

## Psychosocial aspects of anal cancer screening: a review and recommendations

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**Abstract.** Cancer screening programs have the potential to decrease psychosocial wellbeing. This review investigates the evidence that anal cancer screening has an impact on psychosocial functioning and outlines considerations for supporting participants. The review suggested that screening has no significant effect on general mental health but may increase cancer-specific worry. Having worse anal or HIV symptoms, being younger, higher baseline distress or worse histology results were predictive of greater worry. The findings suggest the need to increase education campaigns, particularly targeting those with HIV infection and men who have sex with men. There is a need to develop a consensus on measuring the psychosocial impact of screening and stepped care approaches for responding to any resulting distress.

**Additional keywords:** HIV, HPV, mental health, wellbeing.

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### Introduction

Early detection screening programs are recommended for a variety of cancer types. Although there are well-established population screening programs for other cancers, anal cancer has not been recognised as a high priority for screening until the last 5–10 years.<sup>1–3</sup> High rates of human papillomavirus (HPV) infection and anal cancer in HIV-infected individuals and men who have sex with men (MSM) have led to a growing concern that screening, prevention and early intervention efforts need to be implemented, similar to programs for other cancers.<sup>4</sup> Baseline and annual follow-up anal cytological screening is recommended for HIV-infected individuals in the New York State Guidelines.<sup>1</sup> The need for screening programs has been recognised, with research studies being conducted in North America,<sup>5,6</sup> Europe<sup>7</sup> and Australia.<sup>8</sup>

Progression and regression rates from HPV infection to anal cancer are unknown, but the screening process is similar to the highly effective cervical cancer model.<sup>4</sup> Although there is no universally accepted anal cancer screening or treatment protocol, typically, the screening process involves two stages. A swab is taken and sent for cytological analysis and if further investigation is warranted from non-negative cytology results, a high-resolution anoscopy (HRA; similar to colposcopy) is conducted to determine the extent of disease via biopsy and histology results. The HRA process is potentially uncomfortable

and painful. Additionally, during the waiting periods for both sets of results and for the HRA procedure patients may experience increased distress about the potential for bad news. The severity of the result may have an effect on the psychosocial response. Specifically, different results are likely to convey different levels of perceived risk of disease. For example, the distinction between cancerous and precancerous cytological and histological results can be difficult for patients to understand. In a related area, cervical screening participants found it 'difficult to understand cell changes as anything other than a life-threatening illness'.<sup>9</sup> Levels of education, personal experience with cancer (self or others) and psychological status are all possible moderators of the psychosocial response to screening. Both researchers and clinicians highlight the need to understand the potential psychosocial impact of screening programs, particularly in response to uncertainty associated with screening, procedures and results.<sup>10–14</sup>

### Potential psychosocial impacts of anal cancer screening

The psychosocial impact of anal cancer screening has not been widely investigated in comparison to other forms of cancer. There are numerous studies and systematic reviews examining the psychological effects of cervical,<sup>15</sup> prostate<sup>16</sup> and breast<sup>17</sup> cancer screening programs, and these provide valuable insights into the potential psychosocial effects of anal cancer screening.

The anal cancer screening process is similar to both prostate and cervical cancer screening in several dimensions. For example, they are associated with private parts of the body and are related to sexuality. The screening process has two stages and is very similar to cervical screens and slightly different to prostate screens, which involve a blood test for prostate specific antigen (PSA) followed by transrectal ultrasound-guided and random biopsy.

Increased anxiety, worry about cancer and lower sexual wellbeing have been found with all grades of cervical cytology results.<sup>18-20</sup> Rates of return for repeat testing are lower in those who are most anxious.<sup>19</sup> Men with normal PSA results were less worried than men with benign biopsies even after 12 months. Those with benign biopsies had sought more medical follow-up, talked more to their partners and sought information from the internet.<sup>11,21</sup> It may be that repeat testing, biopsy and concern about false negative biopsies contributed to the ongoing anxiety found, particularly as random biopsy is likely to miss 10% of men with active disease.<sup>21</sup> Although HRA is more targeted than the prostate biopsy process, there may be false negative rates in this process as well.

Other factors that have impacted psychosocial responses are having symptoms before testing, such as men with urinary symptoms<sup>22</sup> or higher anxiety at baseline.<sup>21,23</sup> Having more or less knowledge about the screening and disease are also potential factors. Men who had multiple PSA testing points had increased anxiety at the second and subsequent tests. This may be due to awareness of cancer being raised by the initial PSA result and increasing with each retest.<sup>24</sup> In contrast, having repeated biopsies did not increase anxiety<sup>24</sup> and, although this is speculative, it is possible that repeated biopsy was viewed as a more thorough test and increased reassurance. Being given cervical HPV results increased anxiety,<sup>15</sup> partly due to poor understanding and confusion about HPV infection, particularly the difference between genital warts and high-risk HPV. When women sought information, their anxiety diminished over time.<sup>15</sup> Knowing that HPV can clear on its own and that it would not cause genital warts also reduced anxiety.<sup>25</sup>

Test-specific psychological questionnaires (TSPQs), whether for cervical or prostate screens, compared with generalised psychological questionnaires (GPQs) appear to be associated with a greater sensitivity to psychosocial responses to screening<sup>11,26</sup> and may explain the conflicting results between different studies. Several studies have found that PSA and biopsy results did not increase anxiety, depression or health-related quality of life (QOL) using GPQs.<sup>22-24</sup> It may be important for future studies to utilise TSPQs. There are psychosocial impacts from cervical and prostate screening processes, and the full range of results: better information can improve psychosocial responses.

### Aims

Screening programs have the potential to decrease psychosocial wellbeing and increase avoidance of health testing. There have not been many direct studies in the anal cancer field, so this systematic review will also integrate findings from other relevant cancer screening areas. The aim is to identify the

likely psychosocial effects of anal cancer screening and then suggest how future screening programs could prevent or minimise any negative impacts.

## Method

### Search Strategy

A search of four electronic databases using standard research procedures was conducted in October 2011. The databases were Medline, PsychInfo, Cumulative Index of Nursing and Allied Health Literature and Web of Science. Search terms were entered with combined sets of terms relating to anal cancer, screening and psychosocial impact: (anal) and (cytol\* or screen\*) and (psyc\* or anxi\* or worry). These four searches identified 200 articles; seven were unique and directly relevant to the review. It was not possible to combine the data from these studies in order to conduct a meta-analysis due to the highly variable measures and methods used.

### Inclusion and exclusion criteria

Exclusion criteria were minimal, given the scarcity of publications on this topic. All theoretical, descriptive or empirical studies on the psychosocial characteristics of anal cancer screening were included. Titles and abstracts were reviewed for the following inclusion criteria:

- original research on psychosocial aspects of cancer screening,
- screening for anal cancer,
- published in English.

Articles were further excluded if they described cost-effectiveness, surveyed health care workers only or focussed solely on patients diagnosed with cancer or the effects of cancer treatment.

In order to assess one aspect of study quality and to begin describing the diverse psychosocial domains investigated, studies that used psychological measures with some previously assessed reliability and validity were identified. Measures assessed in other cancer screening contexts (e.g. cervical) were considered to have some established reliability and validity. Table 1 summarises the seven studies.

## Results

### Measures of psychosocial functioning

The articles reviewed used a combination of validated and nonvalidated self-reported psychological measures, which are listed in Table 1. The validated measures can be categorised into GPQs (e.g. the Hospital Anxiety and Depression Scale) and TSPQs such as the Psychological Consequences Questionnaire positive scale, developed to measure the impact of mammography screening on physical, social and emotional domains. The nonvalidated measures were unique to each study and were related to knowledge of HPV, anal cancer and anal Pap tests; attitudes or beliefs; willingness to seek or return to screening, and evaluating screening procedures. All measures that were readily available are in Appendix 1.

**Table 1. Summary of anal cancer screening studies<sup>6,8,27–31</sup>**

LSIL, low-grade squamous intraepithelial lesion; HSIL, high-grade squamous intraepithelial lesion; AIN 2 and 3 & HGAIN, high-grade anal intraepithelial neoplasia; RR, response rate; LTF, lost to follow-up; LCB, lost but came back; RF, regular follow-up; HPV, human papillomavirus; FT work, full-time work; MSM, men who have sex with men; MOS SF-12, Medical Outcomes Study Short Form 12; QOL, quality of life; HRA, high-resolution anoscopy

Author year published, country (study year)	Participants demographics	Design, methods and measures	Main results
<b>Knowledge, attitudes and willingness to have screening (no screening undertaken)</b>			
Pitts <i>et al.</i> 2007, Australia (2005)	n=384 Previous screen 14% Mean age 37 years (16–67) HIV-positive 6% Relationship 47%	Cross-sectional: paper questionnaire at a gay community event Assessed health service use, knowledge, attitudes, and beliefs <sup>A</sup>	Overall low rates of knowledge and previous anal screening. Primary care physicians were the main sources of sexual health check-ups; education needs to be targeted at this group
D'Souza <i>et al.</i> 2008, USA (2005–2006)	n=1917 Previous screen 11% Mean age 48 years HIV-positive 47% Caucasian 63%	Longitudinal: 6-, 12-, 18-month reviews (Visits 43–45 in Multicenter AIDS Cohort Study); interviewer-administered and audio computer-assisted self-interview Anal Pap history, concern about anal cancer, intention to seek screening, perceived screening availability. Men's Attitude Survey <sup>A</sup>	Overall low rates of previous anal screening, concern and intention to seek anal screening Higher rates in HIV-positive patients and in locations where perceived availability of screening was greater MSM rely on primary care physicians for anal health care; training and information needs to be targeted to this group
Truesdale <i>et al.</i> 2010, USA (2007–2008)	n=195 (50 LTF, 49 LCB, 96 RF) Previous screen 100% HSIL <sup>B</sup> 64% Mean age 43 years HIV-positive 49% Caucasian 78% Insurance 92% Relationship 47%	Cross-sectional: MSM previously diagnosed with LSIL or HSIL anal dysplasia; RF and LCB paper questionnaire in clinic LTF via telephone Factors impacting return to screening: subjective emotional experience following the initial HPV-related anal dysplasia diagnosis. Knowledge of Anal Pap & HPV <sup>A</sup> (adapted from Pitts 2007 <sup>27</sup> )	Predictors of screening follow-up include a subjectively upsetting experience during the initial HPV diagnosis, physical symptoms driving the initial visit to the physician and a diagnosis of HSIL
Reed <i>et al.</i> 2010, USA (2009)	n=306 Previous screen 14% Mean age 46 years (18–59) HIV-positive 17% Gay 77% Caucasian 81% Insurance 86% Relationship 48%	Cross-sectional: online survey of gay or bisexual members of Knowledge Networks US household panel Education presented before questions on anal cancer knowledge and concern, anal Pap test history, barriers and guidelines; willingness to participate if test was free or \$150 (available at <a href="http://www.unc.edu/~ntbrewer/hpv.htm">http://www.unc.edu/~ntbrewer/hpv.htm</a> .)	Overall low testing history and knowledge of anal screening. HIV-positive patients were more likely to have been screened, aware of and concerned about anal cancer Willingness to pay for screening was higher in those more worried about anal cancer Cost and lack of education were significant barriers and need to be targeted at the MSM and HIV-positive population.
<b>Evaluation of screening procedure</b>			
Botes <i>et al.</i> 2010, Australia (2008–2009)	n=291 (RR 90%) Mean age 50 years (26–75) HIV-positive 100%	Cross-sectional: evaluation of self-collected anal swab for screening. Ease of self-collection, acceptability, pain and bleeding	53% rated the swab easy to collect and 81% as a highly acceptable method. This provides home collection options to improve cost and privacy.
<b>Psychosocial impact of screening studies</b>			
Tinmouth <i>et al.</i> 2011, Canada	n=104 (RR 67%) AIN 2/3 <sup>B</sup> 14% Mean age 44 years (41–50) HIV-positive 100%	Prospective: paper or online questionnaires at four time points over 6 months (1 week before the screen, 1 week after the screen, 1 week after receiving results, 1 week before 6-month follow-up) with participants of an anal cancer screening study Impact of Events Scale, <sup>A</sup> Illness Intrusiveness Ratings Scale, <sup>A</sup> Psychological Consequences Questionnaire, <sup>A</sup> Hospital Anxiety and Depression Scale <sup>A</sup> and HIV Symptom Index <sup>A</sup> knowledge items	Overall no adverse psychological impact (anxiety and depression) Characteristics associated with greater impact were: having higher baseline distress, being younger and having more HIV-related symptoms Support could be targeted to these individuals with support groups or access to psychologists

Table 1. (continued)

Author year published, country (study year)	Participants demographics	Design, methods and measures	Main results
Landstra <i>et al.</i> 2012, Australia (2008–2010)	<i>n</i> = 163 (RR 60%) HGAIN <sup>B</sup> 17% Mean age 52 years (28–73) HIV-positive 100% Relationship 49%	Prospective: paper questionnaire at three time points over 3 months (at screening, 1 week after swab result and 1 week after HRA result) with participants of an anal cancer screening study Anal Screening Questionnaire, <sup>A</sup> Cancer Worry Scale, <sup>A</sup> Distress Thermometer, <sup>A</sup> MOS SF-12 <sup>A</sup> and Depression Anxiety Stress Scale <sup>A</sup>	Overall no adverse psychological impact (anxiety, depression, stress, QOL) Cancer worry, anal health and optimism for future health ratings were impacted by the process, those requested to return for HRA were more impacted and those who had HGAIN histology results, remained more worried

<sup>A</sup>Validated questionnaires.<sup>B</sup>HSIL, AIN and HGAIN are interchangeable terms for precancerous anal lesions.

### Knowledge, attitudes and willingness to have screening

#### Knowledge

The majority of studies had a knowledge assessment component. The first published study on knowledge was in 2007 by Pitts *et al.*,<sup>27</sup> who found no single item was answered correctly by more than half of the sample and awareness of risk factors was poor. For example, respondents had low awareness of risk factors such as HPV, smoking and being a receptive sexual partner. Although 62% had received a sexual health screen in the past 12 months, this was not associated with better knowledge. Significantly higher knowledge was found in those who had higher education,<sup>27</sup> had ever had an anal Pap screen<sup>28,29</sup> and among those undergoing regular screening compared with patients lost to follow-up (LTF).<sup>30</sup> Amongst participants who had higher levels of knowledge or awareness of screening availability, there was greater willingness to have screening.<sup>28,29</sup>

#### Willingness

Three studies<sup>28–30</sup> investigated factors related to intentions or willingness to participate in screening. Being HIV-infected was related to being more willing to be screened.<sup>28,29</sup> Men indicated they were more willing to have screening that would be free (83%) than if they incurred out-of-pocket costs of \$150 (31%).<sup>29</sup> Those with household incomes over \$60 000 were also more willing to be screened than those earning less.<sup>29</sup> Truesdale and Goldstone<sup>30</sup> investigated factors related to men who have sex with men (MSM) with both low- and high-grade squamous intraepithelial lesions (LSIL and HSIL) returning to screening after 1 year. It was found that having more sexual partners led to greater rates of return, with each additional partner increasing the likelihood of return by 8%. Return to screening was related to being contacted to take part in the study, leading to 7% of LTF participants having further screening and 18% of the LTF participants returning for screening. Twelve percent of MSM indicated that the anal Pap smear was 'too painful to make it worthwhile'.<sup>30</sup>

#### Worry

A variety of concerns or worries were related to knowledge and willingness to have screening. Participants who described learning they had HPV as 'upsetting' were three times more

likely to have regular follow-up (RF) than be LTF.<sup>30</sup> Furthermore, when treatment was prescribed at diagnosis participants were two times more likely to be RF than LTF.<sup>30</sup> Having greater worry about or higher perceived likelihood of getting anal cancer was related to being more willing to have screening. Physical symptoms were strong motivators for the RF group and those who reported physical symptoms were 10 times more likely to return to screening after being LTF.<sup>30</sup> The severity of diagnosis was related to more compliance with screening. Those in the RF group were more likely to have HSIL and those with HSIL were four times more likely to be in the RF group than those with LSIL.<sup>30</sup> Being concerned about anal cancer was higher in HIV-infected men<sup>28</sup> and those having a history of anal warts in the last 6 months or ever.<sup>28</sup> Willingness to have screening was lower when men were concerned about accuracy of the test, or were embarrassed about asking for or having the Pap test.<sup>29</sup>

#### Sexuality

Two of the studies investigated some aspect of sexual function or beliefs. The patients who participated in RF were two times more likely to agree that 'finding out I had HPV made me feel promiscuous'.<sup>30</sup> Those who were recalled for further investigation rated their anal health lower than those who did not need further investigation.<sup>31</sup>

#### Evaluation of screening procedure

One study directly investigated the acceptability of the self-collected Dacron swab screening procedure.<sup>8</sup> The anonymous evaluation found that 53% rated the swab easy to collect, 81% rated the process highly acceptable, 65% reported no pain and 83% reported no bleeding.<sup>8</sup> As these questionnaires were anonymous, they were not able to investigate any factors associated with better or worse responses, and they did not ask about the participants' willingness to repeat the test. Self-collected screening was generally acceptable and therefore has the potential to allow for home testing, which has the potential to reduce the costs of screening programs.

#### Psychosocial impact of screening

Two studies have investigated the psychosocial impact of the screening process longitudinally. Tinmouth *et al.*<sup>6</sup> (Study 1)

used four time points over 6 months and Landstra *et al.*<sup>31</sup> (Study 2) used three time points over 3 months. These studies had different timelines for medical procedures, with Study 1 occurring in a research context. Study 1<sup>6</sup> had the swab and HRA conducted at the same time, thereby giving all participants both procedures and having only one timeframe to wait for results. In contrast, Study 2<sup>31</sup> demonstrated a more common two-stage screening process, where swab results determined who was recalled for HRA, thereby requiring some participants to return and wait for results twice. Both studies found no general impact on psychological health in terms of depression or anxiety,<sup>6,31</sup> nor effects on stress or QOL<sup>31</sup> using GPs.

There was some discrepancy between these studies regarding who is impacted and when. Study 1 found those with anal intraepithelial neoplasia (AIN) grades 2 and 3 (high-grade precancerous lesions) were no more impacted than others with lesser results.<sup>6</sup> In contrast, Study 2 found that being referred for HRA led to higher worry and subsequently those with high-grade anal intraepithelial neoplasia (HGAIN, equal to AIN 2 and 3) continued to be worried.<sup>31</sup> The time of most negative impact in Study 1 was waiting for results to be given.<sup>6</sup> In Study 2, waiting for further investigation by HRA was the time of most impact.<sup>31</sup> These differences may be due to Study 1 using GPs and Study 2 using TSPQs. Alternatively, it may have been due to Study 1 having both the swab and HRA completed in one visit, whereas Study 2 followed a two-step screening process.

Other results of importance in the studies are that participants who received negative results from the HRA were more optimistic about their future health than those who did not need an HRA.<sup>31</sup> Thus, negative results may lead to 'unrealistic optimism'. Characteristics that were predictive of greater worry were being younger, having more HIV symptoms and greater baseline psychological distress.<sup>6</sup> Both studies demonstrated that there is some psychosocial impact from anal cancer screening, namely increased worry and concern, and this is similar to prostate and cervical screening.

### *Limitations of the studies*

These studies have several limitations in common. All studies were completed with gay men only and did not include other at-risk populations, such as women with HIV or prior HPV-related cervical disease, and immunosuppressed transplant recipients. Most participants were Caucasian and well educated, and, in some studies, most had private health insurance. These characteristics may not reflect the general MSM or HIV-infected population. Most of studies used different questionnaires and therefore could not be compared. Participants were voluntary or convenience samples, which may have skewed the results towards participants who were more interested, knowledgeable or more connected to the gay community.<sup>27</sup> Hypothetical statements were used by Reed<sup>29</sup> and these could have failed to anticipate barriers to screening. The availability of screening was not independently determined in D'Souza's study<sup>28</sup> and therefore the lower perceived screening availability may not

reflect the actual availability of screening programs. The two longitudinal screening studies<sup>6,31</sup> used different medical process timelines and swab collection procedures (self collected *v.* clinician collected), making comparison between them difficult.

## **Discussion**

### *Summary of results*

Anal cancer screening appears to generate health worries specific to the procedure. Thus far, research suggests no acute or clinically significant levels of mental health problems as a result of screening. Most screening participants experienced no significant psychosocial impact, but there was some individual variation, suggesting some with particular characteristics were affected more than others. Having worse anal or HIV symptoms, being younger, higher baseline distress or worse histology results were predictive of greater worry. Worry in this context involved repetitive thoughts about the screening and the possibility of having anal cancer. Furthermore, there was generally poor knowledge of anal cancer, anal Pap testing and HPV, or other risk factors and low willingness or intention to screen.

### *Clinical implications: what to consider when setting up routine anal cancer screening*

#### *Education*

Given the low levels of knowledge in the MSMs studied and the links of this to screening adherence, it is important to have targeted education campaigns about the risk of anal cancer and the need for screening. This education is particularly important for high-risk groups such as HIV-infected MSM. Raising knowledge may increase concern and perceived vulnerability, and therefore increase motivation to have screening. Striking the balance between raising awareness and inducing fear is important, as some levels of worry may cause avoidance. For example, women at high risk of breast cancer with mild distress were more likely to have screening than those with moderate distress.<sup>32</sup> Hay *et al.*<sup>32</sup> concluded that cancer worry increases the likelihood of screening, but fear of positive results or the test itself may deter screening.

Primary care physicians were the most common point for sexual health screening and potential contacts for anal cancer screening. Thus primary care physicians are critical to educational efforts and to encouraging screening. It has been suggested that 'primary care physicians should be prepared to counsel their patients about the pros and cons of anal cancer screening, and be familiar with anal health services in their local communities.'<sup>28</sup>

Information about the costs of screening and follow-up care needs to be part of educational campaigns. In areas where there are few public or affordable opportunities, policy advocacy could be very important. Although there are several research studies on anal cancer screening, there is still debate about cost-effectiveness and guidelines for regular screening. Despite such debate, most countries have a need to increase the availability of screening and skilled clinicians in the follow-up of abnormal anal cytology results.

### Managing the screening process

The screening process itself needs to have clear and appropriately pitched education materials. Having communication regarding the procedure itself, expected adverse events and recovery, and nontechnical explanations of results are essential to support the participants.<sup>12,33,34</sup> The potential benefits of information are reflected in findings from cervical screening. Providing written information about the meaning of an abnormal Pap smear resulted in less anxiety and fewer patients thinking they had cancer.<sup>35</sup> Written and verbal explanations of abnormal Pap smear results led to better understanding of results and better attendance for follow-up colposcopy than written information alone.<sup>36</sup>

The choice of materials to gather the swab is also important. Such choices require a balance between the need for good quality specimens and methods that reduce discomfort as part of the collection process. Inadequate specimens have the potential to increase anxiety if results are inconclusive.<sup>19</sup> In the evaluation of self-collected Dacron swabs, 35% reported some level of pain and 17% reported some level of bleeding.<sup>8</sup> In another study, 12% reported that the screening was too painful to be worthwhile.<sup>30</sup> Some clinics use a cytobrush, which gathers more specimens that are satisfactory, and may also be more painful and lead to more bleeding. The vigour which is used in collecting the specimen may also have an impact. Making sure participants are sufficiently prepared for the method used, potential adverse events and the level of pain is important to increase the probability for that person to return for screening. It is also important, given that they may also talk within their social networks and provide word of mouth recommendations or warnings. Providing the option of self-collection rather than clinician collection may give the participant control over the level of pain. Where there is poor availability of screening, doing home screening with self-collection may be an alternative method to reach those at risk.

### Support after screening and results

Waiting for results and further investigation were the times of greatest psychosocial distress. It is these times that participants could benefit from support. Different types of support may be needed by different people. Where possible, it would be helpful to have a variety of support options available such as written information, support staff available by phone or email, patient support groups, or access to a psychologist or social worker. We have developed a stepped care model (outlined in Table 2) to offer suggestions for how to triage those who may need extra support beyond information.<sup>37</sup> Recognition of risk factors for psychosocial distress is an important part of this process (e.g. younger age, physical anal symptoms, more HIV symptoms, higher baseline distress, worse screening results). Using TSPQ was more sensitive than GPQ. For example, the distress thermometer, cancer worry scale or the impact of events scale may be quick and easy ways to check levels of distress or concern at the time of screening. Those with higher levels of baseline distress should be linked to available supports or encouraged to call for support. Other indicators that participants are at risk of a more negative response to screening might include a lack of information-seeking

(raising concerns of avoidance) or the expression of excessively negative emotions about their results.<sup>38</sup>

Similar to the lack of universally accepted protocols for screening, treatment protocols are also not well established, as there is an absence of data from randomised treatment trials of HGAIN showing reduction of anal cancer. One option after screening is active surveillance with no active treatment but ongoing monitoring and assessment. It is estimated that half the men diagnosed with early prostate cancer have unnecessary treatment that has many physical side-effects and negative effects on QOL.<sup>26</sup> Similar concerns may be present for precancerous anal lesions that have significant natural regression rates suggesting they may not worsen with time. Some clinicians may take an active surveillance approach rather than treatment. If this is the case there are some strategies which can be implemented to support the patient. In a review of active surveillance for early prostate cancer, Pickles *et al.*<sup>26</sup> found that this option creates anxiety, but audio-taping treatment consultations for the patient improved understanding and decision-making. The doctor's role in creating clear 'rules' about when to initiate treatment and ways to gain quality information were also important. Another strategy is to actively manage the anxiety that may be created by uncertainty and withholding active treatment. Options such as support groups or therapeutic groups focussed on teaching mindfulness, stress management and other psychological therapies could be offered. One promising therapeutic approach is Acceptance and Commitment Therapy, which helps participants to focus on accepting uncertainty and living a vibrant and valued life even with the ongoing threat of cancer. Use of acceptance-based coping strategies after receiving abnormal cervical Pap smear results was associated with lower psychological distress.<sup>38</sup>

### Supporting return for repeat screening

Empirically supported screening guidelines have not been clearly established but, as with other cancer screening programs, regular screening may be important. Therefore, being able to motivate participants to return is imperative. Finding the balance between reassurance and complacency is essential.<sup>24,31</sup> A concern in the screening process is the phenomenon of 'unrealistic optimism', which has been found to hinder protective health behaviours. Intentions to participate in breast screening were lower when unrealistic optimism was higher.<sup>39</sup> Three years after colorectal screening, the group who were reassured with negative results had significant increases in their body mass index compared with those with positive results.<sup>40</sup> This may reflect unrealistic optimism and a resulting tendency to be less vigilant in following protective behaviours after being reassured. To protect against this phenomenon, clinicians could emphasise known risks such as HIV and HPV infection, numbers of sexual partners, unprotected receptive anal intercourse, and the potential consequences of progression to anal cancer. Truesdale and Goldstone<sup>30</sup> highlight the need to stress the importance of repeat screening so the participant 'hears' the message without becoming too alarmed. They found participants who

**Table 2.** Stepped care model for support following results

Result	Level of worry	Intervention
Cytology	Low worry	No further intervention
	High worry or Presence of risk factors <sup>A</sup>	Give written and verbal information about results and prevention efforts
Non-negative	Low worry	Offer written and verbal information about results and prevention efforts
	High worry or Presence of risk factors <sup>A</sup>	Give written and verbal information about results and prevention efforts. Give contact details for additional support and written information on coping strategies
Histology	Low worry	Offer written and verbal information about results and prevention efforts
	High worry or Presence of risk factors <sup>A</sup>	Give written and verbal information about results and prevention efforts. Give contact details for additional information and support
Precancerous lesions	Low worry	Give written and verbal information about results and prevention efforts
	High worry or Presence of risk factors <sup>A</sup>	Give details of result and treatment plan in written, verbal and recorded format. Give details of support group, psychologist or availability of other clinicians (nurse, social worker) if required
Cancer	Low and high worry	Give details of result & treatment plan in written, verbal and recorded format. Give details of support group, psychologist or other available clinicians (nurse, social worker) if required before transition to oncology services

<sup>A</sup>Risk factors: younger age, physical anal symptoms, HIV symptoms, higher baseline distress.

were more emotionally upset at diagnosis returned for RF. They also recommend that a reminder system should be 'more extensive than a mailed reminder card or short telephone call'. Unnecessary mortality might be prevented by setting clear expectations for regular screening at the initial screening and result-giving stages, and then following up with detailed information and reminders including assertive follow-up of those who do not return.

#### Future directions

Areas needing further research are impacts of screening on HIV-infected women, women with prior HPV-related cervical disease and immunosuppressed transplant recipients, who are also at high risk. Research is also needed to examine the impact of screening on sexual functioning and related emotional responses, such as shame, embarrassment and self-stigma, as both cervical and prostate cancer have shown this to be an issue. For example, does self-stigma prevent people from seeking screening and, if so, how can this barrier be addressed? There is a need to determine what types of support are most effective and we propose the stepped care model outlined in Table 2 as a starting point to develop this research, with a particular focus on motivating regular screening.

#### Conclusions

Anal screening does not appear to have a general impact on mental health but, in some instances, does appear to increase health-related worry. A small proportion of people will need support and the most effective ways to do this have not yet been empirically tested. In order to identify those who will need support, it would be useful to have consensus on a core set of psychosocial screening measures and to establish cut-off points that provide guidance about appropriate levels of response. Similar suggestions emerged from a review of prostate cancer screening.<sup>16</sup> As anal cancer screening is not yet well

established, there is an opportunity to set up a consistent and evidence-based approach to measuring and responding to the psychosocial effects of screening.

#### Conflicts of interest

None declared.

#### References

- 1 New York State Department of Public Health AIDS Institute (NYSDPHAI). Clinical guidelines: human papillomavirus: HIV clinical resource. New York: NYSDPHAI; 2007. Available online at: <http://hivguidelines.org/clinical-guidelines/adults/management-of-stis-in-hiv-infected-patients/human-papillomavirus-hpv/> [verified November 2011].
- 2 Herat A, Whitfeld M, Hillman R. Anal intraepithelial neoplasia and anal cancer in dermatological practice. *Aust J Dermatol* 2007; 48: 143–55. doi:10.1111/j.1440-0960.2007.00369.x
- 3 Palefsky J. Human papillomavirus infection in HIV-infected persons. *Top HIV Med* 2007; 15: 130–3.
- 4 Darragh TM, Winkler B. Anal cancer and cervical cancer screening: key differences. *Cancer Cytopathol* 2011; 119: 5–19. doi:10.1002/cncy.20126
- 5 Chin-Hong PV, Berry JM, Su-Chun C, Catania JA, Da Costa M, Darragh TM, *et al.* Comparison of patient- and clinician-collected anal cytology samples to screen for human papillomavirus-associated anal intraepithelial neoplasia in men who have sex with men. *Ann Intern Med* 2008; 149: 300–63.
- 6 Tinmouth J, Raboud J, Ali M, Malloch L, Su D, Sano M, *et al.* The psychological impact of being screened for anal cancer in HIV-infected men who have sex with men. *Dis Colon Rectum* 2011; 54: 352–9. doi:10.1007/DCR.0b013e31820349c1
- 7 Nathan M, Hickey N, Mayurana L, Vowler SL, Singh N. Treatment of anal human papillomavirus-associated disease: a long term outcome study. *Int J STD AIDS* 2008; 19: 445–9. doi:10.1258/ijsa.2007.007290
- 8 Botes LP, Jin FY, Bourne C, Pett S, Marriott D, Carr A, *et al.* Participants' perspectives of self-collected anal cytological swabs. *Sex Health* 2011; 8: 257–8. doi:10.1071/SH10037

9 Hounsgaard L, Petersen LK, Pedersen BD. Facing possible illness detected through screening—experiences of healthy women with pathological cervical smears. *Eur J Oncol Nurs* 2007; 11: 417–23. doi:10.1016/j.ejon.2007.04.005

10 Stewart-Brown S, Farmer A. Screening could seriously damage your health. *BMJ* 1997; 314: 533–4. doi:10.1136/bmj.314.7080.533

11 McNaughton-Collins M, Fowler FJ, Caubet J-F, Bates DW, Lee JM, Hauser A, *et al.* Psychological effects of a suspicious prostate cancer screening test followed by a benign biopsy result. *Am J Med* 2004; 117: 719–25. doi:10.1016/j.amjmed.2004.06.036

12 Shaw C, Abrams K, Marteau TM. Psychological impact of predicting individuals' risks of illness: a systematic review. *Soc Sci Med* 1999; 49: 1571–98. doi:10.1016/S0277-9536(99)00244-0

13 McCaffery KJ, Barratt AL. Assessing psychosocial/quality of life outcomes in screening: how do we do it better? *J Epidemiol Community Health* 2004; 58: 968–70. doi:10.1136/jech.2004.025114

14 Barratt A, Mannes P, Irwig L, Trevena L, Craig J, Rychetnik L. Cancer screening. *J Epidemiol Community Health* 2002; 56: 899–902. doi:10.1136/jech.56.12.899

15 Szarewski A. Social and psychological aspects of cervical screening. *Expert Rev Obstet Gynecol* 2011; 6: 37–44. doi:10.1586/eog.10.69

16 McNaughton-Collins M, Walker-Corkery E, Barry MJ. Health-related quality of life, satisfaction, and economic outcome measures in studies of prostate cancer screening and treatment, 1990–2000. *J Natl Cancer Inst* 2004; 2004: 78–101. doi:10.1093/jncimonographs/lgh016

17 Brett J, Bankhead C, Henderson B, Watson E, Austoker J. The psychological impact of mammographic screening. A systematic review. *Psychooncology* 2005; 14: 917–38. doi:10.1002/pon.904

18 Gray NM, Sharp L, Cotton SC, Masson LF, Little J, Walker LG, *et al.* Psychological effects of a low-grade abnormal cervical smear test result: anxiety and associated factors. *Br J Cancer* 2006; 94: 1253–62. doi:10.1038/sj.bjc.6603086

19 French DP, Maissi E, Marteau TM. Psychological costs of inadequate cervical smear test results. *Br J Cancer* 2004; 91: 1887–92. doi:10.1038/sj.bjc.6602224

20 Wardle J, Pernet A, Stephens D. Psychological consequences of positive results in cervical cancer screening. *Psychol Health* 1995; 10: 185–94. doi:10.1080/08870449508401948

21 Fowler FJ, Barry MJ, Walker-Corkery B, Caubet J-F, Bates DW, Jeong Min L, *et al.* The impact of a suspicious prostate biopsy on patients' psychological, socio-behavioral, and medical care outcomes. *J Gen Intern Med* 2006; 21: 715–21. doi:10.1111/j.1525-1497.2006.00464.x

22 Brindle LA, Oliver SE, Dedman D, Donovan JL, Neal DE, Hamdy FC, *et al.* Measuring the psychosocial impact of population-based prostate-specific antigen testing for prostate cancer in the UK. *BJU Int* 2006; 98: 777–82. doi:10.1111/j.1464-410X.2006.06401.x

23 Essink-Bot M, de Koning HJ, Nijs HGT, Kirkels WJ, Schroder FH. Short-term effects of population-based screening for prostate cancer on health-related quality of life. *J Natl Cancer Inst* 1998; 90: 925–31. doi:10.1093/jnci/90.12.925

24 Carlsson S, Aus G, Wessman C, Hugosson J. Anxiety associated with prostate cancer screening with special reference to men with a positive screening test (elevated PSA)—results from a prospective, population-based, randomised study. *Eur J Canc* 2007; 43: 2109–16.

25 McCaffery K, Waller J, Nazroo J, Wardle J. Social and psychological impact of HPV testing in cervical screening: a qualitative study. *Sex Transm Infect* 2006; 82: 169–74. doi:10.1136/sti.2005.016436

26 Pickles T, Ruether JD, Weir L, Carlson L, Jakulj F. Psychosocial barriers to active surveillance for the management of early prostate cancer and a strategy for increased acceptance. *BJU Int* 2007; 100: 544–51. doi:10.1111/j.1464-410X.2007.06981.x

27 Pitts MK, Fox C, Willis J, Anderson J. What do gay men know about human papillomavirus? Australian gay men's knowledge and experience of anal cancer screening and human papillomavirus. *Sex Transm Dis* 2007; 34: 170–3. doi:10.1097/01.olq.0000230436.83029.ce

28 D'Souza G, Cook RL, Ostrow D, Johnson-Hill LM, Wiley D, Silvestre T. Anal cancer screening behaviors and intentions in men who have sex with men. *J Gen Intern Med* 2008; 23: 1452–7. doi:10.1007/s11606-008-0698-6

29 Reed AC, Reiter PL, Smith JS, Palefsky JM, Brewer NT. Gay and bisexual men's willingness to receive anal Papapnicolaou testing. *Am J Public Health* 2010; 100: 1123–9. doi:10.2105/AJPH.2009.176446

30 Truesdale MD, Goldstone SE. The fear factor: drivers and barriers to follow-up screening for human papillomavirus-related anal cancer in men who have sex with men. *Int J STD AIDS* 2010; 21: 482–8. doi:10.1258/ija.2010.010070

31 Landstra JMB, Ciarrochi J, Deane FP, Botes LP, Hillman RJ. Psychosocial impact of anal cancer screening on HIV-infected men. *Psycho-oncology* doi:10.1002/pon.3040

32 Hay JL, Buckley TR, Ostroff JS. The role of cancer worry in cancer screening: a theoretical and empirical review of the literature. *Psychooncology* 2005; 14: 517–34. doi:10.1002/pon.864

33 Gray NM, Sharp L, Cotton S, Masson LF, Little J, Walker LG, *et al.* After-effects reported by women following colposcopy, cervical biopsies and LLETZ: results from the TOMBOLA trial. *BJOG* 2009; 116: 1506–14. doi:10.1111/j.1471-0528.2009.02263.x

34 McCaffery K, Waller J, Forrest S, Cadman L, Szarewski A, Wardle J. Testing positive for human papillomavirus in routine cervical screening: examination of psychosocial impact. *BJOG* 2004; 111: 1437–43. [erratum appears in *BJOG* 2004 Dec; 111(12): 1489]. doi:10.1111/j.1471-0528.2004.00279.x

35 Wilkinson C, Jones JM, McBride J. Anxiety caused by abnormal result of cervical smear test: a controlled trial. *Br Med J (Clin Res Ed)* 1990; 300: 440. doi:10.1136/bmj.300.6722.440

36 Wilson JD, Hines B. Nurse counselling for women with abnormal cervical cytology improves colposcopy and cytology follow up attendance rates. *Sex Transm Infect* 2000; 76: 322. doi:10.1136/sti.76.4.322

37 Bower P, Gilbody S. Stepped care in psychological therapies: access, effectiveness and efficiency – narrative literature review. *Br J Psychiatry* 2005; 186: 11–7. doi:10.1192/bjp.186.1.11

38 Lauver DR, Kruse K, Baggot A. Women's uncertainties, coping, and moods regarding abnormal Papapnicolaou results. *J Womens Health Gend Based Med* 1999; 8: 1103–1112. doi:10.1089/jwh.1.1999.8.1103

39 Barnoy S, Bar-Tal Y, Treister L. Effect of unrealistic optimism, perceived control over disease, and experience with female cancer on behavioral intentions of Israeli women to undergo screening tests. *Cancer Nurs* 2003; 26: 363–9. doi:10.1097/00002820-200310000-00004

40 Larsen IK, Grotmol T, Almendingen K, Hoff G. Impact of colorectal cancer screening on future lifestyle choices: a three-year randomized controlled trial. *Clin Gastroenterol Hepatol* 2007; 5: 477–83. doi:10.1016/j.cgh.2006.12.011