

Appendix I

Table 2. Included countries and available information material

Country (region)	Organization	Information leaflet (publication date) and internet link if available	Invitation letter
Australia	Australian Government – Department of Health http://www.cancerscreening.gov.au/internet/screening/publishing.nsf/Content/Home	Do not issue invitations	Do not issue invitations
Canada (Alberta)	Alberta Health Services, Screening For Life http://www.screeningforlife.ca	No response	No response
Canada (British Columbia)	BC Cancer Agency http://www.bccancer.bc.ca/default.htm	Do not issue invitations	Do not issue invitations
Canada (Manitoba)	Cancer Care Manitoba http://www.cancercare.mb.ca	Pap-test: what you need to know (June 2013) http://www.tellevywoman.ca/files/r-papbro-e.pdf (Available from the author (SKK) on request
Canada (New Brunswick)	New Brunswick Cancer Network (NB Department of Health) http://www2.gnb.ca/content/gnb/en/departments/health/NewBrunswickCancerNetwork.html	Do not issue invitations	Do not issue invitations
Canada (Nova Scotia)	Cancer Care Nova Scotia: http://www.cancercare.ns.ca/en/home/default.aspx	Do not issue invitations	Do not issue invitations
Canada (Ontario)	Cancer Care Ontario https://www.cancercare.on.ca	Cervical cancer screening – Find out when it is the right time for you to start screening (May 2012) https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=134072	https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=292805

Canada (Saskatchewan)	Saskatchewan Cancer Agency http://www.saskcancer.ca	A Pap Test Can Save Your Life (July 2014) http://www.saskcancer.ca/PPCC%20Brochure%2007-14	Available from the author (SKK) on request
Denmark (North Denmark Region)	The North Denmark Region http://sundhedsstyrelsen.dk	Screening for cell changes in the cervix (August 2013) (Undersøgelse for celleforandringer i livmoderhalsen) http://sundhedsstyrelsen.dk/publ/Publ2013/08aug/UsCellerLivmoderhals.pdf	https://www.sundhed.dk/content/cms/47/57147_førstegangsinvasion2010.pdf
Denmark (Central Denmark Region)	Central Denmark Region http://www.rm.dk	Screening for cell changes in the cervix (August 2013) (Undersøgelse for celleforandringer i livmoderhalsen) http://sundhedsstyrelsen.dk/publ/Publ2013/08aug/UsCellerLivmoderhals.pdf	http://www.regionshospitalet-randers.dk/siteassets/afdelinger/afdeling-for-folkeundersogelser/pdf-episerver/breve/indk-1.pdf
Denmark (Region Zealand)	Region Zealand http://www.regionsjælland.dk	Screening for cell changes in the cervix (August 2013) (Undersøgelse for celleforandringer i livmoderhalsen) http://sundhedsstyrelsen.dk/publ/Publ2013/08aug/UsCellerLivmoderhals.pdf	Available from the author (SKK) on request
Denmark (Capital of Denmark Region)	The Capital Region of Denmark http://www.regionh.dk	Screening for cell changes in the cervix (August 2013) (Undersøgelse for celleforandringer i livmoderhalsen) http://sundhedsstyrelsen.dk/publ/Publ2013/08aug/UsCellerLivmoderhals.pdf	Available from the author (SKK) on request
Denmark (Southern Denmark Region)	The Southern Denmark Region http://www.regionyddanmark.dk	Screening for cell changes in the cervix (August 2013) (Undersøgelse for celleforandringer i livmoderhalsen) http://sundhedsstyrelsen.dk/publ/Publ2013/08aug/UsCellerLivmoderhals.pdf	Available from the author (SKK) on request
England	NHS Public Health England http://www.cancerscreening.nhs.uk	NHS Cervical Screening (March 2013)	Available from the author (SKK) on request

	k/index.html	http://www.cancerscreening.nhs.uk/cervical/publications/cervicalscreening.pdf	request
Finland	Finnish Cancer Registry http://www.cancer.fi/syoparekisteri/en/	Cervical cancer can be prevented (Cancer i livmoderhalsen kan forebygges) http://www.cancer.fi/%40Bin/31051/screening_livmoderhalsen.pdf	http://www.cancer.fi/@Bin/48798592/Seulonantakutsu_kohtueinglanti.pdf
Ireland	Cervical Check, The National Screening Service http://www.cervicalcheck.ie	About your free smear test http://www.cervicalcheck.ie/fileupload/WomenPublications/CS-PUB-CC-1%20About%20your%20free%20smear%20test.pdf	Available from the author (SKK) on request
New Zealand	National Cervical Screening Program, NSCP https://www.nsu.govt.nz	What women need to know (June 2014) https://www.healthed.govt.nz/resource/cervical-smear-tests-what-women-need-know-%E2%80%93-english-version	http://nationalwomenshealth.adhb.govt.nz/Portals/0/Updated%20MedTech%20Appendices%20Feb%202015.pdf
Northern Ireland	Public Health Agency Northern Ireland http://www.cancerscreening.hscni.net/index.htm	It's best to take the test (August 2012) http://www.cancerscreening.hscni.net/pdf/Cervical_take_test_08_11.pdf	Available from the author (SKK) on request
Norway	Cancer Registry of Norway http://www.kreftregisteret.no		http://www.kreftregisteret.no/Global/informasjon_25-aaar_bokmaal-2014.pdf
Sweden	Swedish Association of Local Authorities and Regions http://www.cancercentrum.se	Questions and answers (October 2014) (Frågor och svar) https://www.cancercentrum.se/globalassets/vara-uppdrag/prevention-tidig-upptackt/gynekologisk-cellprovskontroll/stod-vid-information/fragorosvar_cellpr_rev1final_color.pdf	https://www.cancercentrum.se/globalassets/vara-uppdrag/prevention-tidig-upptackt/mammografi/stod-vid-information/kallelsepaket_mam_gyn_webb_28aug15.pdf
Scotland	NHS, Scotland http://www.healthscotland.com	The Cervical Screening Test: Put it on your List (May 2014)	Available from the author (SKK) on request

www.nhsinform.co.uk/screening

request

Last access date for all websites was 27.09.2015

Appendix II

Table 3. Information presented in invitations for cervical screening.

Information items
<p>Lifetime risk of developing cervical cancer</p> <ul style="list-style-type: none"> “With regular 3-yearly screening one out of 570 women will develop cervical cancer. Without screening one out of 90 woman will develop cervical cancer” – New Zealand
<p>Lifetime risk of dying from cervical cancer</p> <ul style="list-style-type: none"> “With regular 3-yearly screening one out of 1280 woman will die from cervical cancer. Without screening one out of 200 woman will die from cervical cancer” – New Zealand
<p>Absolut risk reduction of death from cervical cancer</p> <ul style="list-style-type: none"> “With regular 3-yearly screening one out of 1280 women will die from cervical cancer. Without screening one out of 200 women will die from cervical cancer” – New Zealand
<p>Relative risk reduction of developing cervical cancer</p> <ul style="list-style-type: none"> “The risk is decreased by 90%” [our translation] - Sweden “Early detection and treatment can prevent cancer developing in around 75% of cases” – England “Regular screening with Pap tests can prevent up to 80% of cervical cancer” – Canada, Manitoba “Four out of five cervical cancers is prevented” [our translation] – Finland “Cervical screening prevents around 7 out of 10 cervical cancers” – Northern Ireland “Prevent eight out of ten cervical cancers” [our translation] – Scotland
<p>Absolute risk reduction of developing cervical cancer</p> <ul style="list-style-type: none"> “With regular 3-yearly screening one out of 570 woman will develop cervical cancer. Without screening one out of 90 woman will develop cervical cancer” – New Zealand
<p>Proportion of screened woman who would be recalled as a result of an inadequate result</p> <ul style="list-style-type: none"> “It happens occasionally that the test is inadequate. 2-3 in every 100 women will be recalled as a result of an inadequate result” [our translation] – Denmark “In around one in 20 tests, the cells cannot be seen properly under the microscope and the test must be taken again” – England “In around one in 20 tests, the cells cannot be seen properly under the microscope and the test must be taken again” – Northern Ireland
<p>Proportion of screened woman who would be recalled as a result of an abnormal result</p> <ul style="list-style-type: none"> “About 5% of all tests show cell changes. If your test shows cell changes you will be assigned a date at a gynaecologist, who will do a new test” [our translation] – Sweden “For one in every 10 women, it detects abnormal cell changes” – Northern Ireland “1 out of ten women receive an abnormal test result” – Scotland “1 in 4 women will have an abnormal pap test in her lifetime” – Canada, Manitoba

Positive predictive value

- “50 out of 100 women, who tested positive for cell changes (mild to severe) will have a normal test result at the next follow up examination” [our translation] – Denmark

Overdiagnosis and overtreatment

- “Overtreatment: You cannot differentiate with certainty between cell changes that will disappear on their own and those that will progress into cancer. Treatment is therefore recommended if a biopsy shows severe cell changes” [our translation] - Denmark
- “A disadvantage is that screening is not 100% accurate. Some of the cell changes that are found by screening, will never progress into cancer, but we do not always know exactly which that is” [our translation] - Sweden
- “Many cell changes that are found by screening are harmless and will disappear on their own” [our translation] - Finland
- “The test can show minor abnormalities in cervical cells, which would have cleared up on their own, and women would never have known about them if they had not been for screening. It is not yet clear which minor abnormalities will develop into cancer and which will not” – England
- “Some but not all changes found by cervical screening test may give an early warning sign of the possibility of developing cervical cancer” – Scotland
- “Most woman who have abnormal test results and who have follow-up tests and/or treatment will never get cancer of the cervix” – Canada, Manitoba

Quantification of overdiagnosis and overtreatment

- “If not treated, between 25% and 50% of the most severe cell changes will progress into cancer” [our translation] - Denmark

Risks related to conisation

- “Very few women will have problems with pregnancy and giving birth after conisation. There is, however, a slightly increased risk of premature birth, A rare complication is severe bleeding” [our translation] - Denmark
- “It is rare that women will have problems with later pregnancies. If a large part of the cervix is treated, the risk of premature birth is, however, increased” [our translation] - Sweden

Quantification of risks related to conisation

- “Between 1 and 8 out of 100 women will experience severe bleeding as a complication to the operation, and 1 in 100 women will get a constriction of the cervix after conisation” [our translation] – Denmark

Psychological distress related to false positive results

- “The examination and waiting for an answer can cause anxiety and worry” [our translation] – Denmark
- “Additional examinations may cause worry” [our translation] – Sweden
- “Many women worry when a minor abnormality is found – England

Pain/discomfort related to the cytology test

- “Most women dislike the examination. Most women, however, accept the examination when they think it is rational or necessary to avoid even greater harm. It is not painful but some women will experience discomfort” [our translation] - Denmark
- “Many women find it unpleasant to lie in a gynecological examination chair, but the examination only takes a couple of

minutes” [our translation] - Sweden

- “The test feels like a small pinch” [our translation] - Finland
- “You might experience some discomfort or pain” and “Some women find having the test an unpleasant experience” – England
- “It may be slightly uncomfortable but should not hurt” – Ireland
- “It should not be painful but some women may find it uncomfortable” – Northern Ireland
- “The test should not be painful but you may find it uncomfortable” – Scotland
- “Some women may find the test uncomfortable, but it does not usually hurt” – New Zealand

False positive results

- “The test reveals abnormal cells and HPV but additional tests show no sign of early stages of cancer” [our translation] - Denmark
- “Most smear test results are normal. Even a result that is not normal is unlikely to mean you have cancer. It may be due to an infection or minor cell changes that are not a cause of concern” – Ireland
- “If HPV is not found, your risk of significant cervical disease is very low and you will not need any further follow-up” – Northern Ireland
- “The results from these test may show that there are no abnormal cells” – New Zealand

Quantification of false positive results

- “50 out of 100 women, who a diagnosed with cell changes (from minor to severe), will receive a normal test result at the follow up” [our translation] - Denmark

False negative results

- “You receive a normal test result even though you in fact have cell changes. Luckily cell changes progress slowly and will most likely not progress to cancer before being detected in a future smear test” [our translation] - Denmark
- “It may not always detect early cell changes that may lead to cancer. Abnormal cells on your slide may not be recognized because 1) sometimes they do not look much different from normal cells 2) there may be very few cells on the slide 3) the person reading your slide may miss the abnormality” – England
- “There is a small risk that cell changes will not be picked up in a smear test. However, any cell changes will usually be picked up in a future smear test” – Ireland
- “There is a small chance that the test misses an abnormality” – Northern Ireland
- “Like other screening tests it is not fool proof. It may miss some changes” – Scotland
- “Pap tests are not perfect. They can miss some abnormal cells” – Canada, Ontario

Quantification of false negative results

- “In 5 out of 100 women, who have a normal test result, the answer is not correct” [our translation] – Denmark

Appeals for participation

- “Accept the screening invitation” [our translation] – Finland
- “Protect yourself with regular Pap-test!” – Manitoba, Canada
- “Cervical screening: it’s best to take the test” – Northern Ireland
- “The Norwegian Health authorities recommend women aged 25 to 69 years to undergo a smear test every third year” [our

translation] – Norway

- “Protect your health, book a pap test today” and “If you have ever had any sexual skin-to-skin contact, you need to have regular Pap tests starting at age 21” – Ontario, Canada
- “Women should have a pap test starting at the age of 21...” – Saskatchewan, Canada
- “The cervical screening test – put it on your list” and “You are now due to have a cervical screening test” – Scotland
- “The National Board of Health and Welfare recommend you to participate every time you are invited” [our translation] – Sweden