

# Effect of culturally competent educational films about prenatal screening on informed decision making of pregnant women in the Netherlands: A cross sectional study

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## ABSTRACT

*Objective:* To evaluate the effect of a culturally competent educational film (CCEF) on informed decision making (IDM) regarding prenatal screening (PS) in a study population consisting of multicultural pregnant women.

*Methods:* A cross-sectional study with 262 women in the control group and 117 in the intervention group. All counselled participants received a self-report questionnaire to obtain data on IDM and only the intervention group received the CCEF. Twenty two percent of the study population had an ethnic minority background and 52% had a low or medium educational level. *Results:* After exposure to the CCEF, knowledge about the Fetal Anomaly Scan (FAS) was significantly increased in ethnic minority women and in 'medium' and 'highly' educated women. Among women in the intervention group who had the intention to participate in FAS, there was an increase of 11% in IDM and a decrease of 12% in uninformed decision making.

*Conclusion:* CCEF leads to a significant increase in the level of knowledge in medium and highly educated groups as well as non-western ethnic minority groups. The increase in IDM among intentional participants in the FAS is promising as well. CCEF's are a valuable complement to counseling about PS.

## INTRODUCTION

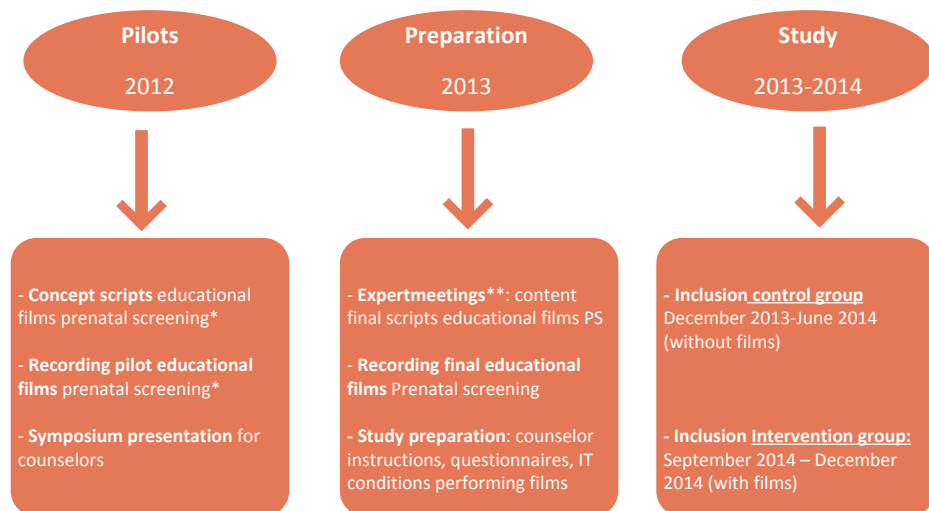
The Dutch nationwide Prenatal Screening (PS) programme, supported by a legislative framework is unique in the world.<sup>1,2</sup> In the Netherlands, all pregnant women should actively be offered counselling about PS, consisting of the first trimester Combined Test (CT), a test for prenatal screening on Down syndrome<sup>1,3</sup> and the second trimester Fetal Anomaly Scan (FAS), screening for structural fetal anomalies.<sup>1</sup> The aim of counselling is to contribute to the autonomous Informed Decision Making (IDM) of pregnant women on participation in PS. An informed decision is made when a woman has adequate decision-relevant knowledge and her attitude towards participating in PS is consistent with her actual participation.<sup>4-6</sup>

In Dutch participants there is a strong association between a lower level of IDM on PS and inadequate information provision about PS. Other contributing factors are a non-Western background, low socioeconomic status (SES) or insufficient Dutch language proficiency.<sup>7-17</sup> International studies on IDM in PS show that pregnant women, especially within ethnic minority groups<sup>21-25</sup>, experience insufficient information provision<sup>18-20</sup> and reported a high percentage of low knowledge and IDM about PS.

Interventions to improve IDM in non-Western or low SES pregnant women should particularly aim to overcome cultural, language and 'information' barriers.<sup>7, 26-28</sup> Peer educators<sup>21, 28, 29</sup> and the use of educational films<sup>30, 31</sup> are promising methods to cope with these barriers. Therefore we combined the strengths of both, by developing CCEF's with peer educators to provide information about PS. We hypothesized that adding a CCEF to regular counselling would increase IDM on participation in PS of non-western pregnant women. With two consecutive cross sectional studies (the IDM-Intervention study) we assessed whether pregnant women made an informed decision more often after seeing the CCEF (Figure 9.1).

## METHODS

The Culturally Competent Educational Films (CCEF's) were developed by the Foundation for Prenatal Screening in the Southwest region of the Netherlands (SPSZN). The films contained decision-relevant information about PS and were recorded in the four different languages that are spoken most often amongst non-western groups in the Netherlands (Dutch, Turkish, Moroccan-Arabic or Moroccan-Berber). Dutch, Turkish and Moroccan peer educators provided standardized information in the CCEF's (Supplement 9.1). To validate the content of the films, expert meetings were organized with experts on language, culture and obstetrics. We performed two consecutive cross sectional studies in the Southwestern region of the Netherlands. Pregnant women were included from December 2013 to June 2014 (control group) and from September



**Figure 9.1** Study design IDM-Intervention study

\* In four languages: Dutch, Turkish, Moroccan-Berber and Moroccan-Arabic

\*\* Separate meetings Focused on Dutch, Turkish, Moroccan-Berber and Moroccan-Arabic language and culture.

PS: prenatal screening

to December 2014 (intervention group) (Supplement 9.2). Participating counsellors (n=33) including midwives, sonographers, physicians and nurses working in hospitals, midwifery practices or sonographic centres included women with a gestational age of up to 24 weeks with a Dutch, Turkish or Moroccan ethnic background [women's country of birth and her parents' country of birth]<sup>32</sup>. Subsequently, we also included women with other ethnic backgrounds. To obtain data on Informed Decision Making (IDM), all respondents received a self-report questionnaire in the language of choice (Dutch, Turkish or Arabic) after counselling. Only the intervention group received the CCEF in the language of choice. The legal use of anonymous data of pregnant women was based on digital informed consent. After the study the participating counsellors filled out a questionnaire to report their experiences with the CCEF's (Supplement 9.3). IDM was measured by a questionnaire which was previously used<sup>9, 33-35</sup> with a general part containing questions on the pregnant woman's background and an IDM specific part with questions about knowledge, attitude and intentional participation in Prenatal Screening (PS) with the Combined Test (CT) and the Fetal Anomaly Scan (FAS).<sup>9, 34, 35</sup> Knowledge was measured using twelve statements about the CT and ten about the FAS with response options 'true', 'not true', and 'do not know'. The total knowledge score ranged from 0 to 10. Attitude towards undergoing the CT or the FAS was measured using a seven point scale, transformed into a 1-10 scale (Supplement 9.4).<sup>4</sup> Intentional participation was measured by asking respondents whether they intended to participate

in the CT and the FAS. We combined *knowledge*, *attitude* and *intentional participation* to calculate the level of IDM.<sup>4</sup> An informed decision was defined as having adequate knowledge (total score > 6.0), a positive attitude towards undergoing the screening (total score > 6.0) and an intention to participate consistent with this attitude. Chi-square tests were used for the associations and differences between maternal characteristics of the control and intervention group and knowledge, attitude towards participating in PS and IDM. To strengthen the comparability between both study groups for the analysis of IDM, we created a separate dataset. In this set we matched two equally large groups of records of control and intervention group women with similar background characteristics on ethnicity, gravidity, parity, educational level and age.

## RESULTS

Table 9.1 shows that the respondents in the control and intervention groups were comparable in terms of background characteristics. Knowledge about the Fetal Anomaly Scan (FAS) was significantly increased in first generation (39% and 50% knowledgeable in respectively control group (CG) and intervention group (IG);  $p < 0.001$ ) and second generation (60% and 67% knowledgeable in resp. CG and IG;  $p < 0.001$ ) ethnic minority groups and 'medium' (70% and 80% knowledgeable in respectively CG;  $p < 0.001$  and IG;  $p < 0.05$ ) and 'highly' educated pregnant women (89% and 93% knowledgeable in respectively CG;  $p < 0.001$  and IG;  $p < 0.05$ ) (Table 9.2). Non-Western (67%,  $p < 0.01$ ) and medium educated (59%,  $p < 0.05$ ) intervention group women had significantly more often a positive attitude towards Combined Test (CT) (table 9.3).

There was an 11% increase of women who made an Informed Decision Making about intentional participation in FAS and a 12% decrease in uninformed decision making about whether or not to participate in FAS in the intervention group (table 9.4).

## DISCUSSION

This study elucidated that Culturally Competent Educational Film (CCEF's) as part of the counseling on Prenatal Screening (PS) do lead to an increase in knowledge and Informed Decision Making (IDM) in specific groups. In comparison with other promising interventions to improve IDM, like group counseling and education<sup>36, 37</sup> and the use of decision aids<sup>38-40</sup>, CCEF's seem to be more suitable for women with a language barrier and lower health literacy levels. Presumably, the overall knowledge increase about the Fetal Anomaly Scan (FAS) in the intervention group can be explained by inadequate counseling about FAS<sup>41</sup> and reduced motivation to be informed about FAS due to misconception that FAS is routine obstetric care<sup>11</sup>, the relatively high Dutch uptake

**Table 9.1** Background characteristics of pregnant women who participated in the 'IDM Intervention study'

	<b>Control group – no film <sup>1</sup></b>				<b>Intervention group – film <sup>1</sup></b>			
	Response n=249		NR n=266		Response n=117		NR n=120	
	N	(%)	N	(%)	N	(%)	N	(%)
<b>Age (years)</b>	<b>249</b>		200		<b>113</b>		81	
≤ 19-29	108	(43)	92	(47)	49	(43)	42	(51)
30-35	114	(46)	84	(43)	55	(49)	32	(40)
≥ 36	27	(11)	20	(10)	9	(8)	7	(9)
<b>Ethnic origin <sup>2</sup></b>	<b>248</b>		234		<b>113</b>		109	
Dutch	193	(78)	143	(61)	84	(74)	71	(65)
Surinamese, Antillean, Cape Verdean	15	(6)	-		4	(4)	-	
Turkish	9	(4)	24	(10)	6	(5)	13	(12)
Moroccan	7	(3)	27	(12)	2	(2)	14	(13)
Other Western	11	(4)	33	(14)	6	(5)	8	(7)
Other non-western	13	(5)	7	(3)	11	(10)	3	(3)
<b>Native / Western / non-Western immigrant <sup>2</sup></b>	<b>248</b>		234		<b>113</b>		109	
Native	193	(78)	143	(61)	84	(74)	71	(65)
Western immigrant	15	(6)	7	(3)	12	(11)	3	(3)
Non-Western immigrant	40	(16)	84	(36)	17	(15)	35	(32)
<b>Generation <sup>2</sup></b>	<b>244 <sup>2</sup></b>				<b>117 <sup>2</sup></b>			
First generation immigrant	24	(10)			13	(11)		
Second generation immigrant	27	(11)			19	(16)		
Native Dutch	193	(79)			85	(73)		
<b>Gravidity</b>	<b>243</b>		190		<b>105</b>		75	
primigravida	91	(37)	64	(34)	33	(31)	28	(37)
multigravida	152	(63)	126	(66)	72	(69)	47	(63)
<b>Parity <sup>2</sup></b>	<b>261</b>				<b>117</b>			
Nulliparous	125	(48)			48	(41)		
Primi/multiparous	136	(52)			69	(59)		
<b>Religion <sup>2</sup></b>	<b>259</b>				<b>117</b>			
Roman Catholic	39	(15)			13	(11)		
Protestant Christian	53	(20)			25	(21)		
Islam	26	(10)			17	(15)		

**Table 9.1** Background characteristics of pregnant women who participated in the 'IDM Intervention study1397969521 (continued)

	Control group – no film <sup>1</sup>				Intervention group – film <sup>1</sup>			
	Response n=249		NR n=266		Response n=117		NR n=120	
	N	(%)	N	(%)	N	(%)	N	(%)
Hinduism, other religion, no wish to answer	12	(5)			7	(6)		
No religion	129	(50)			55	(47)		
<b>Dutch language proficiency <sup>2</sup></b>	<b>262</b>				<b>116</b>			
Fluent	250	(95)			111	(95)		
Limited	7	(3)			2	(2)		
Absent	5	(2)			3	(3)		
<b>Education</b>	<b>249</b>				<b>112</b>			
Low	14	(6)			7	(6)		
Medium	107	(43)			59	(53)		
High	128	(51)			46	(41)		
<b>Urbanity</b>	<b>249</b>		266		<b>113</b>		120	
Rural	30	(12)	41	(15)	12	(11)	15	(13)
Urban	100	(40)	93	(35)	52	(46)	42	(35)
Highly urban	119	(48)	132	(50)	49	(43)	63	(52)

<sup>1</sup> Overview of missing baseline characteristics see Supplement 9.2. <sup>2</sup> Data only available for response –group. Chi<sup>2</sup> testing gave no significant differences in background characteristics comparing control and intervention groups (response and non-response population).

rates of FAS <sup>10</sup>, funding of FAS by health insurance companies and <sup>10</sup> incorrect assumptions about the purpose and performance of the FAS. <sup>15, 16</sup> Especially non-Western and first generation ethnic minority intervention group women are more knowledgeable about FAS than their control group counterparts. Possible explanations are a higher rate of health illiteracy and a decreased level of knowledge about PS within ethnic minority groups <sup>7, 26, 42, 43</sup>, a reduced provision of counseling and educational leaflets about PS (supplement 9.5) and difficulties experienced by healthcare professionals <sup>14, 27, 41</sup> in the counselling of non-western groups. We only found minor attitude changes in intervention group women, suggesting that the films do not change the basic attitude towards PS. This is in contrast with a comparable study in Sweden which used educational films about PS in one language.<sup>44</sup> The analyses of the 'matched dataset' demonstrated an increased IDM in intervention group women who intended to participate in FAS. We believe that the increase of knowledge of intervention group women explains the increase of IDM in both participating and non-participating groups. IDM about inten-

tional participation in the Combined Test (CT) shows contradictory results. A possible explanation is that women tend to receive more detailed information on CT, making

**Table 9.2** Knowledge of Prenatal Screening for control and intervention group

	Knowledge CT		Knowledge FAS			
	Control <sup>1</sup>	Intervention <sup>2</sup>	Control <sup>1</sup>	Intervention <sup>2</sup>	Chi <sup>2</sup>	
	N (%)	N(%)	N(%)	N(%)		
	Adequate knowledge	Adequate knowledge	Chi <sup>2</sup>	Adequate knowledge	Adequate knowledge	Chi <sup>2</sup>
	N=233	N=106		N=196	N=102	
<b>Total group<sup>3</sup></b>	198 (85)	87(82)	0.20	151 (77)	85 (83)	0.20
<b>Age</b>	N=233	N=105		N=196	N=101	
≤35	179(86)	79 (82)	0.45	134 (78)	77 (83)	0.34
≥36	19 (79)	8 (89)	0.52	17 (71)	8 (100)	0.08
<b>Native/western / non-western</b>	N=229	N=106		N=193 ***	N=102 ***	
Native	163 (90)	71 (90)	0.96	127 (85)	70 (91)	0.18
Western	14 (74)	6 (67)	0.70	10 (67)	6 (75)	0.68
Non-western	18 (62)	10 (56)	0.66	12 (43)	9 (53)	0.51
<b>Generation<sup>4</sup></b>	N=48 ***	N=27***		N=43***	N=25 ***	
First	10 (56)	7 (64)	0.66	7 (39)	5 (50)	0.57
Second	22 (73)	9 (56)	0.23	15 (60)	10 (67)	0.67
<b>Education</b>	N=232***	N=105**		N=195 ***	N=102 *	
Low	7 (58)	4 (57)#	0.96	4 (36)	3 (50)#	0.58
Medium	78 (77)	42 (75)	0.75	60 (70)	45 (80)	0.16
High	113 (95)	40 (95)	0.94	87 (89)	37 (93)	0.51
<b>Urbanity</b>	N=233	N=106		N=196	N=105	
L-m urban	19 (73)	3 (60)#	0.55	15 (75)	5 (83)	0.67
highly urban	179 (86)	84 (83)	0.44	136 (77)	83 (83)	0.24

Adequate knowledge: score of ≥ 6 points in knowledge assessment

Chi<sup>2</sup>: comparison between Control and Intervention groups

# chi<sup>2</sup> cell count less than 5.

<sup>1</sup> Chi<sup>2</sup> test within control group for differences in knowledge CT/FAS

<sup>2</sup> Chi<sup>2</sup> test within intervention group for differences in knowledge CT/FAS

<sup>3</sup> Separate Chi<sup>2</sup> testing shows significant differences in level of knowledge about CT and FAS comparing the overall control and intervention population. Significant increase of knowledge within intervention group about 'Content of combined test', 'Screening on neural tube defects with FAS' and 'The fact that FAS is not required' and a decrease of knowledge within the intervention group about 'Risks of invasive prenatal testing'.

<sup>4</sup> No performance of native group in 'generation variable' because similarity with native group 'variable native/western/non-western'.

Significance levels \* P <0.05, \*\* P<0.01, \*\*\* P<0.001



them more knowledgeable *before* watching the films, thus leaving less opportunity for improvement by means of the CCEF's. The fact that 50% of the study population had a low or medium educational level is a unique result in comparison with comparable research which included mostly higher educated women.<sup>44, 45</sup> A limitation of the study is the short inclusion period of the intervention group women. We had to take

**Table 9.3.** Attitude of Prenatal Screening for control and intervention group

	Attitude CT		Attitude FAS			
	Control <sup>1</sup>	Intervention <sup>2</sup>	Control <sup>1</sup>	Intervention <sup>2</sup>	Chi <sup>2</sup>	
	N(%)	N(%)	N(%)	N(%)		
	Positive attitude	Positive attitude	Chi <sup>2</sup>	Positive attitude	Positive attitude	Chi <sup>2</sup>
	N=234	N=106		N=198	N=102	
<b>Total group</b>	121 (52)	59 (56)	0.50	186 (94)	95 (93)	0.79
<b>Age</b>	N=234	N=105		N=198	N=101	
≤35	104 (50)	51 (53)	0.58	163 (95)	87 (94)	0.68
≥36	17 (68)	7 (78)	0.58	23 (89)	7 (88)	0.94
<b>Native/western / non-western</b>	N=230 *	N=106		N=195 **	N=102	
Native	97 (54)	42 (53)	0.91	144 (96)	72 (94)	0.40
Western	12 (63)	5 (56)	0.70	15 (100)	8 (100)	n.a.
Non-western	<b>9 (29)</b>	<b>12 (67)</b>	<b>0.01</b>	24 (80)	15 (88)	0.47
<b>Generation<sup>3</sup></b>	N=50	N=27		N=45**	N=25	
First	10 (50)	7 (64)	0.46	15 (75)	9 (90)	0.40
Second	11 (37)	10 (62)	0.09	24 (96)	14 (93)	0.33
<b>Education</b>	N=233	N=105		N=197	N=102	
Low	8 (62)	3 (43)#	0.42	11 (92)	5 (83)	0.60
Medium	<b>43 (43)</b>	<b>33 (59)</b>	<b>0.05</b>	80 (92)	52 (93)	0.84
High	69 (58)	23 (55)	0.72	94 (96)	38 (95)	0.81
<b>Urbanity</b>	N=234 **	N=106		N=198	N=102	
Low-medium urban	6 (23)	2 (40)#	0.43	20 (100)	6 (100)	n.a.
highly urban	115 (55)	57 (56)	0.85	166 (93)	89 (93)	

# Chi<sup>2</sup> cell count less than 5.

Chi<sup>2</sup>: comparison between Control and Intervention groups

<sup>1</sup> Chi<sup>2</sup> test within control group for differences in attitude CT/FAS,

<sup>2</sup> Chi<sup>2</sup> test within intervention group for differences in attitude CT/FAS,

<sup>3</sup> No performance of native group in 'generation variable' because similarity with native group 'variable native/western/non-western'

Significance levels \* P <0.05, \*\* P<0.01, \*\*\* P<0.001

Positive attitude towards undergoing CT / FAS: score of ≥ 6 points in knowledge assessment

**Table 9.4** Informed decision making in prenatal screening

	<b>General participation<sup>1 2</sup></b>					
	Control group			Intervention group		
	N (%)		Chi <sup>2</sup>	N (%)		Chi <sup>2</sup>
	CT	FAS	Chi <sup>2</sup>	CT	FAS	Chi <sup>2</sup>
	N=235	N=243		N=100	N=106	
<b>Yes</b>	103 (43)	240 (99)	0.22	51 (51)	105 (99)	0.81
<b>No</b>	132 (57)	3 (1)		49 (49)	1 (1)	
	<b>IDM - CT<sup>1</sup></b>		Chi <sup>2</sup>	<b>IDM - FAS<sup>1</sup></b>		Chi <sup>2</sup>
	Control	Intervention		Control	Intervention	
	N(%)			N(%)		
	N=218	N=94		N=187	N=94	
<b>IDM - Participation</b>	86 (39)	41 (44)	0.78	142 (76)	78 (83)	0.12
<b>IDM - Non-participation</b>	96 (44)	38 (40)		0 (0)	1 (<1)	
<b>No-IDM</b>	36 (17)	15 (16)		45 (24)	15 (16)	
	<b>Match- IDM CT<sup>1</sup></b>		Chi <sup>2</sup>	<b>Match-IDM FAS<sup>1</sup></b>		Chi <sup>2</sup>
	Control	Intervention		Control	Intervention	
	N(%)			N(%)		
	N=100	N=92		N=102	N=92	
<b>IDM - Participation</b>	48 (48)	40 (44)	0.80	73 (72)	76 (83)	0.08
<b>IDM - Non-participation</b>	39 (39)	38 (41)		0 (0)	1 (1)	
<b>No-IDM</b>	13 (13)	14 (15)		29 (28)	15 (16)	

<sup>1</sup> Intentional participation during IDM Intervention study

\* During IDM Intervention study

Chi<sup>2</sup> : comparison between Control and Intervention groups

IDM= Informed Decision Making: participation with sufficient knowledge and a positive attitude or non-participation with sufficient knowledge and a negative attitude towards CT / FAS

No-IDM: participation and non-participation with insufficient knowledge about prenatal screening and a non-matching attitude towards prenatal screening with participation and non-participation.

CT= Combined Test

FAS= Fetal Anomaly Scan

Match= matching on similarity in determining characteristics (ethnicity, gravidity, parity, educational level and age) n=111 control and n=111 intervention respondents.

the upcoming availability of the Non-Invasive Prenatal Test (NIPT) and change in the threshold of the CT in the Netherlands (since 2015 all women most pay for the CT), into account. Lastly, we had to reduce ethnic background to a dichotomous variable, Western and non-Western women because of absence of large enough ethnic minority subgroups for reliable statistical analyses.

## **CONCLUSION**

Adding Culturally Competent Educational Film (CCEF's) to counseling about Prenatal Screening (PS) has a significant effect on the increase of knowledge within medium and highly educated groups and non-western immigrant groups. Promising results were seen for the increase of Informed Decision Making among intentional participants in the Fetal Anomaly Scan (FAS) and decrease of uninformed decision making of participants and non-participants in FAS. We recommend an update of the the CCEF's to the current context of PS (including the Non Invasive Prenatal Test, NIPT). A randomized controlled trial would be useful to further build on the evidence for the films.

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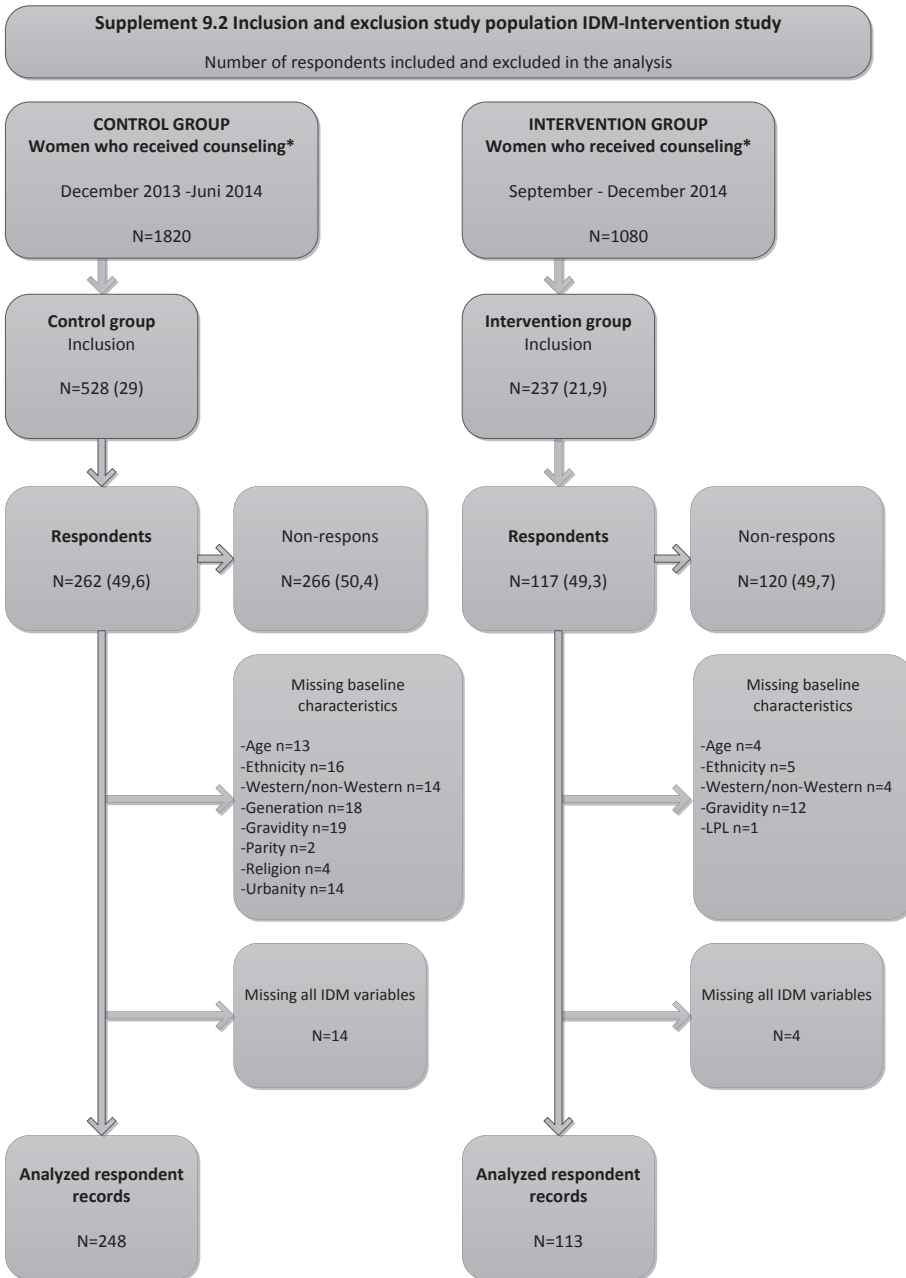
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## SUPPLEMENTS





\* Registered counselling for participating counselors in the study (based on Peridos national database Prenatal Screening).



**Supplement 9.3** Survey counsellors: Use of educational films on prenatal screening

CHARACTERISTICS OF COUNSELORS	Total N=28		OPINION ABOUT EDUCATION FILMS	Total N=28	
	N	%		N	%
<b>Age category counselors</b>			<b>Personal experience with educational films</b>		
20-29	2	(7)	Very good	8	(28)
30-39	9	(32)	Good	18	(64)
40-49	8	(29)	Neutral	1	(4)
50-59	6	(21)	Bad	1	(4)
60-69	3	(11)	Very bad	0	(0)
<b>Counselors organization</b>			<b>Experience of pregnant women with educational films<sup>1,2</sup></b>		
Midwifery practice	5	(18)	Very good	9	(32)
Midwifery practice + ultrasound	6	(21)	Good	17	(61)
Hospital	17	(61)	Neutral	2	(7)
<b>Profession of counselor *</b>			<b>Educational film is useful addition to routine practice?</b>		
Midwife	5	(18)	Yes	26	(93)
Midwife & sonographer	8	(29)	No	2	(7)
Sonographer	7	(25)	<b>Benefits of the educational films*</b>	<b>26</b>	
Nurse	7	(25)	Standardized information provision	10	(38)
Gynecologist / obstetrician	1	(3)	Time efficient	12	(46)
<b>Years of experience in profession</b>			Appropriate for language barriers	7	(27)
≤5 years	6	(21)	More calm information provision	4	(15)
6 - ≤ 10 years	6	(21)	Visualization benefits information prov.	2	(8)
11 - ≤ 20 years	11	(40)	<b>Disadvantages of the educational films*</b>	<b>27</b>	
> 21 years	5	(18)	ICT complications	6	(22)
<b>Years of experience with counseling PS</b>			Other languages needed <sup>3</sup>	3	(11)
1 - ≤ 2 years	4	(14)	Time investment	8	(30)
3 - ≤ 4 years	7	(25)	Educational films incomplete	3	(11)
5 - ≤ 8 years	13	(47)	Other	2	(7)

9 - > 11 years	4	(14)	None	7	(26)
<b>Vision on counseling about PS in general</b>			<b>Time investment use educational film</b>		
Necessary	15	(54)	5-7 minutes	19	(68)
Necessary, but time-consuming & difficult	6	(21)	7-10 minutes	7	(25)
Ambivalent	2	(7)	> 10 minutes	2	(7)
Other	5	(18)	<b>Preferred use of educational films in future*</b>		
<b>Knowledgeable about:</b>			On organizational website	7	(25)
Existence of translated leaflets "Yes"	25	(89)	Before counseling	17	(61)
Acquiring translated leaflets "Yes"	18	(64)	During counseling	9	(32)
Languages of translated leaflets "Yes"	8	(29)	After counseling	2	(7)

<sup>1</sup> Observed by counselor

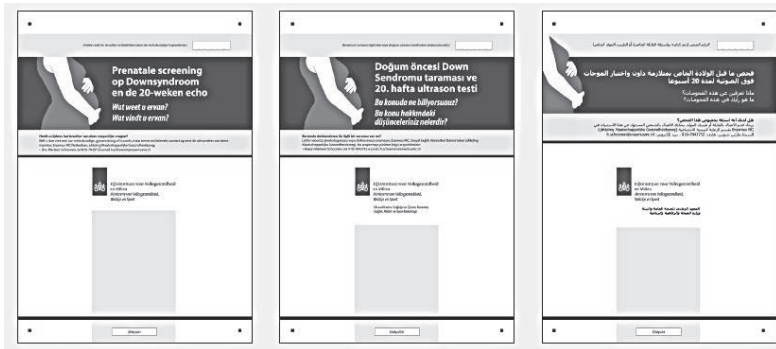
<sup>2</sup> Also answer categories 'bad' and 'very bad', but none of the respondents marked this answer

\*Multiple answer options possible

<sup>3</sup> English and Polish.

**Supplement 9.4** Questionnaire IDM-Intervention study

I Used questionnaires in Dutch, Turkish and standard-Arabic language



II Attitude measure CT and FAS used in the questionnaire

**Participating in prenatal screening for Down syndrome / fetal anomaly screening: What is your opinion?** <sup>1</sup>

What is your opinion of participating in prenatal screening for Down syndrome / fetal anomalies? Please indicate this in the following four questions by marking for each line one of the boxes under the numbers one through seven.

**Example**

If you are of the opinion that participating in prenatal screening for Down syndrome / fetal anomalies would be ‘a bad idea’ for you, mark box 1 in the first line. If your opinion is that it is not such a bad idea, then you should choose one of the numbers more towards the right when making the assessment. If your opinion is that participating in prenatal screening for Down syndrome / fetal anomalies is ‘not a bad idea’ for you, you should then mark box 7. The other three questions should be answered in the same way.

Participating in first trimester prenatal screening for Down syndrome / fetal anomalies is, in my opinion:

<i>A bad idea</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<i>Not a bad idea</i>
	1	2	3	4	5	6	7	
<i>Useful</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<i>Not useful</i>
	1	2	3	4	5	6	7	
<i>Harmful</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<i>Not harmful</i>
	1	2	3	4	5	6	7	
<i>A good idea</i>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<i>Not a good idea</i>
	1	2	3	4	5	6	7	

**Supplement 9.5** Use of translated hardcopy and downloaded leaflets Dutch prenatal screening 2014

Language	Birth rates *	First generation *†	Difficulty with reading Dutch §	Downloads leaflet CT †	Possible no provision translated leaflets CT	Downloads leaflets FAS †	Possible no provision translated leaflet FAS
	n= (%)	n= (%)	n= (%)	n= (%)	n= (%)	n= (%)	n= (%)
<b>Dutch</b>	126.259 † (74)			170.542 **(98)		170.138 ** (99)	
<b>Total Western immigrants</b>	17.635 (10)	10.406 (59)*					
English				1.090 (0,6)		593 (0,3)	
Spanish				208 (0,1)		128 (0,1)	
French				149 (0,1)		80 (0)	
German				141 (0,1)		76 (0)	
<b>Total Non-western immigrants</b>	27.447 (16)	18.961 (69)††					
Turkish	5.873 (3)††	2.978 (51)††	983 (33)††	345 (0,2)	638 (65) ‡‡	168 (0,1)	815 (83) ‡‡
Arabic (Maroccan)	7.424 (4)††	4.432 (60)††	1.063 (24)††	320 (0,2)	743 (70) ‡‡	257 (0,1)	806 (76) ‡‡
Chinese				268 (0,2)		167 (0,1)	
Portugeuse (Cape Verdean)				134 (0,1)		65 (0)	
Papiamento (Antillean)	2.199 (1)††	1.371 (62)††	41 (3)††	109 (0,1)	adequate	45 (0)	adequate
<b>Totaal</b>	<b>171.341</b>			<b>173.306</b>		<b>171.717</b>	

\* Statistics Netherlands Statline: birth rates by ethnicity until December 31 2013. Ref: <http://statline.cbs.nl/Statweb/publication/?DM=SLNL&PA=37884&D1=a&D2=0&D3=0-2,4-9&D4=14-17&HDR=T&STB=G2,G1,G3&VW=T>

† Dutch and Surinamese; both Dutch speaking

‡ More need for translated leaflets within first generation Immigrant groups

§ Statistics Netherlands; difficulty with reading in Dutch, first generation 2006 Ref: <http://www.cbs.nl/nl-NL/menu/themas/dossiers/allochtonen/publicaties/artikelen/archief/2008/2008-2570-wm.htm>

¶ Data request: National Institute for Public Health & Environment (2014).

\*\* Inclusive 170.000 Dutch hardcopy leaflets both CT and FAS

†† Percentage within ethnicity / language group

‡‡ Percentage number pregnant women with difficulty to read in Dutch **minus** number of downloads translated leaflet CT/FAS gave number and percentage of absence