



Risk communication: a strategy to improve access to mammography screening

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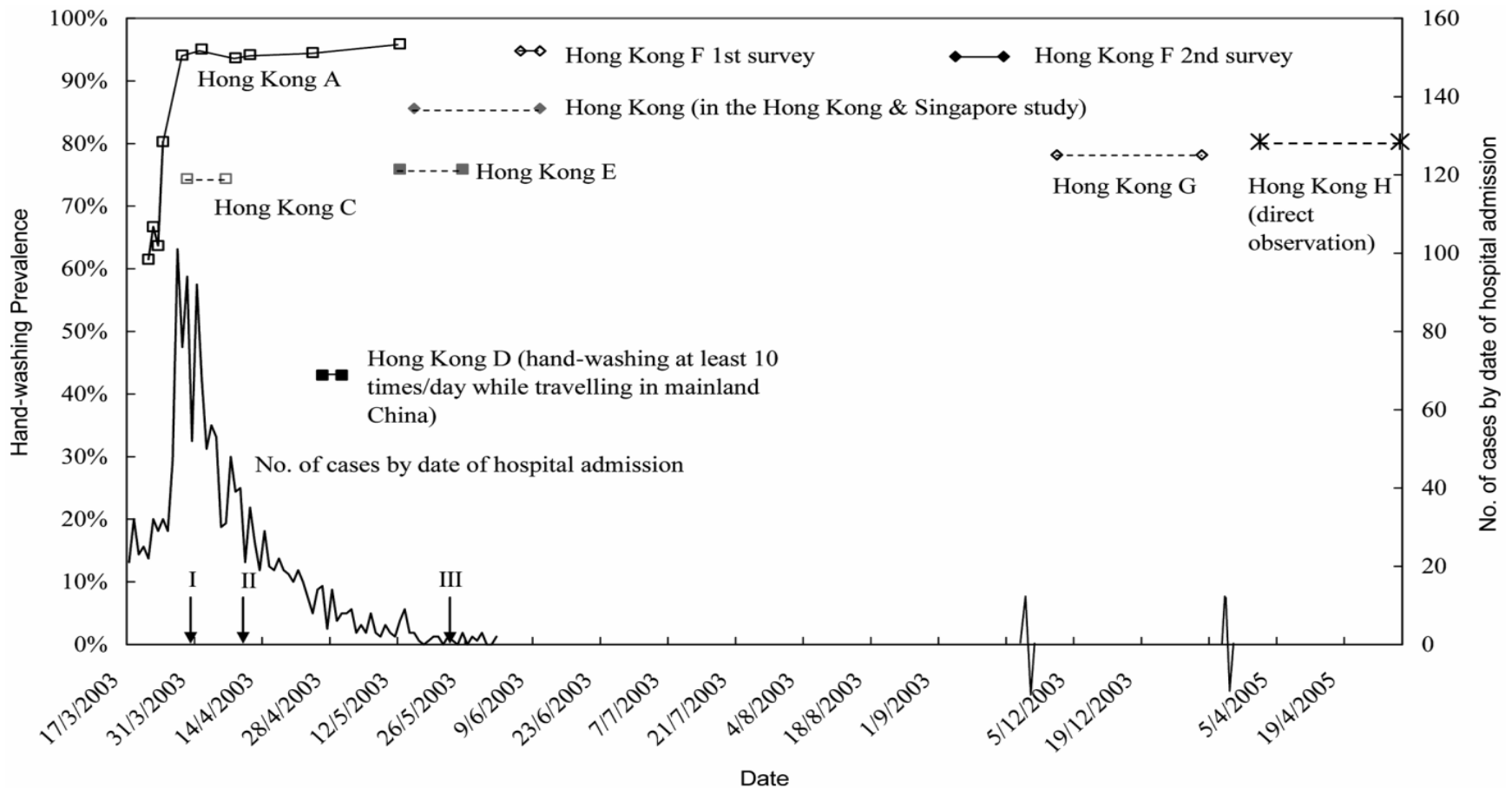


Risk communication in cancer and cancer screening

- Assumptions about the phenomenon of low uptake amongst certain vulnerable groups i.e. migrant minority ethnic (MME) and low-income women
- From KAP (knowledge + attitude = practice) to understanding perceptions of risk.
- KAP model – strategy and intervention tends not to be evidence-based e.g. leaflets.
- Problems of such communication strategy are:
 - One-size-fits-all
 - Translated written materials ignore variations in literacy and health literacy level
 - Lack of cognitive, social and cultural understanding of how people perceive health risks, and how such perceptions guide their actions



How often do you wash your hands? A review of studies of hand-washing practices in the community during and after the SARS outbreak in 2003 (Fung & Cairncross, 2007 Int.J. Environmental Health Research)



Summary results of prevalence of hand-washing behaviours (self-reported or directly observed) by study in Hong Kong, 2003.



Directly observed percentage of air travellers washing their hands after using public restrooms in six airports in North America in August 2003 ($n = 7541$) (Data from Hyde Study)

Airports	Male (%)	Female (%)
Toronto International Airport	95	97
John F. Kennedy Airport, New York City	63	78
O'Hare Airport, Chicago	62	85
San Francisco International Airport	80	59
Dallas/Fort Worth Airport	69	92
Miami Dade County International Airport	70	79
Overall	74	83



- Studies (between 1996 – present) have shown cancer risk and benefit of mammograms are not perceived accurately by women
 - Anxiety or apathy
 - Over-screened or refusal of screening

Informed Choice For All Project

- Aim to investigate, using a participatory action research approach, how the risks and benefits of breast/cervical screening are understood by both health operators and MME and low-income women and to determine a mechanism by which risk information can be effectively communicated to facilitate informed choice



Stage 1 Focus groups and literature and information review	Lay Groups 4 MME groups (Urdu, Bengali, Chinese, African- Caribbean) 1 White group	Published Scientific articles on: Breast cancers and screening	Professional groups: GPs Practice nurses Public health professionals	Results fed into the preparation of Q- statements
Stage 2 Preparation for Q-sorts	Concourse of statements 61 (Breast) statements			Results (Risk perception profiles) fed into Consensus Forum for discussion
Results of Q- sorts	A total 61 individuals from target communities (Pakistani, Bengali, Chinese, African-Caribbean and low income White) and professionals were recruited.			
	Q-sort analysis			
Stage 3 Consensus Forum	Consensus Forum Lay Panel and Professional Panel Agreed on communication foci and frames (i.e. guidance on risks & benefits messages and how they are framed)			Results fed into the draft of guidance and the construction of communication Tool-kits
	The production of the draft of guidance and communication tool-kits			
Stage 4 Field Trial	A Field trial of risk communication tool-kits 10 Community Health Educators (CHE) trained and carried out 230 individual interviews Trial result analysis			All results fed into the writing of final report



What is Q-methodology?

- A scientific approach to study subjectivity
- Overcomes some of the methodological problems of focus groups in comparing beliefs and opinions between social groups
- Supports exploration while retaining transparency, rigour and mathematical underpinnings of quantitative technique



Q-sort and Q analysis

Q-sort: participants are given a set of statements (concourse of opinions available out there) derived from literature review and focus groups, and are asked to rank them on a prepared grid.



Sample of statements (61)

The risk of breast cancer increases when a woman has close relatives (mother/sister) diagnosed with cancer before the age of 40 or below

1

The risk of developing breast cancer increases with age

6

Women who are over 65 are not invited for screening because they are not at risk

51

I would fight the disease all the way, and accept every treatment they offered me

56

1 in 10 breast cancers are in women who have a genetic susceptibility

2

Being tall and overweight will increase the risk of developing breast cancer

7

Nothing can make you live longer, you go when your time is up

52

Smoking and drinking alcohol [lifestyle] can cause breast cancer

57

All women, whatever the ethnic group, are at risk of developing breast cancer

3

Overweight particularly after menopause will increase the risk of developing breast cancer

8

It would never happen to me

53

Stress can contribute to the development of breast cancer

58

Middle class women are more likely to be diagnosed with breast cancer but working class women are more likely to die from it

4

Starting periods early and stopping periods late increases the chance of developing breast cancer

9

You run the risk of anxiety and embarrassment when you go for a mammogram

54

Seeing someone diagnosed with breast cancer who was successfully treated make you more ready to accept screening

59

Breast cancer is overwhelmingly a female disease, the chance of men developing breast cancer is very low (though not zero)

5

Having no children or having children in later life can increase a woman's risk of developing breast cancer by 1/3

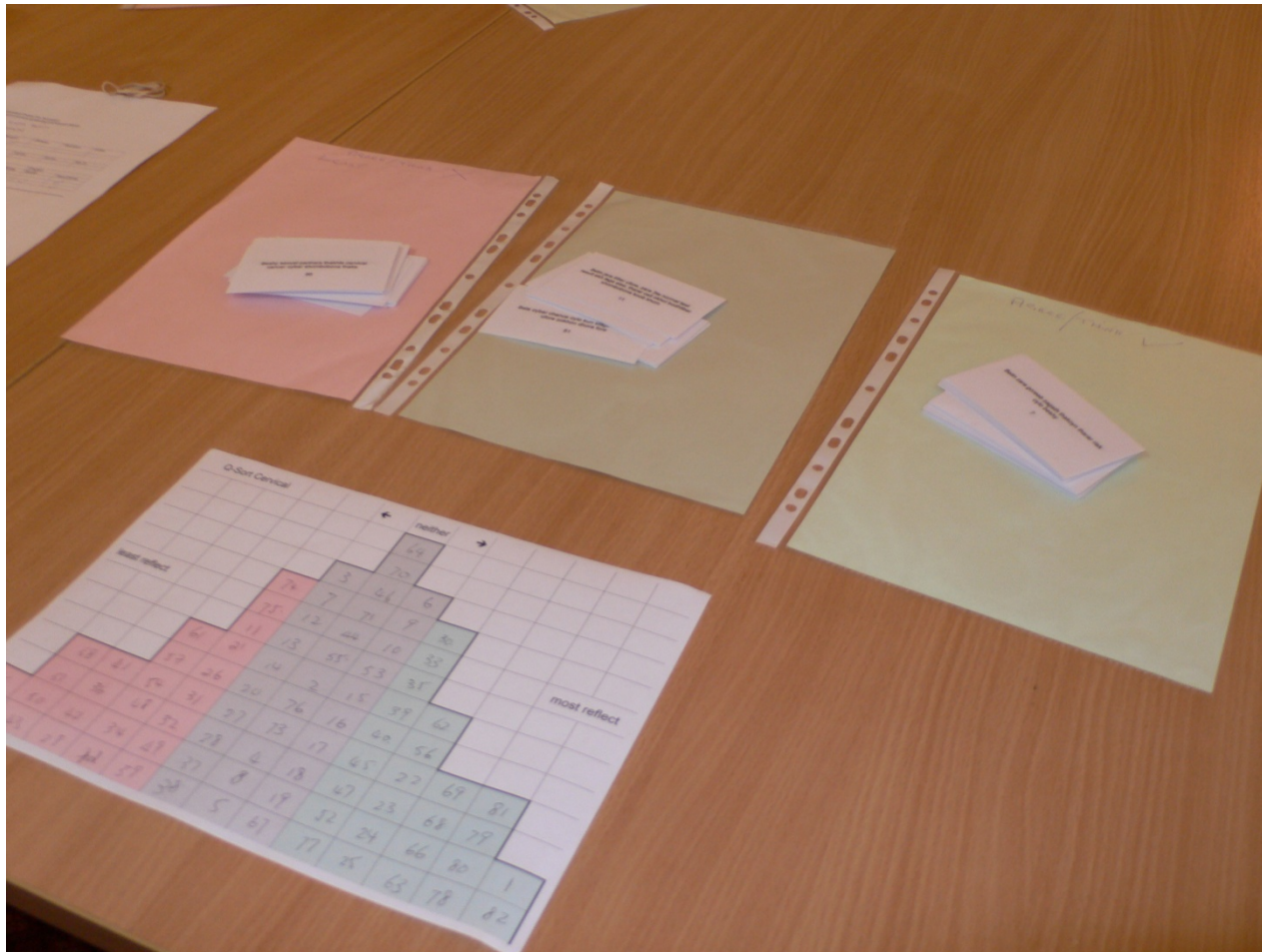
10

Soya milk can prevent breast cancer

55

It is difficult to know what to look for and how to bring your suspicion to the attention of the doctor

60







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C:\PQMETHOD
C:\PQMETHOD\PROJECTS>set EDITOR=c:\pqmethod\ed.com
C:\PQMETHOD\PROJECTS>set VIEWER=c:\pqmethod\view86.com
C:\PQMETHOD\PROJECTS>c:\pqmethod\PQMethod.exe

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PQMethod - 2.11
(November 2002)
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by Peter.Schmolck@unibw-muenchen.de
Adapted from Mainframe-Program QMethod
by John Atkinson at KSU
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The QMethod Page:
http://www.rz.unibw-muenchen.de/~p41bsmk/qmethod/
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Enter [Path and] Project Name:
tunesobjectors

Current Project is ... C:\PQMETHOD\PROJECTS\tunesobj
Choose the number of the routine you want to run and enter it.

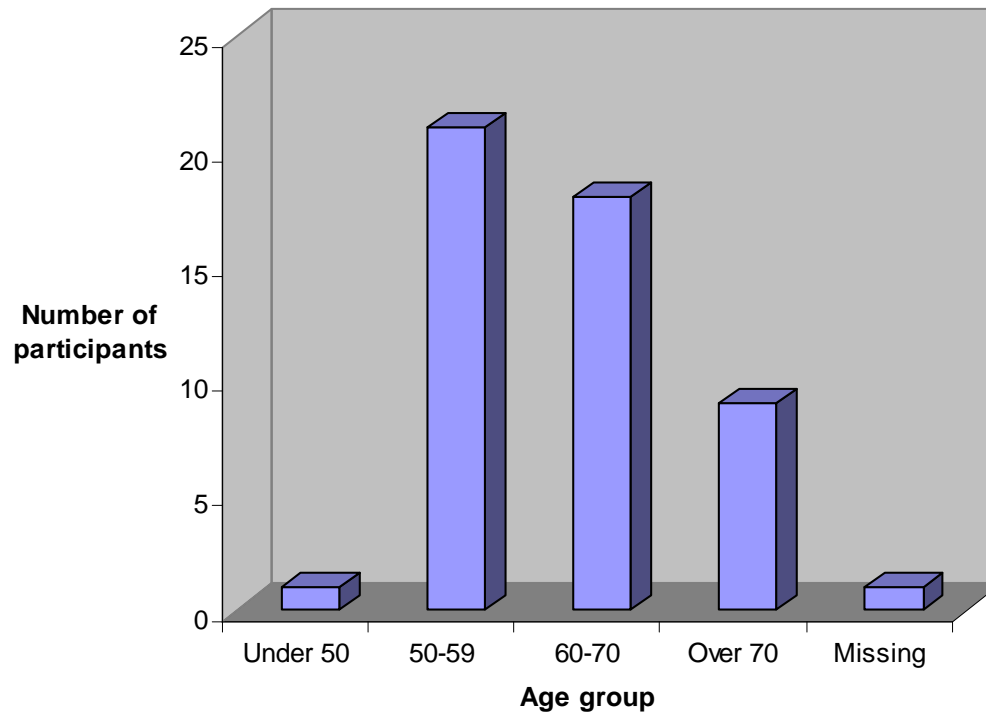
1 - STATES - Enter (or edit) the file of statements
2 - QENTER - Enter q sorts (new or continued)
3 - QCENT - Perform a Centroid factor analysis
4 - QPCA - Perform a Principal Components factor analysis
5 - QROTATE - Perform a manual rotation of the factors
6 - QUARIMAX - Perform a varimax rotation of the factors
7 - QANALYZE - Perform the final Q analysis of the rotated factors
8 - View project files tunesobj.*
X - Exit from PQMethod

Last Routine Run Successfully - (Initial)
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Participation level

	African-Caribbean	Bengali	Chinese	Pakistani	White	Professionals	Total
Breast	8	10	11	11	10	10	61
Cervical	11	10	10	10	10	13	64
Total	19	20	21	21	20	23	125



Age profile of lay participants who took part in Q-sort (breast)

Factor 1: - moderately informed and pro-screening

Statement	F1	F2	F3
56. I would fight the disease all the way, and accept every treatment they offer me	6	0	0
50. Prevention is better than cure (5)	5	2	3
33. If you are screened you will find out about your illness sooner (4)	4	3	2
11. Women who breastfeed long term, have a reduced risk of breast cancer (3)	3	-1	-3
15. Women who have a history of breast problems are at risk of breast cancer (2)	2	0	0
81. Breastfeeding can protect us from developing breast cancer as it gets rid of lumps (2)	2	-4	-1
30. The older you are (after 40) the more likely you will develop breast cancer (2)	2	3	-8
32. The food you eat plays a part in the development of breast cancer (1)	1	-1	-4
17. Alcohol intake is associated with increased risk of breast cancer (1)	1	0	-2
14. Consuming high fat diet in early years increases the risk of developing breast cancer (1)	1	-2	-2
8. The risk of developing breast cancer increases with age (0)	0	8	-4
31. Breast cancer leads to mastectomy and horrific death (0)	0	-3	-5
49. The disease is not talked about very much in the community (0)	0	-3	+3
46. Taking pills to stop breast milk can put you at risk of breast cancer (0)	0	-3	-2
55. Soya milk can prevent breast cancer (0)	0	-3	-3
25. Having a mammogram would expose you to radiation (-1)	-1	1	-3
29. Some people will be called back but most of them will not have cancer (-1)	-1	3	4
26. Breast screening may cause anxiety among women (-2)	-2	2	5
24. Having a mammogram could be painful/uncomfortable (-2)	-2	3	2
4. Middle class women are more likely to be diagnosed with breast cancer but working class women are more likely to die from it (-2)	-2	-1	1
45. Mammograms can cause pain and discomfort (-2)	-2	1	6
39. Knowing someone who has breast cancer would terrify me. (-3)	-3	-3	0
52. Nothing can make you live longer, you go when your time is up (-3)	-3	-2	1
48. There is a risk that a mammogram can harm you when they squeeze your breasts too hard (-4)	-4	-4	0
27. Screening is less effective for younger women (-4)	-4	0	-1
54. You run the risk of anxiety and embarrassment when you go for a mammogram (-4)	-4	-2	2
41. If breast cancer is mentioned to me I just think "that's not me" (-5)	-5	-4	-3
53. It would never happen to me (-8)	-8	-6	-4

PQMethod: Factor analysis distinguishing statements for Factor 1 (Breast cancer and screening)

Factor 2: Medico-official

Statements	F1	F2	F3
6. The risk of developing breast cancer increases with age (6)	0	6	-4
23. Breast screening cannot prevent breast cancer (4)	-3	4	-2
1. The risk of breast cancer increases when a woman has close relatives (mother/sister) diagnosed with cancer before the age of 40 or below (4)	1	4	0
30. The older you are (after 40) the more likely you will develop breast cancer (3)	2	3	-8
59. Seeing someone diagnosed with breast cancer, who was successfully treated make you more ready to accept screening (2)	3	2	3
26. Breast screening may cause anxiety among women (2)	-2	2	5
12. Hormone Replacement Therapy (HRT) increases the risk of women developing breast cancer (2)	-1	2	-1
45. Mammograms can cause pain and discomfort (1)	-2	1	6
36. Breast lumps can be caused by hormones (1)	-1	1	0
25. Having a mammogram would expose you to radiation (1)	-1	1	-3
27. Screening is less effective for younger women (0)	-4	0	-1
5. Breast cancer is overwhelmingly a female disease, the chance of men developing breast cancer is very low (though not zero) (0)	2	0	3
17. Alcohol intake is associated with increased risk of breast cancer (0)	1	0	-2
11. Women who breastfeed long term have a reduced risk of breast cancer (-1)	3	-1	-3
32. The food you eat plays a part in the development of breast cancer (-1)	1	-1	-4
54. You run the risk of anxiety and embarrassment when you go for a mammogram (-2)	-4	-2	2
52. Nothing can make you live longer, you go when your time is up (-2)	-3	-2	1
40. Infection can cause breast cancer (-2)	-1	-2	0
49. The disease is not talked about very much in the community (-3)	0	-3	+3
39. Knowing someone who has breast cancer would terrify me (-3)	-3	-3	0
48. There is a risk that a mammogram can harm you when they squeeze your breasts too hard (-4)	-4	-4	0
41. If breast cancer is mentioned to me I just think "that's not me" (-4)	-5	-4	-3
81. Breastfeeding can protect us from developing breast cancer as it gets rid of lumps (-4)	2	-4	-1
51. Women who are over 65 are not invited for screening because they are not at risk (-5)	-2	-5	-1
53. It would never happen to me (-6)	-8	-6	-4

PQMethod: Factor analysis distinguishing statements for Factor 2 (Breast cancer and screening)

Factor 3: Uninformed anxious and fatalistic

Statements	F1	F2	F3
45. Mammograms can cause pain and discomfort (6)	-2	1	6
42. Screening is not perfect; some people can be misdiagnosed (5)	2	2	5
26. Breast screening may cause anxiety among women (5)	-2	2	5
47. Breast cancer is a big problem in this country (4)	1	1	4
34. If a woman is found to have breast cancer early through X-rays, the survival rate is at least 50 %.(4)	2	0	4
49. The disease is not talked about very much in the community (3)	0	-3	3
60. It is difficult to know what to look for and how to bring your suspicion to the attention of the doctor (3)	-3	-2	2
38. If a woman is diagnosed with breast cancer, it will terrify her family (2)	1	0	2
54. You run the risk of anxiety and embarrassment when you go for a mammogram (2)	-4	-2	2
3. All women, whatever the ethnic group, are at risk of developing breast cancer (2)	4	4	2
52. Nothing can make you live longer, you go when your time is up (1)	-3	-2	1
22. Breast screening save lives (1)	4	5	1
48. There is a risk that a mammogram can harm you when they squeeze your breasts too hard (0)	-4	-4	0
39. Knowing someone who has breast cancer would terrify me (0)	-3	-3	0
19. Breast Screening (Mammography) can detect cancers early (-1)	5	5	-1
35. A woman is more likely to develop breast cancer if someone else in her family has had it (-1)	1	2	-1
61. Breastfeeding can protect us from developing breast cancer as it gets rid of lumps (-1)	2	-4	-1
27. Screening is less effective for younger women (-1)	-4	0	-1
17. Alcohol intake is associated with increased risk of breast cancer (-2)	1	0	-2
8. Overweight particularly after menopause will increase the risk of developing breast cancer (-2)	1	1	-2
43. Obesity at whatever age makes you slightly more prone to developing breast cancer (-3)	2	0	-2
41. If breast cancer is mentioned to me I just think "that's not me" (-3)	-5	-4	-3
25. Having a mammogram would expose you to radiation (-3)	-1	-1	-3
11. Women who breastfeed long term have a reduced risk of breast cancer (-3)	3	-1	-3
32. The food you eat plays a part in the development of breast cancer (-4)	1	-1	-4
53. It would never happen to me (-4)	-8	-6	-4
6. The risk of developing breast cancer increases with age (-4)	0	6	-4
30. The older you are (after 40) the more likely you will develop breast cancer (-8)	2	3	-8

PQMethod: Factor analysis distinguishing statements for Factor 3 (Breast cancer and screening)

Factor interpretation: I would never think 'breast cancer would not happen to me' (53: -8, 41: -5) there is always a chance. If I am diagnosed with breast cancer, I would fight the disease all the way, and accept every treatment they offer me (56: +6). However, prevention is better than cure (50: +5). Therefore, although having your mammogram taken can be a bit painful and uncomfortable (24: -2, 45: -2), it will help me to find out about my illness sooner (33: +4). I don't think screening will cause anxiety among women (26: -1). I, myself am not anxious or embarrassed about having a mammogram taken (54: -4). I am not so concerned about exposing myself to radiation and I don't think the procedure [squeezing my breasts too hard] will harm me (48: -4).

Women who breastfeed long-term have a reduced risk of breast cancer (11: +3), this may be because sometimes women take pills to stop breast milk [when they are lactating] (46: 0). This is an 'unnatural way of stopping the production of breast milk and might cause blockage' and thus put you at risk of cancer (focus group comments). Breast feeding may be a more natural way and it helps to get rid of lumps (61: +2). Women who have a history of breast problems are at risk (15: +2) and age comes into this too (6: 0); as the older you are (after 40) the more likely you are to develop breast cancer (30: +2). However, I don't think screening is less effective for younger women (27: -4). The food that you eat plays a part in the development of cancer (32: +1). I believe alcohol is associated with breast cancer (17: +1) and consuming a high fat diet when you are young increases your risk (14: +1). I am unsure whether drinking Soya milk can prevent breast cancer (55: 0)

I am not fatalistic [Nothing can make you live longer, you go when your time is up] (52: -3), and would not be terrified if I know someone who has breast cancer (39: -3). I do not know whether middle class women are more likely to be diagnosed with breast cancer but working class women are more likely to die from it (4: -2)

Type A (F1) moderately informed and pro-screening



Factor interpretation: The risk of developing breast cancer increases with age (6: +6); the older you are (after 40) the more likely you will develop breast cancer (30: +3). That is why women who are over 65 are invited for screening now because they are more at risk (51: -5). Breast cancer risk increases when a woman has close relatives with cancer (mother/sister diagnosed with cancer before the age of 40 or below (1: +4). Using Hormone Replacement Therapy (HRT) increases the risk of developing breast cancer. Breast lumps can be caused by hormones (38: +1) and infection cannot cause breast cancer (40: -2) Therefore I don't think breastfeeding can have a protective effect, helping to reduced risk (11: -1) because it helps to get rid of lumps (61: -4). I am not sure whether alcohol is associated with increased risk of breast cancer (17: 0).

Breast screening cannot prevent breast cancer (23: +4). In fact, having a mammogram would expose me to radiation (25: +1). Breast screening may cause anxiety among women (28: +2) but I am not anxious or embarrassed when I go for a mammogram (54: -2). I don't think the disease is talked about in the community (49: -3), so if I see someone diagnosed with breast cancer who was successfully treated it would make me more ready to accept screening (59: +2).

I would never think 'breast cancer would not happen to me' (53: -6, 41: -4) there is always a chance. But I am not fatalistic (52: -2).

The statement [breast cancer is overwhelmingly a female disease, the chance of men developing breast cancer is very low (though not zero)], although scientifically sound and population-oriented and distinguishing Factor B from Factors A and C, appears to be irrelevant here (5: 0).]

Type B (F2) Medico-official

Factor interpretation: Breast cancer is a big problem in this country (47: +4). The disease is not talked about very much in the community (49: +3). Screening may cause anxiety among women (28: +5), as it is not perfect; some people can be misdiagnosed (42: -5). However, if a woman is found to have breast cancer early through x-rays, the survival rate is at least 50% (34: +4). Although I might agree that breast screening save lives (22: +1), nothing can make you live longer, you go when you time is up (52: +1).

I don't believe that breast screening can detect cancers early (19: -1). Having your mammograms can cause pain and discomfort (45: +6). If I go, I'll run the risk of being anxious and embarrassed (54: +2). There is a risk that a mammogram can harm you when they squeeze your breast too hard (48: 0) [Factor A -4; Factor B -4] but I don't think it would expose me to radiation (25: -3).

In term of whether I am at risk or not, I think all women, whatever the ethnic group, are at risk of developing breast cancer (3: =2) and there is a chance that I might develop it too (53: -4, 41:-3).

I don't think the risk of developing breast cancer increases with age (6: -4) and that the older you are (after 40) the more likely you will develop the disease (30: -8). Therefore I don't think screening is less effective for young women (27: -1). The food you eat does not play a significant part in the development of the disease (32: -4). I don't believe that being overweight, particularly after the menopause, increases my risk of developing breast cancer (8: -3) nor do I believe obesity (at whatever age) makes me slightly more prone to the disease (43: -3). Drinking alcohol would not increase my risk (17: -2). Breast feeding long term does not reduce breast cancer risk (11: -3) and it can not protect us just because it might help to get rid of lumps (61: -1). I don't think the fact that a woman's family has had breast cancer will mean she is more likely to develop the disease (35: -1)

However, it is difficult to know what to look for and how to bring your suspicions to the attention of the doctor (80: +2). Knowing someone who has breast cancer would terrify me (39: 0) [Factor A -3 and B -3]. I think if I am diagnosed with breast cancer, it will terrify my family (38: +2).

Type C (F3) uninformed, anxious and fatalistic



Type A – Medico-official view

The risk of developing breast cancer increases with age; the older you are (after 40) the more likely you will develop breast cancer. That is why women who are over 65 are invited for screening now because they are more at risk. Breast cancer risk increases when a woman has close relatives i.e. her mother or sisters are diagnosed with cancer before the age of 40. Using Hormone Replacement Therapy (HRT) increases the risk of developing breast cancer. Breast lumps can be caused by hormones and infection cannot cause breast cancer. Therefore, I don't think breastfeeding can have a protective effect, helping to reduce risk because it helps to get rid of lumps. I am not sure whether alcohol is associated with increased risk of breast cancer.

Breast screening cannot prevent breast cancer. In fact, having a mammogram would expose me to radiation. Breast screening may cause anxiety among women but I am not anxious or embarrassed when I go for a mammogram. I don't think the disease is talked about in the community, so if I see someone diagnosed with breast cancer who was successfully treated it would make me more ready to accept screening.

I would never think 'breast cancer would not happen to me'. There is always a chance. But I am not fatalistic.



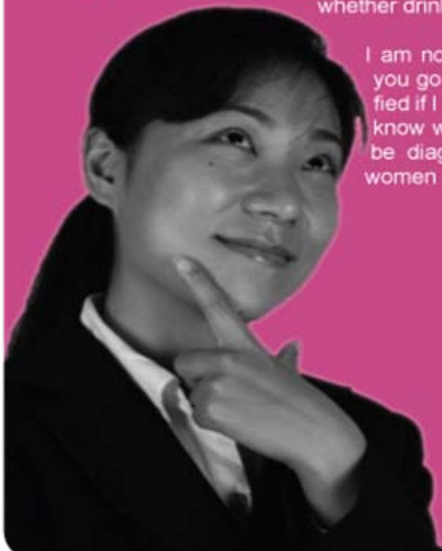
	Type A Medico-official
African Caribbean (8)	2
Bengali (10)	1
Chinese (11)	0
Pakistani (11)	4
White (10)	5
Health professionals (10)	10
Total in clusters	22
Total participants	61

Type B – Moderate informed and pro-screening

I would never think 'breast cancer would not happen to me' there is always a chance. If I am diagnosed with breast cancer, I would fight the disease all the way, and accept every treatment they offer me. However, prevention is better than cure. Therefore, although having a mammogram can be a bit painful and uncomfortable, it will help me to find out about my illness sooner. I don't think screening will cause anxiety among women. I am not anxious nor embarrassed about having a mammogram. I am not so concerned about exposing myself to radiation and I don't think the procedure [squeezing my breasts too hard] will harm me.

Women who breastfeed long-term have a reduced risk of breast cancer; this may be because sometimes women take pills to stop breast milk [when they are lactating]. This is an 'unnatural way of stopping the production of breast milk and might cause blockage' and thus put you at risk of cancer (focus group comments). Breast feeding may be a more natural way and it helps to get rid of lumps. Women who have a history of breast problems are at risk and age comes into this too; as the older you are (after 40) the more likely you are to develop breast cancer. However, I don't think screening is less effective for younger women. The food that you eat plays a part in the development of cancer. I believe alcohol is associated with breast cancer and consuming a high fat diet when you are young increases your risk. I am unsure whether drinking soya milk can prevent breast cancer.

I am not fatalistic [nothing can make you live longer, you go when your time is up], and would not be terrified if I knew someone who has breast cancer. I do not know whether middle-class women are more likely to be diagnosed with breast cancer but working-class women are more likely to die from it.



	Type B Moderate informed and pro-screening
African Caribbean (8)	1
Bengali (10)	8
Chinese (11)	10
Pakistani (11)	3
White (10)	2
Health professionals (10)	0
Total in clusters	24
Total participants	61



Type C – Uninformed, anxious and fatalistic

Breast cancer is a big problem in this country. The disease is not talked about very much in the community. Screening may cause anxiety among women, as it is not perfect; some people can be misdiagnosed. However, if a woman is found to have breast cancer early through x-rays, the survival rate is at least 50%. Although I might agree that breast screening saves lives, nothing can make you live longer, you go when your time is up.

I don't believe that breast screening can detect cancers early. Having a mammogram can cause pain and discomfort. If I go, I'll run the risk of being anxious and embarrassed. There is a risk that a mammogram can harm you when they squeeze your breast too hard but I don't think it would expose me to radiation.

In terms of whether I am at risk or not, I think all women, whatever the ethnic group, are at risk of developing breast cancer and there is a chance that I might develop it too.

I don't think the risk of developing breast cancer increases with age and that the older you are (after 40) the more likely you will develop the disease. Therefore I don't think screening is less effective for young women. The food you eat does not play a significant part in the development of the disease. I don't believe that being overweight, particularly after the menopause, increases my risk of developing breast cancer, nor do I believe obesity (at whatever age) makes me slightly more prone to the disease. Drinking alcohol would not increase my risk. Breast-feeding long term does not reduce breast cancer risk and it cannot protect us although it might help to get rid of lumps. I don't think the fact that a woman's family has had breast cancer will mean she is more likely to develop the disease.

However, it is difficult to know what to look for and how to bring your suspicions to the attention of the doctor. Knowing someone who has breast cancer would terrify me. I think if I am diagnosed with breast cancer, it will terrify my family.



	Type C Uninformed, anxious and fatalistic
African Caribbean (8)	5
Bengali (10)	0
Chinese (11)	0
Pakistani (11)	0
White (10)	1
Health professionals (10)	0
Total in clusters	6
Total participants	61



Demographic distribution across types

	Type A Moderate informed and pro-screening	Type B Medico-official	Type C Uninformed, anxious and fatalistic
African Caribbean (8)	1	2	5
Bengali (10)	8	1	0 (-1)
Chinese (11)	10	0	0 (-1)
Pakistani (11)	3	4	0 (-4)
White (10)	2	5	1 (-2)
Health professionals (10)	0	10	0 (0)
Total in clusters	24	22	6 (-8)
Total participants	61	61	61



What do the Q results mean?

- Unlike focus group, Q offers a different way of looking at opinions about risks
 - Clear lay/professional differences through sources of information i.e. professional/official, lay-media's reworking of scientific evidence
 - Insights into types of opinions rather than types of people
 - Insights into viewpoints are intersected by culture, education, may be even age (not tested)
 - Ethnicity and viewpoint are not isomorphic i.e. no one-to-one relationship



- The content of these viewpoints can be clearly dissected and investigated through distinguishing statements and the relative significance people afford them:
 - Those who have **trust** in the ability of the screening programme to detect breast cancer early from those who have **doubts** about the efficacy of screening
 - Those who have a **positive attitude** towards cancer from those who are afraid of it and appear to be **fatalistic** (confirmed by focus group analysis)



Implications for practice

- Understanding risk factors of the disease is important as well as understanding the risk/benefit of screening
 - Issuing guidance for promoting informed choice
 - Reinforce and refine risk messages
 - Risk communication tool© designed and trialled
- Targeted approach to support vulnerable groups and individuals e.g. African-Caribbeans and South Asians



Grazie per la vostra attenzione