# Evaluation of the HFEA public consultation on hybrid and chimera embryos

Final report: Annexes

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#### **APPENDIX 1. Evaluation questionnaire analysis**

#### HFEA local discussion groups, May 2007

Belfast males: 10 completed questionnaires returned Belfast females: 9 completed questionnaires returned Glasgow males: 9 completed questionnaires returned Glasgow females: 9 completed questionnaires returned London males: 6 completed questionnaires returned London females: 8 completed questionnaires returned Manchester males: 9 completed questionnaires returned Manchester females: 9 completed questionnaires returned Newcastle males: 10 completed questionnaires returned Newcastle females: 10 completed questionnaires returned

Total 89 public participants; total 89 completed questionnaires returned = 100% return rate

## 1 How far do you agree or disagree with the following statements?

There was enough time to fully discuss the issues properly:	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree	Don't know
Belfast males	2 (20%)	5 (50%)		2 (20%)	1 (10%)	
Belfast females	5 (56%)	3 (33%)		1 (11%)		
Glasgow males	2 (22%)	5 (56%)	1 (11%)	1 (11%)		
Glasgow females	5 (56%)	4 (44%)				
London males		4 (67%)	1 (17%)	1 (17%)		
London females	1 (13%)	3 (38%)	2 (25%)	1 (13%)		
Manchester males	1 (11%)	4 (44%)	1 (11%)	2 (22%)		
Manchester females	1 (11%)	7 (78%)	1 (11%)			
Newcastle males	4 (40%)	6 (60%)				
Newcastle females	3 (30%)	3 (30%)	1 (10%)	3 (30%)		
Combined result	24 (27%)	44 (49%)	7 (8%)	11 (12%)	1 (1%)	

The information provided was fair and balanced:	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree	Don't know
Belfast males	3 (30%)	7 (70%)				
Belfast females	5 (56%)	4 (44%)				
Glasgow males	5 (56%)	3 (33%)		1 (11%)		
Glasgow females	4 (44%)	3 (33%)	2 (22%)			
London males		4 (67%)	2 (33%)			
London females	3 (38%)	5 (63%)				
Manchester males	3 (33%)	5 (56%)	1 (11%)			
Manchester females	1 (11%)	6 (67%)	2 (22%)			
Newcastle males	6 (60%)	3 (30%)				
Newcastle females	4 (40%)	6 (60%)				
Combined result	34 (38%)	46 (52%)	7 (8%)	1 (1%)		

I understand and could use the information provided:	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree	Don't know
Belfast males	3 (30%)	7 (70%)				
Belfast females	5 (56%)	3 (33%)	1 (11%)			
Glasgow males	5 (56%)	3 (33%)	1 (11%)			
Glasgow females	4 (44%)	5 (56%)				
London males	2 (33%)	3 (50%)	1 (17%)			
London females	1 (13%)	2 (25%)	3 (38%)			
Manchester males	3 (33%)	6 (67%)				
Manchester females	2 (22%)	4 (44%)	2 (22%)			
Newcastle males	4 (40%)	4 (40%)	1 (10%)	1 (10%)		
Newcastle females	4 (40%)	5 (50%)		1 (10%)		
Combined result	33 (37%)	42 (47%)	9 (10%)	2 (2%)		

I understand the purpose of the consultation:	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree	Don't know
Belfast males	3 (30%)	6 (60%)	1 (10%)			
Belfast females	6 (67%)	3 (33%)				
Glasgow males	6 (67%)	3 (33%)				
Glasgow females	5 (56%)	4 (44%)				
London males	1 (17%)	5 (83%)				
London females	1 (13%)	7 (88%)				
Manchester males	4 (44%)	5 (56%)				
Manchester females	3 (33%)	5 (56%)		1 (11%)		
Newcastle males	3 (30%)	6 (60%)				
Newcastle females	3 (30%)	7 (70%)				
Combined result	35 (39%)	51 (57%)	1 (1%)	1 (1%)		

I understand how the results of the consultation will be used:	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree	Don't know
Belfast males	1 (10%)	6 (60%)	2 (20%)	1 (10%)		
Belfast females	5 (56%)	1 (11%)	3 (33%)			
Glasgow males	3 (33%)	4 (44%)	1 (11%)			
Glasgow females	3 (33%)	4 (44%)	2 (22%)			
London males		2 (33%)	1 (17%)	1 (17%)		2 (33%)
London females	1 (13%)	6 (75%)	1 (13%)			
Manchester males	2 (22%)	6 (67%)	1 (11%)			
Manchester females	3 (33%)	4 (44%)	1 (11%)	1 (11%)		
Newcastle males	2 (20%)	6 (60%)	2 (20%)			
Newcastle females	2 (20%)	6 (60%)	1 (10%)	1 (10%)		
Combined result	22 (25%)	45 (51%)	15 (17%)	4 (4%)		2 (2%)

Attending this discussion group has helped me think more clearly about the issues:	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree	Don't know
Belfast males	3 (30%)	7 (70%)				
Belfast females	6 (67%)	3 (33%)				
Glasgow males	4 (44%)	4 (44%)				
Glasgow females	6 (67%)	3 (33%)				
London males	2 (33%)	3 (50%)		1 (17%)		
London females	5 (63%)	3 (38%)				
Manchester males	8 (89%)		1 (11%)			
Manchester females	4 (44%)	3 (33%)	2 (22%)			
Newcastle males	3 (30%)	7 (70%)				
Newcastle females	6 (60%)	4 (40%)				
Combined result	47 (53%)	37 (42%)	3 (3%)	1 (1%)		

Attending this discussion group has changed my views on these issues:	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree	Don't know
Belfast males	2 (20%)	3 (30%)	4 (40%)	1 (10%)		
Belfast females	1 (11%)	1 (11%)	4 (44%)	1 (11%)	1 (11%)	1 (11%)
Glasgow males	3 (33%)	2 (22%)	3 (33%)		1 (11%)	
Glasgow females	5 (56%)	3 (33%)	1 (11%)	1 (11%)		
London males	1 (17%)		4 (67%)	1 (17%)		
London females	2 (25%)	3 (38%)	1 (13%)	2 (25%)		
Manchester males	3 (33%)	2 (22%)	3 (33%)	1 (11%)		
Manchester females	1 (11%)	4 (44%)		4 (44%)		
Newcastle males	1 (10%)	6 (60%)	2 (20%)		1 (10%)	
Newcastle females	4 (40%)	2 (20%)	1 (10%)	3 (30%)		
Combined result	23 (26%)	26 (29%)	23 (26%)	14 (16%)	3 (3%)	1 (1%)

I learnt something I did not know before:	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree	Don't know
Belfast males	7 (70%)	3 (30%)				
Belfast females	7 (78%)	2 (22%)				
Glasgow males	6 (67%)	3 (33%)				
Glasgow females	8 (89%)	1 (11%)				
London males	2 (33%)	4 (67%)				
London females	4 (50%)	3 (38%)		1 (13%)		
Manchester males	5 (56%)	3 (33%)				
Manchester females	8 (89%)	1 (11%)				
Newcastle males	4 (40%)	5 (50%)				
Newcastle females	7 (70%)	3 (30%)				
Combined result	58 (65%)	28 (31%)		1 (1%)		

I enjoyed taking part:	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree	Don't know
Belfast males	4 (40%)	6 (60%)				
Belfast females	6 (67%)	3 (33%)				
Glasgow males	4 (44%)	4 (44%)				
Glasgow females	8 (89%)	1 (11%)				
London males	1 (17%)	5 (83%)				
London females	5 (63%)	2 (25%)		1 (13%)		
Manchester males	6 (67%)	3 (33%)				
Manchester females	7 (78%)	2 (22%)				
Newcastle males	6 (60%)	3 (30%)				
Newcastle females	6 (60%)	3 (30%)				
Combined result	53 (60%)	32 (36%)		1 (1%)		

I was able to discuss issues that concern me:	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree	Don't know
Belfast males	3 (30%)	4 (40%)	3 (30%)			
Belfast females	5 (56%)	2 (22%)	2 (22%)			
Glasgow males	4 (44%)	3 (33%)	1 (11%)			
Glasgow females	4 (44%)	4 (44%)	1 (11%)			
London males	1 (17%)	4 (67%)	1 (17%)			
London females	2 (25%)	4 (50%)	1 (13%)			
Manchester males	4 (44%)	3 (33%)	2 (22%)			
Manchester females	3 (33%)	4 (44%)	1 (11%)	1 (11%)		
Newcastle males	3 (30%)	6 (60%)				
Newcastle females	2 (20%)	6 (60%)	2 (20%)			
Combined result	31 (35%)	40 (45%)	15 (17%)	1 (1%)		

All participants were treated equally and respectfully, and no single view was allowed to dominate:	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree	Don't know
Belfast males	6 (60%)	4 (40%)				
Belfast females	6 (67%)	3 (33%)				
Glasgow males	5 (56%)	3 (33%)	1 (11%)			
Glasgow females	9 (100%)					
London males	3 (50%)	3 (50%)				
London females	4 (50%)	4 (50%)				
Manchester males	4 (44%)	4 (44%)		1 (11%)		
Manchester females	7 (78%)	2 (22%)				
Newcastle males	4 (40%)	5 (50%)				
Newcastle females	8 (80%)	2 (20%)				
Combined result	56 (63%)	30 (34%)	1 (1%)	1 (1%)		

I am more likely to get involved in these sorts of events:	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree	Don't know
Belfast males	2 (20%)	5 (50%)	2 (20%)			
Belfast females	6 (67%)	3 (33%)				
Glasgow males	3 (33%)	5 (56%)	1 (11%)			
Glasgow females	7 (78%)	8 (89%)	1 (11%)			
London males	2 (33%)	3 (50%)	1 (17%)			
London females	3 (38%)	5 (63%)				
Manchester males	4 (44%)	4 (44%)	1 (11%)			
Manchester females	4 (44%)	1 (11%)	3 (33%)		1 (11%)	
Newcastle males	3 (30%)	3 (30%)	2 (20%)			2 (20%)
Newcastle females	7 (70%)	2 (20%)	1 (10%)			
Combined result	41 (46%)	39 (44%)	12 (13%)		1 (1%)	

# Have you seen any media coverage of the issues discussed at this discussion group?

	Yes	No	Don't know
Belfast males	5 (50%)	2 (20%)	3 (30%)
Belfast females	4 (44%)	5 (56%)	
Glasgow males	4 (44%)	4 (44%)	1 (11%)
Glasgow females	3 (33%)	5 (56%)	1 (11%)
London males	6 (100%)		
London females	2 (25%)	6 (75%)	
Manchester males	2 (22%)	6 (67%)	
Manchester females	2 (22%)	7 (78%)	
Newcastle males	3 (30%)	5 (50%)	1 (10%)
Newcastle females	5 (50%)	5 (50%)	
Combined result	36 (40%)	45 (51%)	6 (7%)

## If yes, did that media coverage affect your own views on the issues?

	Yes	No	Don't know
Belfast males	2 (20%)	2 (20%)	1 (10%)
Belfast females		3 (33%)	1 (11%)
Glasgow males	3 (33%)	1 (11%)	
Glasgow females		2 (22%)	1 (11%)
London males	4 (67%)	2 (33%)	
London females	1 (13%)	1 (13%)	
Manchester males	1 (11%)	1 (11%)	
Manchester females	1 (11%)	1 (11%)	
Newcastle males		3 (30%)	
Newcastle females	2 (20%)	3 (30%)	
Combined result	14 (16%)	19 (21%)	3 (3%)

# What were the best / most successful aspects of the discussion group?

Belfast males	
Hearing (different) views from participants	5 (50%)
Information sheets / info provided	1 (10%)
Information / explanation of embryo research process	1 (10%)
General information / knowledge / learning	1 (10%)
Morality issues	1 (10%)

Belfast females	
General information / knowledge / learning	4 (44%)
Information / explanation of embryo research process	3 (33%)
Good explanations / clear information	1 (11%)

Glasgow males	
General information / knowledge / learning	4 (44%)
Everyone joined in	4 (44%) 1 (11%)
Hearing (different) views from participants	1 (11%)
Good discussion leader / facilitator	1 (11%)

Glasgow females	
Hearing (different) views from participants	3 (33%)
General information / knowledge / learning	3 (33%)
Information sheets / info provided	1 (11%)
Information / explanation of embryo research process	1 (11%)
Sharing own views	1 (11%)

London males	
General information / knowledge / learning	2 (33%)
Everyone joined in	1 (17%)
Information / explanation of embryo research process	1 (17%)
Hearing (different) views from participants	1 (17%)
Good discussion leader / facilitator	1 (17%)
Good explanations / clear information	1 (17%)

London females	
Information / explanation of embryo research process	3 (38%)
Hearing (different) views from participants	2 (25%)
Information / learning on regulation	1 (13%)
Both sides of the argument being represented	1 (13%)
Good explanations / clear information	1 (13%)

Manchester males	
Hearing (different) views from participants	2 (22%)
All / most of them	1 (11%)
Everyone joined in	1 (11%)
Information / explanation of embryo research process	1 (11%)
General information / knowledge / learning	1 (11%)
Good explanations / clear information	1 (11%)
Possible benefits (from the research)	1 (11%)

Manchester females	
Hearing (different) views from participants	3 (33%)
Information sheets / info provided	2 (22%)
General information / knowledge / learning	2 (22%)
Everyone joined in	1 (11%)
Good explanations / clear information	1 (11%)

Newcastle males	
Hearing (different) views from participants	2 (20%)
Discussions	1 (10%)
Information sheets / info provided	1 (10%)
Taking part	1 (10%)
Meeting other people	1 (10%)
Good explanations / clear information	1 (10%)

Newcastle females	
Information / explanation of embryo research process	4 (40%)
All / most of them	2 (20%)
Hearing (different) views from participants	1 (10%)
General information / knowledge / learning	1 (10%)
Good discussion leader / facilitator	1 (10%)
Good explanations / clear information	1 (10%)

Combined result	
Hearing (different) views from participants	20 (22%)
General information / knowledge / learning	18 (20%)
Information / explanation of embryo research process	11 (12%)
Good explanations / clear information	7 (8%)
Information sheets / info provided	5 (6%)
Everyone joined in	4 (4%)
Good discussion leader / facilitator	3 (3%)
All / most of them	2 (2%)
Both sides of the argument being represented	1 (1%)
Discussions	1 (1%)
Information / learning on regulation	1 (1%)
Meeting other people	1 (1%)
Morality issues	1 (1%)
Possible benefits (from the research)	1 (1%)
Taking part	1 (1%)
Sharing own views	1 (1%)

## What were the worst / least successful aspects of the discussion group?

Belfast males	
Not enough time	3 (30%)
• None	2 (20%)
Religious and moral issues	1 (10%)
People's lack of knowledge (on the subject)	1 (10%)
Trying to understand the information	1 (10%)
Needed wider range of views (eg female)	1 (10%)

Belfast females	
Animals mixed with humans / true hybrids	4 (44%)
Issues I didn't agree with	1 (11%)

Glasgow males	
• None	6 (67%)
Animals mixed with humans / true hybrids	1 (11%)

Glasgow females	
• None	4 (44%)
Animals mixed with humans / true hybrids	1 (11%)

London males	
Not enough information	2 (33%)
Everyone agreed – not enough opposing views	1 (17%)
Not enough time	1 (17%)

London females	
• None	5 (63%)
Unanswered questions	1 (13%)

Manchester males	
• None	3 (33%)
Not enough time	1 (11%)
Animal rights	1 (11%)
One strong character (sidetracked discussion)	1 (11%)
Religious and moral issues	1 (11%)

Manchester females	
• None	3 (33%)
Not enough time	1 (11%)
People talking about 'what ifs'	1 (11%)

Newcastle males		
• None	7	7 (70%)

Newcastle females	
• None	4 (40%) 2 (20%)
More information before / not knowing enough before attending	2 (20%)
Felt wanted to know more afterwards	1 (10%) 1 (10%)
Ultimate purpose (of research)	1 (10%)

Combined result		
• None	34 (38%)	
Animals mixed with humans / true hybrids	6 (7%)	
Not enough time	6 (7%)	
More information before / not knowing enough before	2 (2%)	
attending		
Not enough information	2 (2%)	
Religious and moral issues	2 (2%)	
Animal rights	1 (1%)	
Everyone agreed – not enough opposing views	1 (1%)	
Felt wanted to know more afterwards	1 (1%)	
Issues I didn't agree with	1 (1%)	
Needed wider range of views (eg female)	1 (1%)	
One strong character (sidetracked discussion)	1 (1%)	
People's lack of knowledge (on the subject)	1 (1%)	
People talking about 'what ifs'	1 (1%)	
Trying to understand the information	1 (1%)	
Ultimate purpose (of research)	1 (1%)	
Unanswered questions	1 (1%)	

# How do you think this type of discussion group could be improved?

Belfast males	
More time / more in depth / longer	3 (30%)
More information / knowledge / evidence needed	3 (30%) 1 (10%)
Nothing	1 (10%)
More information before the meeting	1 (10%)
More real life predicaments discussed	1 (10%)

Belfast females	
More people need to know about all this	2 (22%)
It worked well / positive / well run / was very good	1 (11%)

Glasgow males	
More time / more in depth / longer	2 (22%)
More information / knowledge / evidence needed	1 (11%)
Nothing	1 (11%)

Glasgow females	
More / wider range of people	5 (56%)
It worked well / positive / well run / was very good	5 (56%) 1 (11%)
Should happen again / more frequently	1 (11%)
More information / knowledge / evidence needed	1 (11%)

London males	
More / wider range of people	1 (17%)
More visual aids (film, diagrams, etc)	1 (17%)
More time / more in depth / longer	1 (17%)
Nothing	1 (17%)

London females	
It worked well / positive / well run / was very good	4 (50%)
Don't know	1 (13%)
Should happen again / more frequently	1 (13%)
More information / knowledge / evidence needed	1 (13%)

Manchester males	
More time / more in depth / longer	5 (56%)
More / wider range of people	2 (22%)
• Food	1 (11%)

Manchester females	
More information / knowledge / evidence needed	2 (22%)
More time / more in depth / longer	2 (22%)
It worked well / positive / well run / was very good	1 (11%)
More information before the meeting	1 (11%)
More information on the outcomes of the process	1 (11%)
Earlier start	1 (11%)

Newcastle males	
Nothing Should happen again / more frequently More time / more in depth / longer	3 (30%) 1 (10%) 1 (10%)

Newcastle females	
Nothing	3 (30%)
More time / more in depth / longer	2 (20%)
More information before the meeting	1 (10%)
More people need to know about all this	1 (10%)

Combined result	
More time / more in depth / longer	16 (18%)
Nothing	9 (10%)
More / wider range of people	8 (9%)
It worked well / positive / well run / was very good	7 (8%)
More information / knowledge / evidence needed	6 (7%)
More information before the meeting	3 (3%)
More people need to know about all this	3 (3%)
Should happen again / more frequently	3 (3%)
• Don't know	1 (1%)
Earlier start	1 (1%)
• Food	1 (1%)
More information on the outcomes of the process	1 (1%)
More real life predicaments discussed	1 (1%)
More visual aids (film, diagrams, etc)	1 (1%)

# How satisfied were you with the discussion group?

Information received before the event:	Very satisfied	Fairly satisfied	Neither satisfied nor dissatisfied	Not very satisfied	Not at all satisfied	Don't know
Belfast males	2 (20%)	3 (30%)	3 (30%)	2 (20%)		
Belfast females	5 (56%)	3 (33%)	1 (11%)			
Glasgow males	3 (33%)	1 (11%)	5 (56%)			
Glasgow females	6 (67%)	2 (22%)	1 (11%)			
London males	1 (17%)	4 (67%)	1 (17%)			
London females	5 (63%)	1 (13%)	1 (13%)			
Manchester males	7 (78%)			1 (11%)		
Manchester females	4 (44%)	4 (44%)	1 (11%)			
Newcastle males	8 (80%)	1 (10%)				
Newcastle females	5 (50%)	3 (30%)	2 (20%)			
Combined result	46 (51%)	22 (25%)	15 (17%)	3 (3%)		

The way the events were run on the day:	Very satisfied	Fairly satisfied	Neither satisfied nor dissatisfied	Not very satisfied	Not at all satisfied	Don't know
Belfast males	6 (60%)	4 (40%)				
Belfast females	7 (78%)	1 (11%)	1 (11%)			
Glasgow males	6 (67%)	3 (33%)				
Glasgow females	8 (89%)	1 (11%)				
London males	4 (67%)	1 (17%)	1 (17%)			
London females	7 (87%)	1 (13%)				
Manchester males	6 (67%)	2 (22%)				
Manchester females	8 (89%)	1 (11%)				
Newcastle males	8 (80%)	1 (10%)				
Newcastle females	9 (90%)	1 (10%)				
Combined result	69 (78%)	16 (18%)	2 (2%)			

Overall satisfaction with the event:	Very satisfied	Fairly satisfied	Neither satisfied nor dissatisfied	Not very satisfied	Not at all satisfied	Don't know
Belfast males	5 (50%)	5 (50%)				
Belfast females	6 (67%)	2 (22%)	1 (11%)			
Glasgow males	4 (44%)	5 (56%)				
Glasgow females	8 (89%)	1 (11%)				
London males	4 (67%)	2 (33%)				
London females	8 (100%)					
Manchester males	6 (67%)	1 (11%)	1 (11%)			
Manchester females	8 (89%)	1 (11%)				
Newcastle males	7 (70%)	2 (20%)				
Newcastle females	9 (90%)	1 (10%)				
Combined result	65 (73%)	20 (22%)	2 (2%)			

# What did you hope to get out of coming to this discussion group?

Belfast males	
General information / knowledge / learning / understanding	5 (50%)
Information / knowledge of new developments / the topic /	3 (30%)
the research	
To understand others views	1 (10%)

Belfast females	
Information / knowledge of new developments / the topic / the research	2 (22%)
General information / knowledge / learning / understanding     To give own opinion / air views	1 (11%) 1 (11%)

Glasgow males	
General information / knowledge / learning / understanding	4 (44%)

Glasgow females	
Information / knowledge of new developments / the topic / the research	6 (67%)
General information / knowledge / learning / understanding     To give own opinion / air views	2 (22%) 1 (11%)

London males	
General information / knowledge / learning / understanding     Information / knowledge of new developments / the topic / the research	2 (33%) 1 (17%)

London females	
General information / knowledge / learning / understanding	4 (50%)
Information / knowledge of new developments / the topic /	1 (13%)
the research	
Purpose of new experiments	1 (13%)

Manchester males	
Information / knowledge of new developments / the topic / the research	3 (33%)
General information / knowledge / learning / understanding     Money	3 (33%) 1 (11%)

Manchester females	
General information / knowledge / learning / understanding     Information / knowledge of new developments / the topic /	6 (67%) 2 (22%)
the research • To understand others views	1 (11%)

Newcastle males	
Information / knowledge of new developments / the topic / the research	2 (20%)
General information / knowledge / learning / understanding	1 (10%)

Newcastle females	
Information / knowledge of new developments / the topic / the research	4 (40%)
General information / knowledge / learning / understanding	4 (40%)

Combined result	
General information / knowledge / learning / understanding	32 (36%)
Information / knowledge of new developments / the topic /	24 (27%)
the research	
To give own opinion / air views	2 (2%)
To understand others views	2 (2%)
Purpose of new experiments	1 (1%)
Money	1 (1%)

## 8 Did the discussion group deliver what you hoped / expected?

	Completely	Mostly	Partly	Not really	Not at all
Belfast males	3 (30%)	6 (60%)			
Belfast females	4 (44%)	1 (11%)	3 (33%)		
Glasgow males	3 (33%)	2 (22%)			
Glasgow females	6 (67%)	3 (33%)			
London males		2 (33%)	1 (17%)		
London females	3 (38%)	4 (50%)	1 (13%)		
Manchester males	3 (33%)	3 (33%)	1 (11%)	1 (11%)	
Manchester females	4 (44%)	4 (44%)	1 (11%)		
Newcastle males	5 (50%)	2 (20%)			
Newcastle females	3 (30%)	9 (90%)			
Combined result	34 (38%)	36 (40%)	7 (8%)	1 (1%)	

# 9 How important do you think it is to involve the public in discussing these sorts of issues?

	Very important	Fairly important	Not very important	Not at all important
Belfast males	8 (80%)	1 (10%)		
Belfast females	7 (78%)	1 (11%)		
Glasgow males	5 (56%)			
Glasgow females	9 (100%)			
London males	3 (50%)			
London females	8 (100%)			
Manchester males	7 (78%)	1 (11%)		
Manchester females	9 (100%)			
Newcastle males	6 (60%)	1 (10%)		
Newcastle females	9 (90%)	1 (10%)		
Combined result	71 (80%)	5 (6%)		

# 10 Is there anything else you would like to add?

Belfast males	
Enjoyed it / thanks / very interesting	1 (10%)

Belfast females	
There should be more coverage (media) on this issue	1 (11%)

Glasgow males	
Enjoyed it / thanks / very interesting     Veny well run	1 (11%)
Very well run	1 (11%)

Glasgow females	
There should be more coverage (media) on this issue	1 (11%)

London females	
Enjoyed it / thanks / very interesting	1 (13%)
Very well run	1 (13%)

Manchester females	
Would like to be kept informed on this issue	1 (11%)
Enjoyed it / thanks / very interesting	1 (11%)

Newcastle males	
Would like more information	1 (10%)
Would like to be kept informed on this issue	1 (10%)

Newcastle females	
Would like to be involved in the next stages of this process	1 (10%)

Combined result	
Enjoyed it / thanks / very interesting	4 (4%)
There should be more coverage (media) on this issue	2 (2%)
Very well run	2 (2%)
Would like to be kept informed on this issue	2 (2%)
Would like more information	1 (1%)
Would like to be involved in the next stages of this process	1 (1%)

# APPENDIX 2. Evaluation questionnaire analysis HFEA Reconvened public meeting

London, 7 June 2007

Total number participants: 44
Total number of questionnaires returned: 44

# How far do you agree or disagree with the following statements?

	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree
There was enough time to fully discuss the issues properly	23 (52%)	15 (34%)	4 (9%)	2 (5%)	
The information provided was helpful and unbiased	12 (27%)	27 (61%)	2 (5%)	2 (5%)	
I understood and could use the information provided	14 (32%)	22 (50%)	8 (18%)		
There was too much information to take in	5 (11%)	7 (16%)	10 (23%)	20 (45%)	1 (2%)
I understand the purpose of the consultation	15 (34%)	21 (48%)	5 (11%)		
I understand how the results of the consultation will be used	13 (30%)	23 (52%)	7 (16%)	1 (2%)	
I think the HFEA will take the results of our discussions into account in making their decisions	15 (34%)	22 (50%)	7 (16%)		
I learnt something I did not know before	24 (55%)	19 (43%)			
Attending this event has helped me think more clearly about the issues	23 (52%)	18 (41%)	2 (5%)		
I enjoyed taking part	27 (61%)	16 (36%)	1 (2%)		
I was able to say everything I wanted to	22 (50%)	22 (50%)			
All participants were treated equally and respectfully	24 (55%)	20 (45%)			
No single view was allowed to dominate unfairly	22 (50%)	21 (48%)		1 (2%)	
There was a good mix of people	26 (59%)	16 (36%)	1 (2%)		
I am more likely to get involved in these sorts of events as a result of attending this one	24 (55%)	18 (40%)	2 (5%)		

# Have you heard about the issues discussed today in the media (TV, radio, newspapers, etc)?

Yes	25 (57%)
No	17 (39%)
Don't know	0

If yes, please state anything specific that you heard in the media that affected your own views:

Issues mentioned were:	
Stem cells from skin	3
Blindness / macular degeneration	2
Cloning	2
Stem cells donated by baby sibling	1

<sup>&</sup>quot;It's a hotly debated subject and I just moulded my own views" (male, 16 - 24 years)
"BBC report on stem cells to potentially cure a condition that causes blindness" (male, 25 - 39 years)

#### Which information provided did you find most useful?

Information sent out in advance for the event	13 (30%)
Information sheets provided on the day	24 (55%)
Information provided by experts on the day	30 (68%)
Information provided on the website	2 (5%)

Other (please say what)?

Information from table facilitator	1
Information from scientist / expert	1

## 4 Was there anything missing from the information provided?

Yes	1 (2%)
No	30 (68%)
Don't know	13 (30%)

If yes, please say what was missing:

More evidence on use of chimera and	
hybrid embryos	1

<sup>&</sup>quot;Back up evidence for the use of chimera and hybrid embryos and the benefits of those" (female, 40 - 54 years)

# Has being involved in this event made any difference to what you think about these issues?

Yes, a lot	19 (43%)
Yes, a little	12 (27%)
Uncertain	6 (14%)
No, not really	7 (16%)
No, not at all	0

If yes, please say what made a difference and how it affected your views:

Gained greater / clearer understanding	7
Having the facts / information provided	5
Reinforced views	1
Concerns diminished	1
Thought about the views of others	1
Changed mind on animal testing	1
Regulations	1
Moderated views	1

<sup>&</sup>quot;Having information explained in more depth. Reasons for using embryos that aren't 100% human and having my concerns diminished" (female, 25 - 39 years)

#### What were the best / most successful aspects of the event?

Listening to / views from experts / panel (including 3 mentioned by name: Dr King, Professor Shaw, Josephine	21
Quintavalle)	8
Gaining understanding / information /	
knowledge	5
Group discussions	5
Opportunity to question the experts /	
panel	3
Facilitator (Elaine)	2
Hearing views of other participants	2
Everything / all	2
• Lunch	1
Listening to different ethical views	1
Meeting people	1
Covered pros and cons	1
Lots of questions answered	

<sup>&</sup>quot;Made me think about the different views of others" (male, 25 - 39 years)

<sup>&</sup>quot;Having the facts" (female, 16 - 24 years)

#### What were the worst / least successful aspects of the event?

None / nothing	12
Disagreed with views of experts / did not	
like particular experts (mentioned 3 by	5
name: Professor Lipton, Professor	
Shaw, Josephine Quintavalle)	
Problems with acoustics / noise	3
Too long	3
Room too cold	2
Needed more time	1
Panel did not answer questions properly	1
Long time sitting down	1
Still uncertain	1
Discussion wandered off point	
sometimes	1
Science too complex	1
Fear of the unknown	1
Travel	1
• Food	1
L	

## 8 How <u>satisfied</u> were you with the event?

	Very satisfied	Fairly satisfied	Uncertain	Not very satisfied	Not at all satisfied
The information provided	34 (77%)	8 (18%)	2 (5%)	0	0
The way the event was run on the day	36 (82%)	7 (16%)	1 (2%)	0	0
Overall satisfaction with the event	35 (80%)	9 (20%)	0	0	0

<sup>&</sup>quot;The different points of view from the speakers" (female, 16 - 24 years)

<sup>&</sup>quot;The opportunity to question the speakers and listen to their presentations. The amount of information and the level at which it was pitched was just right" (female, 40 - 54 years)

<sup>&</sup>quot;Getting to know more about this topic and meeting other people from everywhere" (female, 25 - 39 years)

<sup>&</sup>quot;Lots of points were cleared up" (female, 55 - 65)

<sup>&</sup>quot;Getting the right information from the right people" (female, 16 - 24 years)

<sup>&</sup>quot;The different views from the speakers. This made the whole discussion more realistic" (female, 16 - 24 years)

<sup>&</sup>quot;It covered any query anyone might have" (female, over 65 years)

#### 9 What was the most important benefit for you personally in taking part in this event?

Learning / knowledge / information about the issue	19
Putting own views forward / had opinion	
heard	3
Taking part on important issue	3
Thinking about the issues / mental	
challenge	2
Hearing different views	2
Money	2
Shaped own view	1
A good experience	1
Having public opinion valued	1
Balanced arguments from experts	1
Will try to keep up with developments	1
Being reassured on the subject	1

<sup>&</sup>quot;To be aware of how our government values the public view. To experience a balanced argument from the experts" (woman, 40 - 54 years)

# How important do you think it is to involve the public in discussing these sorts of issues?

Very important	41 (93%)
Fairly important	3 (7%)
Not very important	0
Not at all important	0

#### 11 Is there anything else you would like to add?

Thank you / enjoyable / good work	4
<ul> <li>More of this sort of thing needed</li> </ul>	1

<sup>&</sup>quot;Very well run by OpinionLeader" (female, 40 - 54 years)

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<sup>&</sup>quot;Receiving the information first hand" (female, 25 - 39 years)

<sup>&</sup>quot;Information / mental challenge - enjoyed thinking about the subjects and related issues" (male, 16 - 24 years)

<sup>&</sup>quot;Taking part in something that may change medical science (and the overnight stay and money!)" (female, 40 - 54 years)

<sup>&</sup>quot;Taking part and hopefully making a difference" (male, 16 - 24 years)

<sup>&</sup>quot;I'm not sure if what we say actually makes any difference in these policies but it's interesting to be involved nonetheless" (male, 16 - 24 years)

<sup>&</sup>quot;Just very interesting" (female, 40 - 54 years)

# **APPENDIX 3. Evaluation questionnaire analysis** HFEA open public meeting

London, 26 June 2007

Total number participants: 153

Total number of questionnaires returne: 75 = 49%

# How far do you agree or disagree with the following statements?

	Strongly agree	Agree	Unsure	Disagree	Strongly disagree
I enjoyed the debate	39 (52%)	29 (39%)	4 (5%)	2 (3%)	-
I understand the purpose of this consultation and how I can continue to take part	37 (49%)	34 (45%)	2 (3%)	-	-
The panel represented a balanced range of views on the issues	23 (31%)	35 (47%)	6 (8%)	6 (8%)	1 (1%)
No single view was allowed to dominate unfairly	19 (25%)	37 (49%)	9 (12%)	6 (8%)	2 (3%)
All the main issues were covered	7 (9%)	31 (41%)	17 (23%)	13 (17%)	4 (5%)
Attending this event has changed my views	-	11 (15%)	13 (17%)	20 (27%)	28 (37%)
It is important to consult the public on these issues	53 (71%)	15 (20%)	5 (6%)	2 (3%)	-

## 2 How satisfied were you with the event?

Very satisfied	30 (40%)
Fairly satisfied	39 (52%)
Unsure	2 (3%)
Not very satisfied	3 (4%)
Not at all satisfied	0

# 3 Any other comments:

<ul> <li>Some issues not explored fully enough:</li> <li>umbilical cord stem cells - 3</li> <li>adult stem cells - 2</li> <li>what the boundaries should be - 1</li> <li>ethics - 1</li> </ul>	9
<ul> <li>what next / slippery slope - 1</li> <li>whether human embryo is human being - 1</li> </ul>	
<ul> <li>Panel needed other members:</li> <li>more scientists on 'anti' side - 2</li> <li>too many antis - 1</li> </ul>	7
<ul> <li>more scientists doing this research - 1</li> <li>more scientists - 1</li> <li>an academic ethicist - 1</li> </ul>	

animal ethics - 1	
Too much shouting / hijacking	6
Nick Ross / chairing very good	4
• Debate too complex / emotive for public,	4
who need more information before being	
consulted	
Some voting questions poorly phrased	3
Excellent / well done / worthwhile	3
Debate needs to reflect religious views	2
These discussions are important / need	2
more of them	
Creation and use of human embryos is	2
wrong	
Scientific background / knowledge does	2
not create more bias but more	
knowledge	
Debate spilled over into too broad	2
issues (e.g. ethics about animal	
research / use of embryos generally)	

The following points were mentioned once each:

- · The meeting tended to confuse the basic issues
- · The meeting was biased towards anti-embryo research
- · Chairman was biased (in favour of the research)
- The audience was not a 'diverse' public
- · This research is wrong
- · Information materials good
- · The panel was balanced
- · The opponents to the research behaved badly
- · Clear strong regulation is the answer
- "Complex issues like these need a lot of debate. Discussions like this should be encouraged"
- "Clearly religious arguments from the floor were very strong. The Parliamentary Select Committee must reflect the religious background and be proportionate in the make-up of the Committee. (P.S. I am not religious)"
- "The HFEA presentation was very simplistic: vox pop is not a satisfactory methodology for deciding ethical issues on complicated matters the HFEA should seek legal advice whether it should involve itself in licensing embryonic and adult stem cells. Also all 'voices' should be heard no voice should be silenced. The HFEA is no longer an 'independent source' of information treatment and embryo research. It has become an active participant with a set agenda, limiting options to one type of stem cells"
- "I do agree with public consultation but on such an emotive issue I think issues can become confused through lack of understanding by many people of the general public. My scientific understanding (degree in embryology, UCL) doesn't bias me towards hybrids, merely makes me more informed"
- "The people who shouted should have been chucked out, not given the microphone"
- "I appreciated the prepared materials and Nick [Ross's] skilful mediation"
- "Should have stuck with the scripted questions. Got hijacked by the hotheads on each side from the floor"
- "What we didn't get into is that if the laws should be opened up on these issues, how much further the scientist would go into areas which are potentially dangerous"
- "You can't stop science or progress. Better that UK has very clear regulations and looked to as world leader in regulating all ES research <u>including</u> allowing animal embryo research"
- "The discussion went off topic a fair bit, its important for debate but the issue was quite specific and we ended up discussing very broad issues not really up for discussion a tricky task though, on the whole well done!"

- "I feel that the panel should also have had on it a medical scientist engaged in adult stem cell technology and/or cord blood cell work. The assumption in the debate was that only embryonic stem cells can be used for research around treatment of degenerative diseases. That assumption by HFEA and the UK Department of Health is completely false"
- "I have had loved ones suffer from terrible diseases but I still feel that this medical research is wrong regardless of its effectiveness"
- "The public must be informed if they are to be consulted. I believe that the 'would you feel happy to be treated with ...' question would be answered differently in different circumstances. I do not believe that because I have a degree in science it makes me biased it just makes me more knowledgeable"
- "Chairman was biased in favour of hybrid embryo research unfortunate that chair should take strong position"
- "The phrasing of the questions was confusing and amateur. For example the question on receiving therapies 'from' human / animal embryos did not make it clear if it included therapies derived from <a href="knowledge">knowledge</a> derived from this area, and the question on the benefits outweighing 'any' ethical issues is confusing since the pursuit of benefits is itself an ethical one (so the question could be read as 'ethical concerns' vs 'benefits', which is a false dichotomy ...). A further comment is that people should not be allowed to yell out and interrupt"

#### Some information about you

Gender	
Male	32 (43%)
Female	43 (57%)

Age	
16 - 24	9 (12%)
25 – 39	27 (36%)
40 - 54	18 (24%)
55 - 65	11 (15%)
Over 65	9 (12%)

You describe yourself as:	
White British	52 (69%)
White other	7 (9%)
Asian or Asian British	6 (8%)
Black or Black British	5 (7%)
Other	0

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#### **APPENDIX 4. Guiding Principles for Public Dialogue**

# OFFICE OF SCIENCE AND INNOVATION THE GOVERNMENT'S APPROACH TO PUBLIC DIALOGUE ON SCIENCE AND TECHNOLOGY

#### The need for public dialogue on science and technology

- The Government believes that If the UK is to take full advantage of the
  opportunities for creating wealth and improving quality of life offered by
  scientific discovery and technological development, it is crucial that we develop
  new approaches to bring scientists and the public together in a constructive
  dialogue to explore emerging issues.
- 2. Our **aim** is for a society where the public, the broad science community and policy makers feel comfortable in handling issues raised by science and technology and feel a joint sense of purpose in ensuring that the full benefits of science and technology are realised for society.
- Our **objective** is to build confidence in decision-making related to the undertaking, development and overall governance of science and technology; to build on the public's generally positive views of science - and to both maximise the opportunities offered by new areas of science and technology and minimise potential downsides.
- 4. We want to elicit both the aspirations and concerns of the UK population in the development of new areas of science and technology. Our **approach** will be to enrich decision-making by gathering and analysing broad intelligence on the full range of issues (technological, scientific, environmental, social, ethical, legal and economic) related to emerging new areas of science and technology and their governance. Such dialogue will inform, rather than determine policy and decision-making by those empowered to do so.
- 5. We will facilitate this through robust, timely, inclusive and properly resourced dialogue that is clearly linked into decision-making processes around science and technology. Such dialogue will involve the public, scientists (both publicly and privately funded), policy makers and other perspectives, and will explore existing or potential opportunities as well as concerns related to ethical, health, safety and environmental issues.
- 6. We will ensure that dialogue is informed, drawing on evidence and information from a wide variety of sources. It will operate according to the principles of openness, honesty and fairness, designed to generate mutual understanding of views and underpinned by a willingness to take account of the outcomes of such dialogue in decision-making. We will communicate the reasons for our decisions widely and in a clear and timely manner.
- 7. We are committed to **listening to and taking account** of views expressed in our policy and decision making. We believe strongly that public dialogue will help us to identify and deal with the issues arising.

8. We are committed to embedding and improving our approach to public dialogue on science and technology. We will promote a coherent approach across Government and beyond; continually reviewing policy, guidance and experience to ensure that our approach is compatible with and contributes to good practice. We will ensure that the learning gained from this approach is disseminated widely within the science, engineering and technology community and beyond.

#### Principles for public dialogue on science and technology

- 9. Based on theoretical understandings and practical experience, the essential elements of public dialogue on science and technology are set out below. The Government has adopted the approach set out in this document, but recognises that this guidance will continue to be refined as experience grows.
- 10. The key principles for public dialogue seek to ensure that:
- the conditions leading to the dialogue process are conducive to the best outcomes (Context)<sup>1</sup>
- the range of issues covered in the dialogue are relevant to participants' interests (Scope)
- ensuring that the dialogue process itself represents best practice in design and execution (**Delivery**)
- the outputs of dialogue can deliver the desired outcomes (Impact)
- the process is shown to be robust and contributes to learning (Evaluation).
- 11. In fulfilling these principles, it is recognised that the specific context of each issue will determine the relative importance of each of the following principles. However as far as practicable, public dialogue on science and technology aims to:

#### 12. Context<sup>2</sup>

- a) Be clear in its purposes and objectives from the outset
- b) Be well timed in relation to public\_and political concerns. It will commence as early as possible in the policy/decision process
- c) Feed into public policy with commitment and buy-in from policy actors
- d) Take place within a culture of openness, transparency and participation with sufficient account taken of hard to reach groups where necessary
- e) Have sufficient resources in terms of time, skills and funding
- f) Be governed in a way appropriate to the context and objectives.

<sup>&</sup>lt;sup>1</sup> The means by dialogue can impact upon policy and decision-making will be specific to each organisation involved in the dialogue process and each issue under consideration. It is important, therefore, that organisations involved dialogue address their own institutional arrangements and working practices to ensure effective application of dialogue processes.

<sup>&</sup>lt;sup>2</sup> It is probably advisable to embark upon a dialogue process, where these requirements cannot be met.

#### 13. Scope

- a) Cover both the aspirations and concerns held by the public, scientists in the public and private sector, and policy-makers.
- b) Be focussed on specific issues, with clarity about the scope of the dialogue. Where appropriate we will work with participants to agree framings that focus on broad questions to encourage more in-depth discussion. For example we might start by asking, "How do we provide for our energy needs in the future?" rather than starting by asking "should we build new nuclear power stations?"
- c) Be clear about the extent to which participants will be able to influence outcomes. Dialogue will be focussed on informing, rather than determining policy and decisions.
- d) Involve a number and demographic of the population that is appropriate to the task to give robustness to the eventual outcomes<sup>3</sup>

#### 14. Delivery

- a) Ensure that policy-makers and experts promoting and/or participating in the dialogue process are competent in their own areas of specialisation and in the techniques and requirements of dialogue. Measures may need to be put in place to build the capacity of the public, experts and policy makers to enable effective participation.
- b) Employ techniques and processes appropriate to the objectives. Multiple techniques and methods may be used within a dialogue process, where the objectives require it.
- c) Be organised and delivered by competent bodies
- d) Include specific aims and objectives for each element of the process
- e) Take place between the general public and scientists (including publicly and privately funded experts) and other specialists as necessary. Policy-makers will also be involved where necessary.
- f) Be accessible to all who wish to take part with special measures to access hard to reach groups, including considerations of appropriate venues and technical equipment in line with the Disability and Discrimination Act 1995<sup>4</sup>. Where the objectives require it, media partners may be needed to ensure that the process reaches the wider population.
- g) Be conducted fairly with no in-built bias; non-confrontational, with no faction allowed to dominate; all participants treated respectfully; and all participants enabled to understand and question experts claims and knowledge.

<sup>&</sup>lt;sup>3</sup> Where advice is sought very early on in decision-making on an issue that is not yet known about by the public this may be a "narrow but deep" approach, where there is some knowledge and the impact is likely to be wide-ranging, soon, and or controversial, an approach involving a wider number of people may be appropriate. This must be decided on a case by case basis.

<sup>&</sup>lt;sup>4</sup> Download the Disability Rights Commission's very useful guide to access at <a href="http://www.drc-gb.org/library/publications/services">http://www.drc-gb.org/library/publications/services</a> and transport/organising accessible events.aspx?basket=add&pub=Org anising+Accessible+Events%7cSP13

- h) Be informed This will include providing participants with information and views from a range of perspectives, and access information from other sources.
- i) Be deliberative allowing time for participants to become informed in the area; be able to reflect on their own and others' views; and explore issues in depth with other participants. The context and objectives for the process will determine whether it is desirable to seek consensus, or to map out the range of views.
- j) Be appropriately 'representative' the range of participants may need to reflect both the range of relevant interests, and pertinent socio-demographic characteristics (including geographical coverage). At times, there may be a need to enable participants to be self-selecting. In these circumstances, there will be measures in place to take account of potential any bias this may cause. NOTE: Public dialogue does not claim to be fully representative, rather it is a group of the public, who, after adequate information, discussion, access to specialists and time to deliberate form considered advice which gives a strong indication of how the public at large feel about certain issues. The methodology and results need to be robust enough to give policy makers a good basis on which to make policy.

#### 15. Impact

- a) Ensure that participants, the scientific community and policy-makers and the wider public can easily understand the outputs across the full range of issues considered.
- b) Ensure that participants' views are taken into account, with clear and transparent mechanisms to show how these views have been taken into account in policy and decision-making.
- c) Influence the knowledge and attitudes of the public, policy-makers and the scientific community towards the issue at hand.
- d) Influence the knowledge and attitudes of the public, policy-makers and the scientific community towards the use of public dialogue in informing policy and decision-making.
- e) Encourage collaboration, networking, broader participation and co-operation in relation to public engagement in science and technology
- f) Be directed towards those best placed to act upon its outputs<sup>5</sup>.

#### 16. Evaluation

a) Be evaluated in terms of process and outcome, so that experience and learning gained can contribute to good practice

b) Ensure that evaluation commences as early as possible, and continues throughout in the process

<sup>&</sup>lt;sup>5</sup> For example, directing dialogue on aspirations to the scientific and business communities will help to inform decisions on setting research priorities. Similarly, Government will gain a better view of the potential of new technologies. Directing dialogue on concerns to the Government will help inform decisions on regulatory responses - scientists and businesses will also increase their understanding of (and responsiveness to) the public.

- c) Ensure that evaluation addresses the objectives and expectations of all participants in the process
- d) Be evaluated by independent parties (where appropriate)

#### The purpose and status of this document

- 17. This document sets out a set of guiding principles by which the process of public dialogue on science and technology-related issues might effectively be taken forward. This has been developed by the OSI in collaboration with policy-makers, practitioners, academics and representatives of the scientific and business communities working in the areas of science policy and public engagement. The OSI is very grateful to all those who have contributed to the development of these principles.
- 18. These guidelines are compatible with the Government's code of practice on consultation (published January 2004)<sup>6</sup>, and provide more detail on the Government's proposed approach to public dialogue set out in the Science and Innovation Investment Framework 2004-2014 (published July 2004)<sup>7</sup>.
- 19. This document should, therefore, be considered in relation to the following:
  - Consultations and Public Dialogue activities on specific science and technology related issues to be carried out by (or on behalf of) departments, advisory committees, agencies or Non Departmental Public Bodies (including Research Councils).
- 20. This document will be kept under review, and the guidance will be revised and reissued periodically.

<sup>&</sup>lt;sup>6</sup> www.cabinet-office.gov.uk/regulation/consultation/code.htm. As with the code on consultation, UK non-departmental public bodies and local authorities are encouraged to follow this guidance. Devolved Administrations are free to adopt this guidance should they wish to do so.

www.hm-treasury.gov.uk./spending review/spend sr04/associated documents/spending sr04 science.cfm