008). Increased VCT uptake and

Table 8. Multivariate logistic regression model assessing factors associated with VCT in 2008.

	Adjusted odds ratio	95% Confidence interval	*p*-value
Age	1.01	0.99–1.03	0.09
Gender			
Male	1 (Reference)		
Female	0.43	0.32–0.58	< 0.001
Education (school)			
Primary	1 (Reference)		
Secondary	1.92	1.15–3.22	0.01
Tertiary	2.71	1.47–5.00	0.001
Employment	0.98	0.81–1.18	0.80
Knowledge score	0.92	0.84–1.01	0.09
Stigma score	1.07	1.01–1.13	0.03

decreased stigma may have been the result of the targeted education campaign as reflected in the increased knowledge scores, and the fact that a quarter of the sample had accessed information through community talks. The increase in numbers of people accessing VCT may also be related to the widespread availability of ART. In addition, the research activities may have contributed to increased knowledge, as a 10th of participants' accessed HIV information through research studies. It is noteworthy that the decrease in stigma was seen at a time when the availability of ART had increased in the community. It is possible that the availability of ART encouraged people to know their status and may have resulted in lower stigma associated with the disease, as patients on ART show improvement in health and are encouraged to disclose their status to family or friends. Similar findings have been reported in studies conducted in countries such as Haiti (Farmer, 2001 in Maughan-Brown, 2010), Brazil (Abadia-Barrero & Castro, 2005) and rural China (Cao, Sullivan, & Wi, 2005). This is in contrast to data reported by Maughan-Brown (2010), which suggested that ART provision was not associated with decreased stigma. However, the Maughan-Brown study recruited a younger population (14–22 years of age) and was implemented earlier in an ART programme and at a lower ART coverage than achieved in our study community.

We encountered limitations in our study. Firstly, the second survey was not administered to the same participants as the baseline survey and therefore matched analyses were not possible. These studies therefore report changes in the overall attitudes and knowledge in the community and do not show changes in specific individuals. However, this study was a conducted in a random sample drawn from a well-defined community, and therefore selection bias

should be minimised and the findings representative of the wider community. Secondly, the questionnaire was self-administered, and while the advantage of this approach is potentially more honest responses, incomplete data were also obtained for some questions. While some questionnaires from the first survey were discarded due to substantial amounts of missing data, these were not necessary in the second survey. The higher education level and better participant training of the second survey sample may account for the improved questionnaire completion. Thirdly, we did not recruit illiterate participants and literacy may influence access to VCT or attitudes to PLWHA. Lastly, we cannot causally link the changes shown in this study to any one intervention implemented in this community: a number of potential influences include community-wide education programmes associated with numerous research studies, other community-based programmes, as well as the impact of the availability of ART.

This study demonstrates that levels of HIV-associated stigma can be reduced over time in a community burdened with a high HIV prevalence, and this reduction is associated with an increase in reported HIV testing. Since HIV testing is the entry point to all HIV prevention and treatment interventions, initiatives to reduce stigma in communities affected by this disease should be encouraged.

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HEALTH ECONOMICS LETTER

ELICITING THE LEVEL OF HEALTH INEQUALITY AVERSION IN ENGLAND

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ABSTRACT

Health inequality aversion parameters can be used to represent alternative value judgements about policy concern for reducing health inequality versus improving total health. In this study, we use data from an online survey of the general public in England ($n = 244$) to elicit health inequality aversion parameters for both Atkinson and Kolm social welfare functions. We find median inequality aversion parameters of 10.95 for Atkinson and 0.15 for Kolm. These values suggest substantial concern for health inequality among the English general public which, at current levels of quality adjusted life expectancy, implies weighting health gains to the poorest fifth of people in society six to seven times as highly as health gains to the richest fifth. Copyright © 2016 John Wiley & Sons, Ltd.

1. INTRODUCTION

Improving total population health and reducing health inequality are two important objectives of health policy. When these two objectives conflict, Health-Related Social Welfare Functions (HRSWFs) can be used to articulate the trade-off between them. Economists have explored the properties of several SWFs, which aim to capture these trade-offs in the form of a single inequality aversion parameter. The Atkinson Index (Atkinson, 1970) and Kolm Index (Kolm, 1976) are two such forms, concerned with relative and absolute concepts of inequality widely used in the income inequalities literature. A range of two person HRSWFs have also been proposed (Wagstaff, 1991; Abásolo and Tsuchiya, 2004), and there have been various attempts to elicit health inequality aversion parameters for some of these functions from interview data of members of the public in England (Dolan and Tsuchiya, 2011; Edlin *et al.*, 2012) and Spain (Abásolo and Tsuchiya, 2013).

Building on the questionnaire instrument employed in these existing studies, we have previously conducted methodological work to develop and validate a video animation that vividly presents different viewpoints and their implications on distribution of health, designed to encourage respondents to think carefully about their responses (Cookson *et al.*, 2015). The contribution of this paper is to elicit inequality aversion parameters for the Atkinson and Kolm SWFs by using online survey data from the general population in England that incorporates this video animation. These parameter values can help to inform health policy makers in England who wish to explicitly incorporate social value judgements concerning health inequalities into decisions regarding the allocation of healthcare resources.

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2. METHODS

2.1. Survey

Details of the survey methods and sample selection are reported in Appendix A in the Supporting Information. Respondents were presented with information highlighting inequalities in expected years of life in full health at birth between the richest and poorest fifths of people in England. Respondents made a series of seven pairwise choices between two programmes, which would increase expected years in full health. In each choice, Programme A favoured the richest fifth and Programme B the poorest fifth. In the first choice, Programme A provided an increase of seven years to the rich and three years to the poor and Programme B provided an increase of three years to the rich and eight years to the poor. In each successive choice, the years gained by the poor group in Programme B were gradually reduced, while everything else was fixed. In each choice, the respondents were asked to decide whether the government should choose Programme A, Programme B or whether the two programmes were 'equally good'.

2.2. Categorisation

To elicit the inequality aversion parameters, we developed a response classification system, which is shown in Appendix B. The point at which the respondent 'switches', or becomes indifferent, between the programmes was used to categorise respondents and derive the level of inequality aversion. Those categorised as 'Pro-Rich' prefer health gains to the better-off, 'Health Maximisers' are concerned only with increasing total health, 'Weighted Prioritarians' give greater weight to the health of the worse-off, 'Maximin' respondents are concerned only with improving the health of the worst-off and 'Egalitarians' value reducing health inequality so much that they are willing to sacrifice potential health benefits to the worst-off.

Figure 1 illustrates a range of iso-welfare curves for the Atkinson Index, plotted at different levels of inequality aversion corresponding to four selected responses. The horizontal and vertical axes represent the quality-adjusted life expectancy of the poorest and the richest fifths, respectively. Point (62,74) is the initial
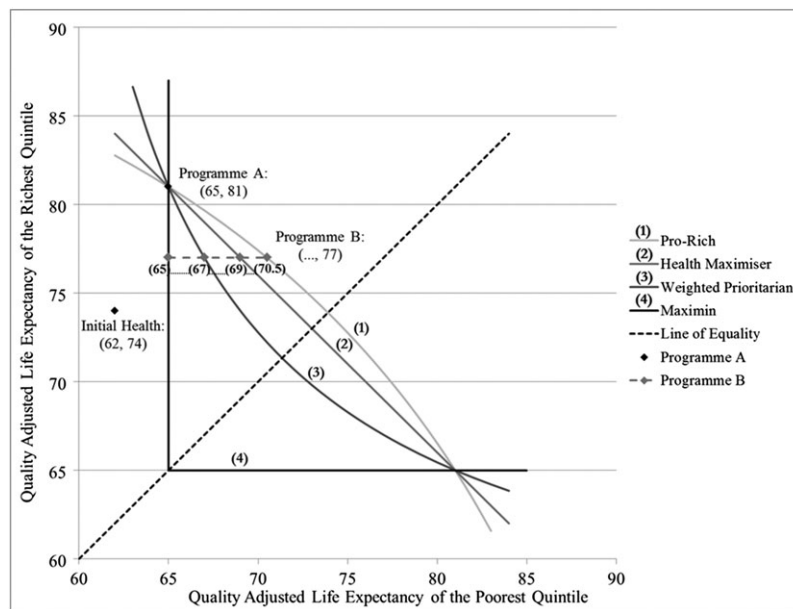

Figure 1. Iso-welfare curves representing response categories

distribution of health, while point (65,81) represents Programme A, which remains fixed through the seven choices. The dashed line from (65,77) to (70.5,77) gives the range of values from Programme B.

2.3. Social welfare functions and equally distributed equivalents

The equally distributed equivalent (EDE) level of health builds on the concept of EDE income, defined as the mean level 'which if equally distributed would give the same level of social welfare as the present distribution' (Atkinson, 1970). It provides an index of social welfare standardised to the mean level of health, which enables the comparison of different health distributions. The equations for the EDEs used in this paper are as follows:

$$EDE_{Atkinson} = \overline{H}.\left[\sum_i \left(\frac{H_i}{\overline{H}}\right)^{1-\varepsilon} f(x_i)\right]^{1/(1-\varepsilon)} \tag{1}$$

$$EDE_{Kolm} = \overline{H} - \left[\left(\frac{1}{\alpha}\right)log\sum e^{\alpha.(\overline{H}-H_i)}f(x_i)\right] \tag{2}$$

In these equations, ε and α are the inequality aversion parameters for the Atkinson and Kolm HRSWFs respectively, where both are unbounded. The greater the value of ε and α, the greater the aversion to inequality. H_i is the level of health (quality-adjusted life expectancy) for subgroup i, $\overline{H}$ is the mean level of health for the entire population and $f(x_i)$ is the proportion of the population in subgroup i. Unlike most previous studies, our data allow the elicitation of negative parameters for individual respondents representing 'inequality seeking' judgements and positive parameters representing 'inequality averse' ethical judgements.

2.4. Parameter elicitation

The point where a given respondent switches from one programme to the other, or selects equally good, is interpreted to reflect the point at which the respondent is indifferent between the two programmes. The implied inequality aversion parameter for each respondent can then be established by numerically solving the EDE equations.

2.5. Establishing a population average

In order to represent an inequality aversion parameter for the population, we use the median response rather than the mean. This is because the inequality aversion parameter approaches infinity for Maximin responses (Dolan and Tsuchiya, 2011). To make the analysis sample as representative as possible, population weights for England for age, gender, income and education were derived from Understanding Society Wave 4 (Essex., 2015) and used to weight sample responses to construct a response set representative of the general population. Further details of this weighting can be found in Appendix C. To allow for uncertainty, we estimate 95% confidence intervals for each parameter by using a non-parametric bootstrap of the survey data, resampling from the population weighted raw data 2000 times.

2.6. Sensitivity analyses

Our classification scheme focused on 'logical' response patterns, in which only one 'switch' is observed or one programme is selected throughout, and the results reported are for those responses that were consistent with this classification. We also conducted sensitivity analyses by using more permissive inclusion criteria, as explained in Appendix D.

3. RESULTS

An online survey generated usable data from 244 respondents whose data were used in the base case analysis (see Appendix C for the characteristics of the analysis sample and Appendix D for a breakdown of those excluded for providing invalid data). Figure 2 illustrates the distribution of responses for each category, after sample re-weighting. Just over half, 50.98%, of the responses were Weighted Prioritarian, but there were substantial responses in the tails of the distribution with 15.58% being Pro-Rich and 26.98% being Egalitarian. The vast majority of respondents, 81.51%, were willing to trade-off some total health in order to reduce health inequality and only 2.91% were strict Health Maximisers. The parameters for each categorical response, for each SWF, can be found in Appendix E.

The elicited inequality aversion parameters, and the EDE level of health they imply, are given in Table I. The results imply that at initial levels of quality-adjusted life expectancy, incremental health gains to the poorest fifth of people in society should be weighted between 6 and 7 times as highly as incremental health gains to the richest fifth. Sample weighted bootstrapping revealed that the 95% confidence intervals did not exceed the category in which the median response was located. Furthermore, the median response did not change with the population weighting.

The median inequality aversion parameters were robust to sensitivity analyses using larger samples (see Appendix D for details).

4. DISCUSSION

4.1. Comparison to previous literature

There have been a number of previous empirical studies of health inequality aversion using the same basic questionnaire instrument in England (Williams *et al.*, 2005; Dolan and Tsuchiya, 2007; Dolan and Tsuchiya, 2009; Dolan and Tsuchiya, 2011) and Spain (Abásolo and Tsuchiya, 2004; Abásolo and Tsuchiya, 2008; Abásolo and Tsuchiya, 2013). All of these studies have found that the majority of the population is willing to sacrifice a substantial amount of total health in order to reduce health inequality, as have most studies using different instruments (Edlin *et al.*, 2012; Attema *et al.*, 2015). In most cases, it is not possible to extract comparable inequality aversion parameter central estimates, because parameters were not reported or are not comparable. However, Dolan and Tsuchiya (2011) report an equivalent
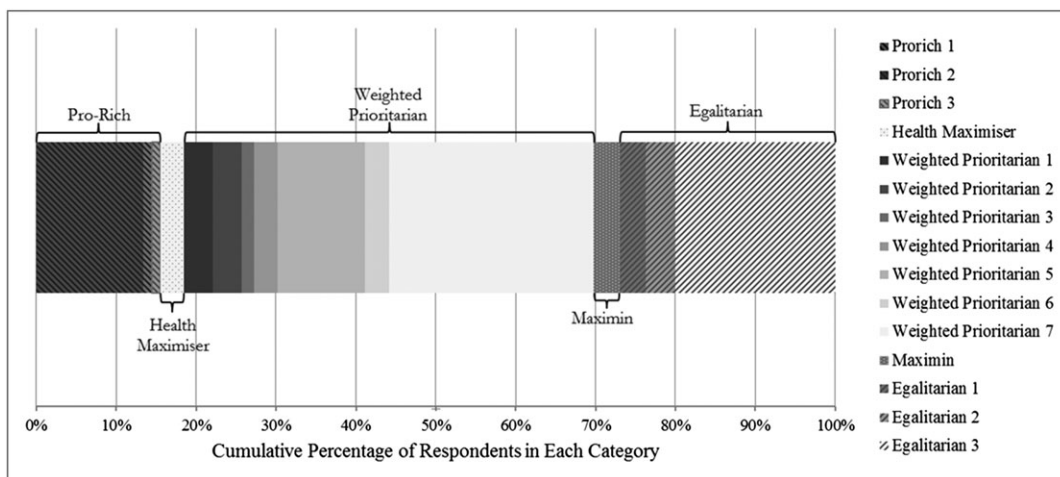

Figure 2. Weighted distribution of categorical responses (*n* = 244)

Table I. Base case inequality aversion parameters with 95% confidence intervals

SWF	Median[a]	Implied weight[b]
	(95% CI)	(95% CI)
Atkinson (ε)	10.95	6.95
	(10.95–10.95)	(6.95–6.95)
Kolm (α)	0.15	6.20
	(0.15–0.15)	(6.20–6.20)

[a]Median preference identified through bootstrapping; population weights used.
[b]Implied weight of marginal health gain to poorest fifth of the population compared with the marginal health gain to the richest fifth of the population at initial health.

Atkinson ε value of 28.9, which is considerably larger than our value of 10.95. There are multiple factors that could explain this difference. One may be that their study did not use a 'slow thinking' intervention (such as our e-learning video animation; Cookson *et al.*, 2015), which may reduce the proportion of respondents expressing extreme inequality aversion (Appendix F); another may be that their study used face-to-face rather than online administration, which is more likely to be associated with social desirability bias leading to more extreme egalitarian responses; a third may be that their study used half-year response categories, which allow more extreme inequality aversion to be expressed. Two of the studies in Spain, Abásolo and Tsuchiya (2004) and Abásolo and Tsuchiya (2013), found such extreme inequality aversion that the Atkinson ε value was not identifiable as the median response violated monotonicity—i.e. Programme B was selected in all choice pairs.

4.2. Application to distributional cost-effectiveness analysis

To illustrate how this value could be used in practice, we present an example from a distributional cost-effectiveness study of two different ways of spending the same fixed budget for increasing uptake of a pre-existing universal bowel cancer screening programme (Asaria *et al.*, 2015). Distributional cost-effectiveness analysis (DCEA) uses inequality aversion parameters to explore the implications of alternative social value judgements when comparing different policy options that involve trade-offs between improving total health and reducing health inequality. When using standard cost-effectiveness analysis, which considers only average quality-adjusted life year gains, it is more cost-effective to spend the budget on a 'Universal' reminder programme rather than a 'Targeted' reminder that reduces health inequality by targeting the most income deprived. As Figure 4 of their paper illustrates, DCEA identifies the threshold level of inequality aversion above which the 'Targeted' reminder becomes cost-effective ($\varepsilon = 8$ and $\alpha = 0.12$). Thus, the corresponding parameter values generated in our study ($\varepsilon = 10.95$ and $\alpha = 0.15$) suggest that the targeted intervention is the intervention that should be chosen in order to maximise social welfare allowing for inequality aversion. Table II illustrates this by computing EDE quality-adjusted life years per 100 000 for different levels of inequality aversion applied to this example.

Table II. QALY and EDE QALY gains per 100 000 population

	Programme	
	Targeted	Universal
Gains in average QALYs ($\varepsilon = \alpha = 0$)	3850	4000
Gains in Atkinson EDE QALYs ($\varepsilon = 10.95$)	3310	3260
Gains in Kolm EDE QALYs ($\alpha = 0.15$)	3300	3270

5. CONCLUSION

Atkinson's and Kolm's inequality aversion parameters were elicited by using an online survey of members of the general public in England. The vast majority of people, 81.51%, were willing to sacrifice gains in total health in order to reduce health inequality. The responses indicate substantial aversion to health inequality among the English general public, in line with findings from previous studies. If these responses are taken at face value, they imply that marginal health gains to the poorest fifth should be given between 6 and 7 times the weight of health gains to the richest fifth. The inequality aversion parameters elicited provide values that can be used within methods such as DCEA. Through using these methods, societal decision-makers can evaluate health policies that have the dual objectives of improving population health and reducing health inequality.

CONFLICT OF INTEREST

The authors have no conflict of interest.

ETHICAL STATEMENT

We obtained research ethics approval from the University of York Health Sciences Research Governance Committee, in a letter dated 23 May 2013. The main ethical issues involved informed consent and data security to ensure participant responses were kept anonymous and no personal data disclosed.

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SUPPORTING INFORMATION

Additional supporting information may be found in the online version of this article at the publisher's website.