MJA
The Medical Journal of Australia

Appendix

This appendix was part of the submitted manuscript and has been peer reviewed. It is posted as supplied by the authors.

Appendix to: Williams JH, Carter SM, Rychetnik L. Information provision in cervical screening in Australia. *Med J Aust* 2014; 201: 295-297. doi: 10.5694/mja13.10999.

Limitations of the information communicated to women through National Cervical Screening Program (NCSP), state and territory materials*

WHAT IS THE ISSUE?	WHY IS THIS ISSUE A LIMITATION?	EXAMPLES FROM EXISTING MATERIAL AND SUGGESTED ALTERNATIVES
Benefits are expressed in percentages or relative risks	Audiences will overestimate benefit of screening if benefits are expressed as relative risks or percentages.[13] Relative risks or percentages cannot be interpreted without knowing the underlying disease rate. Different age groups have different underlying risk, and thus benefit differently from screening.[14] Without knowing the underlying disease rate that applies to them, audiences cannot understand how likely it is that the test may benefit them.	EXAMPLES: Public communications about cervical screening commonly expressed benefit using relative risk or percentages: e.g. • 7 of 9 programs use 'up to/over 90% effective' • 1 program uses 'reduce risk by up to 96%' • 1 program expressed as fraction '9/10 … can be prevented' ALTERNATIVES: Communicate frequency or absolute risk. Consider differentiating between different groups of women. For example: In Australia, cervical cancer incidence has dropped from 17 cases/100,000 women p.a. in 1991 to 9 cases/100,000 women p.a. in 2009. AIHW estimates 1200 invasive cancers were prevented by screening in 2009.[7] (Note: this was communicated by 2 programs, see below). In the screening target audience, cervical cancer incidence is highest in women aged 50-54. 87 women in Australia in this age group developed cervical cancer in 2009. It is lowest in women aged under 25 (12 cancers in 2009).[7]

Benefits are expressed as number of cancers prevented or lives saved; the number needed to screen is not communicated	If communicators promote numbers of cancers prevented but not number of people screened to achieve that, audiences cannot judge how much effort or burden is required to achieve the benefit. Communicating number needed to screen per invasive cancer avoided would allow audiences to balance benefits against costs, effort and burden.	EXAMPLES: A minority of programs gave the number of cancers prevented or lives saved p.a. • 2 of 9 programs said screening prevented 1200 cancers p.a. • 1 program erroneously said screening *saved* 1200 lives p.a. However no programs discussed how many women needed to be screened to achieve that. ALTERNATIVES: Communications could specify the number of women who need to be screened, at what interval, for how many years, to prevent 1 case of cervical cancer or save 1 life from cervical cancer. However at present this information is not available for Australia, so new research would be needed to enable this to occur.
Probability of spontaneous regression is insufficiently explained	Most dysplasia, including high grade changes, will regress spontaneously. The very real challenge for any program is that it is not possible to identify which women will experience regression and which will progress to invasive cancer. This means some women are likely to be treated unnecessarily. Some women, if they understood the probability of spontaneous regression, may be more comfortable with active monitoring (as is recommended for low grade changes) rather than immediate treatment. Anxiety about abnormal results may also be lessened. This may make it easier for both women and their clinicians to follow clinical guidelines. If communications discussed spontaneous regression, audiences may be better able to make a judgement about treatment options.	EXAMPLES: Only 5 of 9 programs say that most abnormal results would regress spontaneously. ALTERNATIVES: Of 100 women tested aged under 25, 16 will have abnormal results. Abnormal results are less common as a woman ages. In the 65-69 age group fewer than 4 women can expect an abnormal result.[7] Abnormal cells are not cancer but some have the potential to become cancer over time. Abnormalities, especially low grade ones, usually regress spontaneously. The majority of high grade changes (HSIL) also regress but screening is not able to identify which lesions could become cervical cancer. As a result, women with HSIL are referred for further investigation.

Risks of screening are not communicated	All screening brings risks or harms as well as benefits. For audiences to understand the benefit-risk trade-off, they need to understand what the risks or harms might be. The most important risks of cervical screening relate to overtreatment. These are: • The potential for subsequent cervical incompetence • Potential adverse perinatal outcomes • Anxiety	EXAMPLES: Risks or harms associated with screening were not directly addressed in any materials collected ALTERNATIVES: While the Pap test itself is not risky, there are risks of associated with further investigation and cell removal. Treatment can sometimes cause bleeding and infection, and can affect future pregnancies. The risks are greatest for young women because they are more likely to have abnormal screening results and more likely to have future pregnancies.[10, 11]
The limitations of the pap test are insufficiently explained	All tests, including the pap test, have limitations. The main limitations of conventional cytology are: • Human error, which is addressed through quality control processes but cannot be eliminated. • Incomplete ability to detect precursors of invasive cervical cancer. Cervical screening using the pap test is most effective in protecting against squamous cell carcinomas: the NCSP prevents around 70% of squamous cell carcinomas of the cervix.[7] However these make up only 66.5% of invasive cervical cancers. Cervical screening is less effective in relation to other types of cervical cancer for sampling reasons. If communications leave out the limitations of the test, audiences may overestimate the protective benefits of participation in screening.	EXAMPLES: • 2 of 9 programs said the Pap is 'not perfect' • 2 mentioned potential for problems in taking and reading slides. • 5 mentioned that Pap testing is effective only in preventing squamous cell carcinomas (referred to as the most common form) in some materials. ALTERNATIVES: Cervical screening is effective in preventing many cases of cervical cancer. Like all cancer screening tests, Pap testing is not perfect. Errors can occur during smear taking and reading. Some cell changes happen in areas that are difficult or impossible to sample and may be missed. For that reason, it is important to follow up any changes even if you have regular negative test results. Changes include: bleeding after sex or between periods, pain or discomfort during sex, an unusual discharge.

Communication does not acknowledge that that screening is voluntary	The NCSP is designed to maximise participation across the Australian population. This is intended to decrease cervical cancer morbidity and mortality in the population. However for each individual woman, screening may or may not provide any benefit, and this benefit may or may not be offset by harms and burdens. It is important to respect the autonomy of individual women and communications have an obligation to acknowledge that participation in screening is voluntary and women are free to be screened or not in accordance with their values. Women may need support to make a decision about whether to be screened.	EXAMPLES: 1 program brochure stated in 2012 that having a Pap test is an individual choice. In 2013 the publication was revised and the sentence omitted. At time of writing no program materials advise women that screening is voluntary. ALTERNATIVES: Cervical screening is an individual decision. If you have any questions about whether screening is right for you, discuss them with your health care provider.

*We collected English language printed and electronic materials from each screening program and analysed them for two key messages central to consent: voluntariness; and discussion of benefit, risk of harms, and limitations of the test. Five of the programs make their printed and audio-visual materials available for download from their respective websites. The NCSP and one other program, have a combination of downloadable and free to order materials available. We called the two remaining organisations, which mailed hard copies of the materials in use in their jurisdiction. The downloads and phone requests resulted in 18 pamphlets and booklets, 14 posters, five information sheets, two videos, and two information packs for healthcare professionals. Nine websites belonging to the national, state and territory programs were searched and relevant material analysed. The information represents the breadth of what was publically available in 2012-13 but it should be noted that materials are continually revised as campaigns change.

It should be noted that some materials are more measured in their approach to informing and employ fewer persuasion tools. Many recommend speaking to a GP or other health worker. Some contain inaccuracies about the natural history of cervical cancer and its risk factors.

A detailed table outlining communications by program and a list of the materials consulted by program from Sept 2012 to March 2013 is available from the authors.