Citizens’ Jury on information for women about breast screening

Report to Informed Choice about Cancer Screening

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December 2012
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<td>Deborah Rozansky and Joanne Rule</td>
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Executive summary and recommendations

Introduction

Informed Choice about Cancer Screening at King’s Health Partners commissioned the Office for Public Management (OPM) to design and run a Citizens’ Jury to consider how to present the benefits and harms of breast screening generated by the Independent Review of Breast Screening in October 2012 in the information sent to women invited for screening.

The objectives of the jury were to seek recommendations on how to present information in the leaflet accompanying the invitation to attend breast screening, in particular:

- How to describe the mortality benefit associated with breast screening using words and the size of the benefit using graphics;
- How to describe the risk of overdiagnosis associated with breast screening using words and graphics;
- The level of detail on overdiagnosis needed for an informed decision;
- Whether ductal carcinoma in situ should be described and the level of detail;
- How to set out the mortality benefit and risk of overdiagnosis against each other in such a way that women can make an informed choice; and
- How to describe the scientific uncertainty around current estimates of mortality benefit and overdiagnosis.

Approach

Citizens’ juries are used to gain an informed view from a small group of members of the public on controversial and complex issues where there is no existing public consensus about how to proceed. Unlike other qualitative engagement methodologies such as focus groups, which focus on eliciting “top of mind” preferences and opinions, deliberative methodologies give the time and space for participants to understand and consider complex evidence in detail, looking at all perspectives on an issue before coming to a view.

Over the course of a jury, participants are able to probe, challenge and discuss the issues with expert witnesses as well as among themselves, before being asked to formulate a set of recommendations on the issue at hand. Juries do not make decisions, but generate recommendations that are then used to inform decision-making.

Juries are designed to allow participants to represent their own views directly to policymakers.

The Jurors

The jury comprised 25 women from the Greater London area between the ages of 47 and 73, all of whom had been invited to have screening on the NHS breast screening programme. Jurors were recruited using a purposive sampling approach in order to achieve a group that was broadly reflective of the national population for this age group and gender. OPM over-recruited by 5 women in order to achieve a target sample of 20. In practice all 25 recruited women attended on all three days of the jury.

Quotas were set to ensure representation of women who had and had not attended breast screening in a ratio that would be broadly reflective of screening uptake within the NHS.
breast screening programme (i.e., 73 per cent uptake of screening). Women who had previous experience of breast cancer were not recruited because they are not the target group for the information leaflet. Quotas were also set according to age, employment status; ethnicity, sexuality and disability to ensure a spread of experiences.

The women who attended the jury were recruited “on-street” - on high streets and outside community centres in 11 London boroughs between 20th October and 16th November 2012.

The agenda and expert witness presentations

The jury was held over three days, Day 1: Monday 19th, Day 2: Tuesday 20th and Day 3: Thursday 22nd November 2012.

On Day 1 the jury heard evidence from five expert witnesses: Professor Malcolm Reed on understanding breast cancer and the NHS Breast Screening programme, Dr Alison Jones on the treatment of breast cancer, Patsy Whelehan on how breast screening works, Dr Mike Michell on issues related to breast screening and Dr Alison Chapple on patient experiences.

On Day 2 the jury heard from three expert witnesses: Professor John Dewar on the evidence of the Independent Breast Screening Review (the ‘Marmot Review’), including mortality benefits and overdiagnosis, Professor Angela Coulter on communicating complex health issues, Professor David Spiegelhalter on communicating uncertainty and complex information and Roger Felton on communicating the look and feel of information in the leaflet.

On each day jurors had time to deliberate over each of the expert witness presentations, ask questions of the witnesses, and engage in a series of table and plenary discussions designed to facilitate their understanding of the issues. On Day 3 the jury worked towards developing their recommendations. Keypad voting was used on the final day in order to help build consensus recommendations and identify remaining areas of difference.
## Recommendations

The jury’s consensus recommendations are set out below along with areas where disagreement or lack of consensus remained.

<table>
<thead>
<tr>
<th>How to describe the mortality benefit associated with breast screening using words and the size of the benefit using graphics</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Jury consensus recommendations</strong></td>
</tr>
<tr>
<td>• The jury recommended using the figure of 1,300 lives saved per year.</td>
</tr>
<tr>
<td>• The jury recommended that the expressions of benefits include a figure for the number of women receiving a ‘normal result’ from screening - as part of any icon array or statement of benefit.</td>
</tr>
<tr>
<td>• The jury supported communicating information about the <strong>benefits of early diagnosis</strong>.</td>
</tr>
<tr>
<td>• The jury expressed a preference for benefit and harm statistics presented alongside one another in a simple format.</td>
</tr>
<tr>
<td>• The jury made a strong recommendation <strong>rejecting the 22,000 life years saved figure</strong>.</td>
</tr>
<tr>
<td>• The jury recommended not using <strong>too many numbers</strong>, and expressed a general preference for whole numbers rather than percentages or decimals.</td>
</tr>
<tr>
<td>• The jury <strong>rejected bar chart graphics</strong> and <strong>line graphs</strong>.</td>
</tr>
<tr>
<td>• The jury <strong>broadly recommended icon arrays be presented as ‘people’ rather than ‘dots’</strong>.</td>
</tr>
<tr>
<td>• Jurors expressed preference for icon arrays depicting women. Twenty out of 25 jurors preferred icon array graphics to a pie chart.</td>
</tr>
<tr>
<td>• The jury recommended figures on mortality benefit to be expressed in terms of <strong>women attending rather than women invited to screening</strong>.</td>
</tr>
<tr>
<td><strong>Areas of disagreement/lack of consensus</strong></td>
</tr>
<tr>
<td>• Two tables of jurors used ‘lives saved’ in their consensus statements, but there were differing individual views on whether the 1,300 figure would be better expressed as ‘deaths prevented’ or ‘lives saved’. Thirteen of 25 jurors preferred ‘lives saved’.</td>
</tr>
<tr>
<td>• Beyond the 1,300 figure, there were differing preferences for what would be useful information to include, and there were differing views on the words used to talk about mortality benefits. Some preferred narrative descriptions that connected screening and treatment with mortality benefits. Others favoured summary figures explaining outcomes from the screening programme in the form of cancers diagnosed, deaths from breast cancer prevented as well as risks of overdiagnosis.</td>
</tr>
<tr>
<td>• Beyond a rejection of bar charts and line graphs, there were differing views on preferred graphics; some jurors favoured pie charts, while others favoured different formats of icon arrays.</td>
</tr>
</tbody>
</table>
### How to describe the risk of overdiagnosis associated with breast screening using words and graphics

<table>
<thead>
<tr>
<th>Jury consensus recommendations</th>
<th>Areas of disagreement/lack of consensus</th>
</tr>
</thead>
<tbody>
<tr>
<td>• The jury recommended overdiagnosis figures to be expressed in terms of: ‘of the xx number of women screened, xx would have a normal result, xx would be diagnosed with cancer and xx would be diagnosed with a cancer which might not have caused any problems in the woman’s lifetime if it had been undetected.’</td>
<td>• There were differing views about whether the figure of 4,000 cases of overdiagnosis each year was helpful to include, some found these figures ‘frightening’ and had concerns that they might deter women from attending.</td>
</tr>
<tr>
<td>• The jury recommended explaining that there are differences between cancers which might cause a problem in one’s life time and those which might not – they recommended describing overdiagnosis in these terms.</td>
<td></td>
</tr>
<tr>
<td>• The jury recommended that the term ‘overdiagnosis’ was unhelpful from a patient perspective. They preferred the term ‘overtreatment’ to describe the possible outcomes of screening.</td>
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</tbody>
</table>

### The level of detail on overdiagnosis needed for an informed decision

<table>
<thead>
<tr>
<th>Jury consensus recommendations</th>
<th>Areas of disagreement/lack of consensus</th>
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</thead>
<tbody>
<tr>
<td>• The jury strongly recommended using the term <strong>overtreatment</strong> to explain the impact of ‘overdiagnosis’ from a patient experience perspective.</td>
<td>• Beyond the jury’s recommendation for the term ‘overtreatment’ there were different preferences for the words and level of detail used to explain overtreatment.</td>
</tr>
<tr>
<td>• Twenty one jurors preferred the term overtreatment to overdiagnosis.</td>
<td>• There were a small number of jurors who questioned whether information on overdiagnosis should be included.</td>
</tr>
<tr>
<td>• The jury recommended statements in words which described the issue in ‘layperson’s terms’ rather than using the term ‘overdiagnosis’ as a way to approach the topic.</td>
<td></td>
</tr>
<tr>
<td>• The jury recommended using the terms “risk” or “disadvantage” over “harm”.</td>
<td></td>
</tr>
<tr>
<td>• The jury recommended figures on overdiagnosis /overtreatment to be expressed in terms of <strong>women attending rather than women invited to screening.</strong></td>
<td></td>
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</tbody>
</table>
### Whether ductal carcinoma in situ (DCIS) should be described and the level of detail

<table>
<thead>
<tr>
<th>Jury consensus recommendations</th>
<th>Areas of disagreement/lack of consensus</th>
</tr>
</thead>
<tbody>
<tr>
<td>• The jury recommended some basic information explaining what DCIS is in words, with numbers showing what proportion of cancers detected it represents.</td>
<td>• There were differing views on the level of detail to include about DCIS, particularly whether or not to include any images.</td>
</tr>
<tr>
<td>• The jury recommended that the concept of DCIS as a “pre cancer” was not helpful.</td>
<td>• Some talked about wanting information about DCIS given in the context of overdiagnosis / overtreatment and described in terms of invasive and non-invasive cancer.</td>
</tr>
</tbody>
</table>

### How to set out the mortality benefit and risk of overdiagnosis against each other in such a way that women can make an informed choice

<table>
<thead>
<tr>
<th>Jury consensus recommendations</th>
<th>Areas of disagreement/lack of consensus</th>
</tr>
</thead>
<tbody>
<tr>
<td>• The jury recommended presenting benefits and ‘harms’ side-by-side alongside one another in a simple format.</td>
<td>• There were different preferences for the ordering of information, some wanted a short statement about the benefits in words followed by numbers and graphics explaining benefits and harms/risks, others wanting information about benefits, followed by risks concluding with overall benefits. Others wanted all information on the benefits and ‘disadvantages’ displayed side-by-side.</td>
</tr>
<tr>
<td>• The jury recommended explaining that attending screening isn’t a simple decision; that you need to understand the benefits and risks/pros and cons when making a decision that is right for you.</td>
<td>• Twelve jurors preferred “first express the benefits and harms separately, and then express them together.” 8 “express the benefits and harms together” and 4 “express the benefits and harms separately”.</td>
</tr>
<tr>
<td>• The jury recommended that data be expressed as far as possible from a woman’s point of view - ‘what might happen to me’ or ‘women like me’, and using denominators as well as graphics that help make the information feel more personal. For example, by looking at what might happen to a group of 200 or 250 women.</td>
<td>• Jurors differed in their preferences for meaningful denominators and graphical presentations, indicating the need for more testing on these issues. However, most expressed a preference for using the same denominator where possible.</td>
</tr>
</tbody>
</table>

### How to describe the scientific uncertainty around current estimates of mortality benefit and overdiagnosis

<table>
<thead>
<tr>
<th>Jury consensus recommendations</th>
<th>Areas of disagreement/lack of consensus</th>
</tr>
</thead>
<tbody>
<tr>
<td>• The jury was clear that there was uncertainty about screening outcomes and about medical interventions and that this should be</td>
<td>• There was limited consensus from the jury about how to present scientific uncertainty. When talking about uncertainty, the women</td>
</tr>
</tbody>
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acknowledged but less sure how to do this.

tended not to refer to the size of the benefits or harms. Rather, they talked about the uncertainty of medical interventions and uncertainty associated with screening outcomes.

- Asked which mattered most, 15 jurors voted reassurance and accuracy mattered equally, 7 voted that accuracy mattered most and only 3 that reassurance mattered most.

**Additional recommendations from the Jury**

The jury acknowledged that different people have different information needs, something reflected in strong **recommendations to make the leaflet as accessible as possible**, and for the **provision of supplementary detailed information and case studies** for people to choose to access if they wish.

The jury also acknowledged the challenge of presenting complex information in a concise way. They reflected that they had benefited from the conversations they had had in the Citizen's Jury and that other women would not have this benefit. In this context some jurors **recommended that ‘having a conversation’ was the best way to communicate and consider complex information**.

Some members of the jury said that they felt it was important not to make the leaflet too frightening or ‘off-putting’. Some jurors focussed on how to reach women who might be hesitant about attending and **recommended that information on harms and risks should not be off-putting** for them by being too ‘frightening’. This view was held in the context of support for informed choice and a good understanding of their role as citizen jurors.

Additional recommendations from the jury are summarised below:

- Include some basic information about breast cancer, the different types and stages of cancer, risk factors and details about screening and its rationale. Images can be useful.
- Include a detailed explanation about the process of screening, including what might happen at each stage and indicative timings. Diagrams and flow charts can help.
- Incorporate signposting within the leaflet so that women will know where to go for more information to help them make a decision about screening.
- Ensure the leaflet is accessible and acceptable to women of different literacy levels, ethnic, religious and social backgrounds.
1. Introduction

The Independent Breast Screening Review (the ‘Marmot Review’), commissioned by Cancer Research UK and the Department of Health (England) reported in October 2012. The review concluded that while the evidence suggests that breast screening extends some women’s lives, it does so at a cost. The Review estimated that while screening prevents about 1,300 breast cancer deaths per year in the UK, it leads to about 4,000 women each year aged 50-70 having treatment for a condition that would never have troubled them. There was a strong recommendation from the Review that women should be given information “that is clear and accessible before they go for a mammogram so they can understand both the potential harms and benefits of the process.”

The development of this information is being taken forward by the Informed Choice about Cancer Screening (ICCS) team at King’s Health Partners. The team has been leading a consultation into how best to promote informed choice in cancer screening. Informed Choice about Cancer Screening has sought the views of the public, professionals, experts, academics and patient groups and received over 1,100 responses to a public survey and consultation. The approach being developed by the ICCS team will be used to produce information on all NHS Cancer Screening Programmes. Following the Marmot Review, the development of a new breast screening invitation and leaflet is a priority for the team.

As part of this new approach to developing information for people invited for screening, ICCS Informed Choice about Cancer Screening at King’s Health Partners commissioned the Office for Public Management (OPM) to design and run a Citizens’ Jury. The key aim of the Jury being to gain women’s perspectives about how to present information in the leaflet accompanying the letter inviting women to attend screening, supporting them to make an informed choice. The jurors were 25 women aged between 47 and 73, and the jury was held over three days – the 19th, 20th and 22nd November 2012.

The objectives of the Jury were to seek recommendations on how to present information in the leaflet, in particular:

- How to describe the mortality benefit associated with breast screening using words and the size of the benefit using graphics;
- How to describe the risk of overdiagnosis associated with breast screening using words and graphics;
- The level of detail on overdiagnosis needed for an informed decision;
- Whether ductal carcinoma in situ should be described and the level of detail;
- How to set out the mortality benefit and risk of overdiagnosis against each other in such a way that women can make an informed choice; and
- How to describe the scientific uncertainty around current estimates of mortality benefit and overdiagnosis.

During the course of the jury, jurors heard evidence from nine expert witnesses about the science and treatment of breast cancer, the process of breast screening and the NHS Breast Screening Programme, the recommendations of the independent review of breast screening, and effective ways to present complex information in words, numbers and graphics. The jurors deliberated about each of the expert witness presentations, asking questions of the witnesses, and engaging in a series of table and plenary discussions designed to facilitate
consensus around recommendations. In addition, individual voting keypads were used to gather opinions and preferences about the key issues.

This report describes the process of the jury, details its deliberations and summarises its recommendations.

2. Approach

Given the challenges involved with developing the new invitation letter and leaflet, the Informed Choice about Cancer Screening team wanted to understand the perspectives of women who will be receiving the new leaflet. They wanted their views about how best to present the information to help women to make a choice about whether or not to attend for screening. A Citizens’ Jury was chosen as one way to do this as it is an engagement approach which is particularly well-suited to deliberating on complex issues to gain insight into citizens’ perspectives where there are complex, strong and competing views.

Citizens’ juries invite members of the public to hear evidence from a range of expert witnesses on a particular issue. The jury is designed to encourage members to develop a considered opinion on an issue, taking into account all available information and involving the fair and balanced presentation of different, often opposing, points of view. Information and evidence is presented to jurors by expert witnesses.

Citizens’ juries are used in order to gain an informed view from a small group of members of the public on controversial and complex issues where there is no existing public consensus about how to proceed. Juries do not make decisions, but generate recommendations that are then used to inform decision-making. Unlike other qualitative engagement methodologies such as focus groups, which focus on eliciting “top of mind” preferences and opinions, deliberative methodologies give the time and space for participants to understand and consider complex evidence in detail, looking at all perspectives on an issue before coming to a view. Participants in a citizens’ jury are given more time to consider, interrogate and deliberate and learn from the information and evidence provided for them, than in other engagement approaches.

Over the course of the event, jurors are able to probe, challenge and discuss the issues with witnesses as well as among themselves, before being asked to formulate a set of recommendations. Juries are designed to allow participants to represent their own views directly to policy-makers.

The recommendations made by citizens’ juries do not produce the kinds of statistically verifiable results found in quantitative social research. They do indicate the considered opinions of a small group of citizens who have been provided with evidence and information, time for discussion and consideration:

Citizens’ juries operate according to set principles, including:

- The jurors are recruited to be a cross-section of a community.
- There is sufficient time for questioning, deliberation and scrutiny of evidence to enable complex issues to be considered and to get beyond an initial ‘top of mind’ responses.
- All viewpoints are given consideration, with the evidence and information presented being balanced as far as possible.
- The jury is not a decision-making body, but policy makers are expected to take the jury’s recommendations seriously and to provide a response to jurors.
- Time is provided for immersion in the issues and information as ‘individuals’.
- Time is provided for jurors to discuss, clarify and question witnesses.
- Time is provided to review evidence and questions to reach considered view and develop recommendations as ‘citizens’.

Juries are facilitated by people who are independent of the organisation commissioning the jury. The facilitator’s role is to prompt the jurors to deliberate - not to lead them in any particular direction - the evidence, ask questions, and facilitate jurors to make recommendations on an issue. A lead facilitator acts as the chair for proceedings, framing key objectives, keeping witness presentations to time, and facilitating plenary feedback.

A question and answer briefing on the Citizens’ Jury on information for women about breast screening can be found here.

### 3. Recruitment of the jury

OPM managed the recruitment of 25 women from the Greater London area between the ages of 47 and 73, all of whom were eligible to be invited to the NHS breast screening programme. Jurors were recruited using a purposive sampling approach in order to achieve a group that was broadly reflective of the national population for this age group and gender. OPM over-recruited by 5 women in order to achieve a target sample of 20. In practice all 25 recruited women attended on all three days of the jury.

Purposive sampling allows quotas to be set to ensure participants are broadly representative of different ages, ethnicities, socio-economic and employment statuses. It is used in qualitative research and engagement where relatively small numbers of participants are involved and where ‘random’ or ‘representative sampling’ based on the electoral roll is not appropriate or practically feasible. Purposive sampling also allows control for the representation of participants fitting particular profiles that may determine attitudes towards the questions being discussed.

Quotas were set in the case of this Jury to ensure representation of women who had and had not attended breast screening in a ratio broadly reflective of screening uptake within the NHS breast screening programme (i.e., 73 per cent uptake of screening). Women who had previous experience of breast cancer were not recruited because they are not the target group for the information leaflet. Quotas were also set according to age, employment status, ethnicity, sexuality and disability to ensure a spread of experiences.

The women who attended the jury were recruited “on-street” - on high streets and outside community centres in the 11 London boroughs of Brent, Barnet, Camden, Croydon, Enfield, Greenwich, Haringey, Lambeth, Newham, Tower Hamlets and Waltham Forest between 20th October and 16th November 2012. Recruiters used a recruitment questionnaire which ensured that the quotas for age, ethnicity, socio-economic, employment and breast screening uptake were met. In total 128 women were approached, 119 of whom were eligible according to the agreed quotas. Ninety three women declined, citing time, family and work commitments and simply not wanting to take part. Twenty five women (20 per cent of the total approached) agreed to take part.
4. Sample

The jury comprised 25 women between the ages of 47 and 73, all of whom had been invited to attend breast screening. Of these 10 had not attended screening, 4 of which were over 53 years old. Fifteen had attended screening, roughly mirroring the proportion of uptake in the UK of 73 per cent mentioned above. A demographic profile of jury participants can be found below:

Figure 2: Composition of the jury

<table>
<thead>
<tr>
<th>Age</th>
<th>Socio Economic Group</th>
<th>Work status</th>
<th>Ethnicity*</th>
<th>Disability</th>
<th>Screening attendance</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>8 aged</td>
<td>8 A/B</td>
<td>8 working full-time</td>
<td>14 White British</td>
<td>19 - no reported disabilities or long term conditions</td>
<td>10 had not attended screening</td>
<td>25 all of whom had been invited to attend screening</td>
</tr>
<tr>
<td>47 – 53</td>
<td>8 C1/C2</td>
<td>6 working part-time</td>
<td>2 White other</td>
<td>4 were over 53 years old</td>
<td></td>
<td></td>
</tr>
<tr>
<td>years old</td>
<td>9 D/E</td>
<td>8 retired</td>
<td>9 Black African/Caribbean</td>
<td>15 had attended screening</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10 aged</td>
<td>8 A/B</td>
<td>3 not in employment</td>
<td>19 - no reported disabilities or long term conditions</td>
<td>10 had not attended screening</td>
<td></td>
<td></td>
</tr>
<tr>
<td>54-64</td>
<td>8 C1/C2</td>
<td></td>
<td>4 were over 53 years old</td>
<td>4 were over 53 years old</td>
<td></td>
<td></td>
</tr>
<tr>
<td>years old</td>
<td>9 D/E</td>
<td></td>
<td>6 - with physical disability, mental health or long term condition</td>
<td>15 had attended screening</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 aged</td>
<td>8 A/B</td>
<td></td>
<td>19 - no reported disabilities or long term conditions</td>
<td>10 had not attended screening</td>
<td></td>
<td></td>
</tr>
<tr>
<td>65-73</td>
<td>8 C1/C2</td>
<td></td>
<td>4 were over 53 years old</td>
<td>4 were over 53 years old</td>
<td></td>
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<tr>
<td>years old</td>
<td>9 D/E</td>
<td></td>
<td>6 - with physical disability, mental health or long term condition</td>
<td>15 had attended screening</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*One particular recruitment challenge was recruiting women from Bangladeshi, Indian and Pakistani backgrounds. This quota was not met and feedback from recruiters indicated that although women from these BME backgrounds were approached and were keen to take part, particular barriers to their participation included the time commitment conflicting with their family obligations (including child care) and for some, particularly older women, a language barrier.

Jury members are referred to as “jurors”, “women”, “participants” and “the Jury” through the course of this report.

5. Agenda

The jury was designed to give time for jurors to hear from nine expert witnesses covering the following topics:

- Understanding breast cancer.
- How is breast cancer treated?
- What is the NHS Breast Screening programme and why has there been a review?
- How the breast screening programme works.
- Issues related to screening.
- Understanding patient experiences.
- Understanding evidence from the Marmot Review including overdiagnosis.
• Communicating complex health issues.
• Communicating uncertainty and complex information, communicating numbers.
• Communicating the look and feel of the leaflet.

In order to manage deliberations, and allow each jury member to contribute, jurors sat at one of three round tables for the course of the jury. Each table was facilitated by an OPM facilitator. Following each witness presentation, jurors had time at their tables to reflect on the information presented and generate questions for the expert witness with the aim of clarifying issues that they did not understand. All witness presentations took place on Days 1 and 2 of the jury. There was then a one day break, designed to allow the women to reflect on the evidence they had heard. The jury was reconvened for a final half day session on Day 3, which was designed to facilitate the development of recommendations for each of the key objectives. A detailed agenda can be found in Appendix A and expert witness biographies in Appendix B. Video recordings of each of the expert witness presentations are available on the Informed Choice about Cancer website, here.

6. Day 1

6.1 Introductions

The first session on Day 1 allowed jurors time to get to know one another and share their experiences of breast screening. It gave time for jurors to ask questions about the purpose of the jury and the agenda.

Jurors who had attended screening talked about their different experiences, some positive, some less positive. There was some uncertainty about what to expect from screening for women who had not yet attended.

Some jurors had early questions around accessibility for people with disabilities, provisions for homeless women, and a need to a focus on people who don’t understand the screening process and who don’t attend, for whatever reason. A few mentioned being afraid of screening.

There were discussions amongst some jurors about recent media coverage of women electing to have mastectomies as a preventative measure; a TV programme where someone had experienced unnecessary treatment and general worries about the competency of doctors and, in the words of some jurors, the concept of ‘misdiagnosis’.

There was confusion amongst some about how frequently women are called for breast screening and spontaneous questions about why screening starts at 47 (“why not younger?”) and stops at 70/73 (“why not older?”).

6.2 About the Jury - Keypad polling

During this session jurors were polled in order to establish the self-reported importance they placed on different ways of making decisions about their health care and treatment including:

- Doing my own research.
- Discussing with family and friends.
- A recommendation from a health professional.
- My family’s medical history.
Citizens’ Jury on information for women about breast screening

- Understanding the potential benefits and risks of different options.
- The seriousness of the condition/issue.

Results are not reported here as not all 25 jurors voted in this session. Broadly, women indicated they made decisions with input from a variety of people and sources, as well as using their own judgement. Most placed a high level of importance on “a recommendation from a health professional”, “my family’s medical history” and “understanding the potential benefits and risks of different options” and “seriousness of the condition/issue” in making a decision about their health. Full results from the polling on Day 3 can be found in Section 8.

6.3 Understanding breast cancer

In the first witness session on Day 1 jurors listened to presentations from Professor Malcolm Reed and Dr Alison Jones. The objectives for this session were for jurors to learn about breast cancer, its types and stages, risk factors, treatment and outcomes. The session was also designed to help jurors to understand the rationale behind breast screening and to allow them to ask questions and gain clarification from the expert witnesses. The expert witness sessions are summarised below:

Understanding Breast Cancer

Witness 1: Professor Malcolm Reed - Professor of Surgical Oncology and Head of the Department of Oncology, University of Sheffield

- How common is breast cancer? - epidemiology, including risk factors, and, survival.
- Two main routes to diagnosis - screening and symptomatic presentation.
- Symptoms of breast cancer - clinical presentation.
- How is breast cancer diagnosed - covering the triple assessment.
- Types of breast cancer.
- Stages of breast cancer (including DCIS) and why this matters, in relation to treatment options and survival.

How is breast cancer treated? Understanding treatment and decision-making

Witness 2: Dr Alison Jones - Consultant Medical Oncologist and Senior Lecturer at the Royal Free and University Hospitals London

- How is breast cancer treated?
- Non-surgical management, adjuvant therapy, neo-adjuvant therapy.
- Management of advanced disease.
- Shared decision-making about breast cancer treatment in particular for DCIS and stage 1.

What is the NHS Breast Screening Programme and why has there been a review?

Witness 1: Professor Malcolm Reed - Professor of Surgical Oncology and Head of the Department of Oncology, University of Sheffield

- Introducing the NHS Breast Screening Programme and its rationale (emphasising early detection not prevention).
- Benefits and harms of screening.
Why we have had a review of the effectiveness of breast screening.

6.4 Overview of discussions

Jurors reflected that it was useful and interesting to learn about the different types of breast cancers and how these spread — and most said that this was new information for them. Some talked about finding it useful to understand how breast cancer was diagnosed and how it might spread to other parts of the body.

Whilst some jurors responded that the information in the presentation had ‘scared’ them, others said that it had been ‘comforting’ to hear that tumours can often be found to be benign. Some also felt that it was good to hear that there is a ‘whole team of people’ involved in the care of people who are diagnosed with breast cancer, as they felt this was reassuring. Many jurors were particularly interested in hearing about the role of the ‘Breast Care Nurse’ which they had not heard about before.

6.5 Juror questions

A key focus for the table discussions was around prevalence and epidemiology in the context of personal risk factors, perhaps because as jurors learned more about breast cancer they had worries about their own personal risk of developing it. Specifically, jurors had questions about the prevalence of breast cancer for different age groups, the impact of breast feeding, the menopause, HRT, stress and lifestyle factors on women’s risk of breast cancer. Some wanted to know how prevalence had changed over the last twenty years, and to what extent changes in prevalence were a result of an increase in screening and diagnosis. Some also wanted to know what proportion of breast cancer is inherited and how much is sporadic. Within this focus on personal risk factors, some jurors also wanted more information on the symptoms of breast cancer and some felt that these had not been explained clearly enough in the presentations in this session.

The questions generated by jurors for Professor Malcolm Reed around breast cancer focussed on the following:

- **Prevalence and risk factors** – jurors wanted to know more about personal risk factors and there was particular uncertainty around the impact of the menopause and HRT on one’s personal risk of developing breast cancer. Others had questions about what affects the speed at which a cancer develops. One juror wanted to know if you can be the first woman in a family to be genetically predisposed to developing breast cancer.

- **Secondary cancers** – some jurors had questions about what percentage of women get secondary cancers, whether breast cancer can be a secondary cancer from somewhere else and if and how it can be known whether a secondary cancer is the same as the original breast cancer.

- **DCIS** - jurors wanted more detail about the ‘calcium deposits’ mentioned and about DCIS in general and there appeared to be some confusion amongst jurors about what was seen on the mammograms and what was actually happening within the ducts.

- **Language** - One participant was concerned about the use of the term ‘carcinoma’ – and asked if this could be explained in laymen’s terms, suggesting including a glossary with the information provided for women when they are invited to attend breast screening.

Having heard about the range of different possible treatments for breast cancer, participants had questions relating to how decisions are made about what treatment is
appropriate. Some were particularly interested in hearing whether patients had a choice in deciding whether to undergo radiotherapy or chemotherapy (as a result of concerns about the potential harmful effects of these treatments).

The questions generated by the jurors for Dr Alison Jones around breast cancer treatment focussed on:

- **Efficacy of radiotherapy and chemotherapy** – jurors wanted more information on the efficacy of different types of treatment. Reflecting that one witness presentation had indicated that radiotherapy appears to have little impact on outcomes, some jurors asked why it is used in this case. Jurors had specific questions around how long would you live with and without chemotherapy and also whether you can ever have an ‘all clear’ (in their words). One juror wanted to know what the difference is between radiotherapy and chemotherapy and specifically when might you have either, or both? Others wondered if these treatments come under nuclear medicine. A juror on one table initially did not understand why you couldn’t have a blood test to screen for breast cancer – other jurors corrected her that this is not possible at the current time. Some had concerns about the accuracy of x-ray readings and wanted reassurance that the health professionals looking at the x-rays had sufficient training to be able to identify or ‘see’ any possible ‘lumps’.
  One juror asked:
  ‘How carefully do doctors look at these results?’

- **Side effects of treatment** - Jurors wanted to know more about the side-effects of treatment and at what point these are made clear to a patient. Others wanted to know about the impact of radiotherapy on the breast. Some jurors wanted to understand the differences between the side effects of chemotherapy on secondary and primary cancers. Some other jurors asked whether if you decided not to have treatment, you could opt back in again if you changed your mind. Similarly, some had questions about the extent to which radiotherapy can (in their words) cause, cancer.

- **Quality assurance** - Some wanted to know about the extent to which there was a ‘standard’ approach to the breast cancer patient pathway across the country, and linked to this wondered whether there was a ‘postcode’ lottery with some areas being able to provide better treatment, greater access to and more joined up working between health professionals.

Questions generated for Professor Malcolm Reed on the NHS Breast Screening programme were focussed on:

- **Screening itself** – jurors wanted to know whether screening stops at 73 even if you have a family history of breast cancer. Some women with daughters talked about their worry that their daughters would not be invited to screening until they are 47. Others wanted to know if screening focuses on areas of the breast particularly susceptible to breast cancer. Some had specific questions about the length of time between screening and potentially being recalled.

- **NHS and private** – some jurors wanted to know if you decided to have private screening and / or treatment if you could go back to the NHS and also what the differences were between being screened on the NHS or privately.

- **Investment** – jurors had questions about investment in the screening programme and specialist nurses and whether this was under threat in the current economic circumstances. Others had questions about whether there is a budget per head for treatment.
6.6 Understanding breast screening

In the second witness session on Day 1 jurors listened to presentations from Patsy Whelehan on how the breast screening programme works and an introduction to screening issues from Dr Mike Michell. The aim for the session was to help jurors understand the process and experience of breast screening, to understand overdiagnosis and its implications and to allow jurors to ask questions and gain clarification from the expert witnesses. The expert witness presentations are summarised below:

**How the breast screening programme works**

Witness 3: Patsy Whelehan - Senior Research Radiographer (Breast imaging), Division of Cancer Research, Medical Research Institute, University of Dundee

- For jurors to understand the process and experience of breast screening.
- For jurors to understand overdiagnosis and its implications.
- To allow jurors to ask questions and gain clarification from expert witnesses.
- To explore jurors’ initial views on what and how much information about breast screening should be provided in the invitation to attend screening.

**Issues related to screening**

Witness 4: Dr Mike Michell - Consultant Radiologist, King’s College Hospital, Director, South East London Breast Screening Programme and King’s National Breast Screening Training Centre.

- Problems related to screening - overdiagnosis, DCIS, false positives, false negatives, and psychological distress.

6.7 Overview of discussions

Following both Patsy Whelehan and Dr Mike Michell’s presentations, participants talked more about their own experiences of breast screening, which were varied. Some reported having positive experiences with little pain or discomfort and health professionals who were sensitive and helpful. Others reported the opposite. Some also talked about their personal experiences of being recalled and the stress that this had caused them.

Jurors reported varying experiences at different screening locations. There was discussion on one table about the difference between the ‘quality’ and up-to-dateness of screening equipment in hospitals versus mobile units. Some expressed the view that the mobile units were “drab” and that they “can’t be nice for the people that work there”. One juror talked about the telephone line not being staffed when she had called to try to change an appointment. Another mentioned arriving at a mobile unit to find it closed and no one following up with her to reschedule her appointment.

Jurors reported their differing levels of knowledge about what the process would be like, before they went for screening. Some had looked up breast screening on the internet and others reported knowing nothing. One participant reported never having been for screening as she was too scared after hearing about her mother’s negative experience. Jurors liked the patient pathway diagram presented by Patsy Whelehan (see Figure 3 below) and felt that it was important to tell women what the process looks like and what the possible outcomes
might be for any individual - jurors felt this would be particularly valuable for those women who have never been.

Some jurors suggested that it would be useful to have a timeline for the pathway diagram similar to the one presented by Witness three, see figure 3 below.
Figure 3: Patient Pathway Diagram

- **Invitation**
  - Includes allocated appointment time and place.
  - Information leaflet enclosed.
  - Appointment can be changed or cancelled by calling the breast screening office.

- **Attendance for mammography**
  - Breast screening unit may be within a hospital, at a non hospital permanent location, or a mobile unit.
  - Mammograms read by two specialists.

- **Results letter**
  - Should be within two weeks of screening.
  - Results letter posted direct to the client; result also sent to GP.
  - Sometimes mammogram has to be repeated for quality reasons.

- **No suspicion of cancer:**
  - New invitation sent three years later

- **Further investigation needed:**
  - Appointment to attend assessment centre
  - May include further mammography, ultrasound scan, needle biopsy...

- **Appointment for needle biopsy result**
  - With discussion of treatment options if needed
  - Normal or benign (non-cancer): discharged to receive routine screening three years later

- **Treatment**

- Very occasionally, early re-screen is advised.

Appointment should be within one week of biopsy.

Appointment should be within three weeks of initial screening.

Appointment can be changed or declined by calling the breast screening office.
6.8 Juror questions

Questions related to Breast Screening were focussed on:

- **Safety** – some participants had general questions about how ‘safe’ having a mammogram is, e.g., whether the radiation itself causes harm, whereas others had specific questions relating to how often the equipment is subjected to quality checks. Some had specific questions about current advances in screening technology and why equipment can’t be made more comfortable. Jurors also had questions about what the differences were between mobile units and hospitals. Some jurors had questions about whether the screening process is different for women with breast implants.

- **About the screening process** – Some wanted to know if having smaller or larger breasts had an impact on how painful the screening was and the extent to which an accurate reading could be taken. Others had questions about the frequency of screening and asked why it was every three years. Others had questions around the male staff involved post screening and wondered if cultural differences were being considered. Some jurors had questions about outreach to vulnerable populations, for example homeless women or women not registered with GPs.

- **Psychological help** – some jurors wanted more information about the psychological help on offer and what it involves. Some suggested that a pre-visit might help in deciding whether or not to go for screening and in preparing women to attend screening for the first time in relation to knowing what to expect.

- **DCIS / breast cancer** – participants had questions about DCIS and breast cancer screening. One wanted to know when it was first discovered as a medical condition. The notion of calcium deposits observed on the mammogram was confusing to some women. One wondered whether being calcium deficient would mean that the cancer would not show up on the mammogram. Another asked whether the pattern of the calcium deposit indicated whether the cancer would become an invasive or non invasive cancer. Jurors asked if DCIS could be diagnosed through a biopsy. There was some confusion over DCIS and overdiagnosis at this stage. Some jurors continued to use the term “misdiagnosis” for example:

  ‘The scariest aspect for me is the issue of misdiagnosis of DCIS and the clinical treatment of the above, what is the true medical outcome?’

- **Other questions about the context for the jury** – One juror had concerns that health professionals are trying to get people to opt out of screening as the system was struggling to cope with demand and limited budgets. Another had questions as to whether this issue had come up because of the media coverage about the doctor who had conducted mastectomies on women who had not needed them.

**Patient experiences**

Witness 5: Dr Alison Chapple, Medical Sociologist, Department of Primary Care Health Sciences, University of Oxford

The last witness session on Day 1 involved jurors listening to an introduction by Dr Alison Chapple and watching a series of videos from “Healthtalkonline” highlighting a range of positive and negative experiences of screening by patients. The objective for the session was to allow jurors to hear about different experiences of breast screening and breast cancer and its management, to understand how patients have made decisions about
attending breast screening and breast cancer treatment options after diagnosis.

The videos which jurors watched are available here:

[Insert link to ICCS/healthcare online presentation]

After watching the videos, participants were asked to reflect on the question: “Listening to these experiences, what information about screening would have been helpful for these women beforehand or during the process?”

6.9 Overview of discussions

Jurors reflected that the “Healthtalkonline” website is a good resource for information because if you wanted to seek it out you could, but they also considered that people are very individual in terms of their information needs. Jurors spontaneously talked about how individuals vary in their preferences for sources and types and amounts of information; one juror commented:

‘Some people want information, some people don’t want information.’

Some reflected that the examples in the videos were all of women who had had treatment (as opposed to profiling any women with a ‘normal’ result) which they felt would have been useful. Others talked about the fact that, apart from one black woman that there were no BME women in the videos, and a few jurors commented that the women profiled all seemed ‘middle class’. Some jurors talked about the needs of people with different languages and a mix of visuals and words.

Rather than focus on the experiences presented in the videos, participants tended to talk more broadly about what they thought should be included in the leaflet or pre-screening information – in different media - for women and what the process should be like.

Reflecting on the video format, some felt that there could be a DVD sent to women who are invited for breast screening for the first time, which could include detail about what the process is like. Other jurors reflected that information should be made available via different media (face to face, over the phone and on TV were all spontaneously mentioned). Some jurors pointed out that not everyone has internet access and also that people have different literacy and English language levels. Some suggested that information could be provided at GP surgeries. Jurors talked about specialist nurses being good to have informal conversations with about the process beforehand and the value of a ‘cup of tea and a chat’ was talked about by a number of jurors.

Jurors were asked to take a moment to themselves to identify and write down: “What information would you like to receive when you are invited for breast screening?” – Responses included:

Information, all of it - with recommendations but emphasis on it being a chosen option.


Easy to understand, plain language - phone numbers to talk to someone if needed

The whole process of relaying the information in layman’s language so that all understand. Making the word cancer less frightening

Sympathetic approach by screening staff

Informed choice
Knowing the symptoms of breast cancer
Friendly face or voice
Pros and cons of breast screening process
Time to process information

The jurors made some early reflections at the end of Day 1, responding to the question: “What information about breast cancer and breast screening is important for you?”

- **The leaflet should include information about the process of screening** – jurors felt that this was particularly important for those women who haven’t been for screening before, as there is a ‘fear of the unknown or the unseen’. Some felt a picture of the machine should be included.

- **The language used needs to be sensitive** – Some participants reported that the current leaflet/invitation sounds almost ‘accusatory’ with a focus on ‘you should....’ rather than ‘we believe...’. One juror commented that the current invitation letter and leaflet are very “verbose”.

- Jurors suggested the leaflet should acknowledge that ‘this might be frightening’ and reassure patients that even if breast cancer is detected there are a range of treatments that can be very effective, and that they will have all the support they need. Similarly, it should also reassure patients who are recalled that ‘if you need to be recalled there will be a team of people here to look after you.’

- There was also some concern about ‘myths’ and ‘misinformation’ around breast cancer and screening which jurors felt could be usefully addressed in the leaflet. At the same time some jurors mentioned the importance of honest information, e.g., some women found screening painful and acknowledging that screening is not 100 per cent in finding all breast cancers.

- **The leaflet should include sympathetic graphics** – some jurors reported that most leaflets have a very ‘corporate’ image or style, and that the breast screening leaflet needs to include graphics that are meaningful to women (no further detail on what type of graphics at this stage).

- The leaflet should include some information about the types and stages of breast cancer.

Other suggestions included: including information about one’s risk of getting cancer, a list of the health professionals you may come in contact with and a website to look up further information if you wanted to.

7. Day 2

7.1 Understanding evidence from the Marmot Review

In the first witness on Day 2 jurors listened to a presentation from Professor John Dewar which introduced them to evidence from the Marmot Review. The objectives for the session were: for jurors to understand the potential benefits and harms of breast screening, over time, as presented by the Marmot review (especially mortality and overdiagnosis). For jurors to understand the uncertainty around estimates of benefits and harms of breast screening, as presented by the Marmot review. To introduce jurors to the importance of communicating the mortality benefits and overdiagnosis risks of screening in a way that promote informed choice, and to allow jurors to ask questions and gain
clarification from Professor John Dewar. A summary of his presentation of evidence is provided below:

**Understanding evidence from the Marmot Review**

Witness 6: Professor John Dewar - Consultant Clinical Oncologist and Honorary Professor at Ninewells Hospital

- Information about the Marmot Review and the mortality benefits (deaths avoided) of breast screening.
- Evidence from the review about overdiagnosis.
- Summarising the main conclusions of the Review.

### 7.2 Overview of discussions – mortality benefits

The information presented on mortality benefits generated questions for the women and many reflected that the evidence prompted them to think about risks and harms that they had not previously considered. Many of the jurors’ discussions, in response to Professor John Dewar’s witness presentation, were concerned with how the figures in the presentation had been worked out. Specifically some jurors wanted to know whether the breast cancer mortality figures were all made up of women who had died from breast cancer or whether they could have died from related diseases. Jurors struggled with understanding the idea of cancer which had spread to other parts of the body: this was a new idea for some and they saw it as conceptually different from ‘dying of breast cancer’. There was a lot of discussion around the concept of “best estimates” which was unsettling for some jurors who wanted more certainty, and in one juror’s words “actual figures”. This indicated early difficulties for some in understanding the concept of uncertainty in scientific evidence. Some were very uncomfortable that doctors were uncertain - in the words of one juror:

> ‘How the hell are they able to spend all this money [on medical research] and not be able to tell whether a cancer is a bad cancer or a good cancer?’

Some jurors expressed feeling overwhelmed by the amount of information presented in this session, with some noting that “too much information muddles…” Other jurors said that some of the graphs were confusing and could have been labelled better to make them easier to understand. In discussion, jurors tended to refer to the summary figures provided as these were the easiest for them to understand. At this stage jurors started to recommend the need to communicate summary figures with information about breast cancer and breast screening – but also breast awareness.

There was some discussion around wanting reassurance and peace of mind. When probed for an explanation about what this statement meant, the jurors mentioned the large number of women who were told they had normal results. This was seen as a clear advantage of screening. In addition, the normal results provided psychological benefits (so jurors thought). In one juror’s words:

> ‘We’ve only talked about benefits and disadvantages of people diagnosed, but the huge benefits (peace of mind) of women given the all clear show the clear advantage of screening.’

Jurors showed an early preference for the “1,300 breast cancer deaths avoided” statistic as opposed to “22,000 life years” which was seen as confusing, and indeed was misinterpreted by some jurors at this stage as “lives saved”.

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Some jurors also commented that the figure of 43 (out of the 10,000 women invited to screening) deaths prevented did not seem like a very high figure to them.

### 7.3 Overview of discussions – overdiagnosis

Overdiagnosis was initially, and throughout the course of the Jury, a difficult concept to understand for most jurors. Jurors described the concept from a patient experience perspective and as such focused on the implication for treatment and outcomes. There was some confusion about whether overdiagnosis represented ‘misdiagnosis’, and mistakes made by doctors, as well as early questions about whether in fact it could be more usefully understood as “over treatment”. Jurors grappled with the fact that, in one juror’s words:

> ‘There is overdiagnosis because of screening but screening has obvious benefits.’

Some jurors felt strongly that because the doctors cannot say for certain if a cancer would become invasive, it is best to have the cancer removed and to be treated. Others wanted to know why, when chalky deposits were detected on a mammogram, doctors had to act immediately and why they couldn’t monitor the cancer over time to understand at what rate it was growing in order to decide whether treatment was necessary:

> ‘Why do they have to act so immediately? Is there no window of opportunity when they can say, let’s see what it does in the next 6 months and then decide on treatment?’

There were also worries expressed that raising doubts (about the limitations and ‘risks’ or harms of screening) might discourage women from attending screening. Furthermore, when asked about how information on overdiagnosis should be expressed some jurors expressed the view that it might scare some women, one said “you can throw it [the leaflet] away if it is too much information” and another “if you want more information about overdiagnosis you should be able to ask for it”.

### 7.4 Juror questions

Jurors’ questions tended to focus, as on Day 1, on clarifying personal risk factors. Some had specific questions around overdiagnosis and DCIS.

- **Personal risk factors** – some jurors had continuing questions about the influence of HRT on women’s risk of developing breast cancer, some jurors wanted to know what proportion of women who take HRT go on to develop breast cancer.

- Jurors also started to express that they would value information on the number of women with normal results from screening to put the diagnosis figures into context (and provide them with reassurance).

- **Treatment outcomes** – Some women wanted to know if it was possible to be given the ‘all clear’.

> ‘What about if you have a mastectomy and the affected area is ‘taken out’, are you never actually cured from breast cancer?’

Finding out that doctors do not know how fast and whether a cancer will grow quickly or spread made some of the women question how doctors could predict how long someone was going to live with a cancer.

Some table discussions also revisited the topic of treatment; some jurors wanted to know more about the use of alternative therapies in the treatment of breast cancer and also more about endocrine therapies mentioned.
- **Evidence used in the review** – some jurors had questions about the evidence used in the Marmot Review, asking why it didn’t include any UK studies and what the ethical considerations of randomised control trials are. They also wanted to know whether the breast cancer mortality figures were all made up of women who had died from breast cancer, cancer which had spread to other parts of the body or whether they could have died from related diseases.

- Some jurors had questions about the prevalence of breast cancer before screening was introduced. One juror asked:
  
  *‘Were records of mortality in 1950 as precise as they are now?’*

  And another:

  *‘Do the estimated figures have a built in allowance for advances in treatments?’*

  Jurors felt they wanted to know more about the background to the study and where Professor John Dewar felt the Department of Health and Cancer Research UK wanted the study to go.

- There were also questions of **clarification around statistical concepts**. One juror asked:

  *‘What does frequency mean?’*

- **DCIS** – jurors had continued questions about DCIS and treatment, some jurors wondered why DCIS is treated, especially if it is low grade and “pre-cancerous”. Professor John Dewar responded by explaining that in approximately 20-30 per cent of cases, DCIS will become an invasive cancer.

- **Overdiagnosis** – jurors also had continuing questions about overdiagnosis including, if people are overdiagnosed is there a way to know this and choose to stop treatment? Other questions were focussed on the estimates of over-diagnosis from a population perspective and from a woman’s perspective, jurors wanted to understand what the ‘population perspective’ and the ‘woman’s perspective’ were. One juror had questions about whether the question of over diagnosis connected with the cost effectiveness of the screening programme.

- **Screening schedule** – One juror talked about the scenario where a woman had a negative result and then a month later developed a very aggressive cancer. The jurors noted at one table that some women believed falsely that screening prevents cancer.

- **Investment in the screening programme** - Concerning evidence presented on the Marmot Review recommendations and evaluating cost effectiveness, one juror wanted to know “is investment in the screening programme in question?”

Extended discussions at jurors’ tables’ allowed jurors to consider Professor John Dewar’s presentation in more detail and specifically consider the evidence presented on mortality benefits and potential harms. They responded to the following question: “Thinking about what you have heard so far, what information about the benefits / harms of breast screening would you like to receive when you are invited for breast screening? What makes you say this? And is there anything else you need to find out about in order/ want to be repeated to understand this?”
7.5 Mortality benefits (deaths avoided by) of breast screening

There was emerging strong sense amongst the jury as group, that they recognised and were reassured by the fact that the possibility of having cancer found through screening was small. This was reflected in some jurors’ early emerging recommendation for figures on normal results to be expressed as a benefit of the screening programme.

The jurors on one table asked a woman who had not attended screening, what information she would need to decide to attend screening. This woman said she would need to know there were benefits. Other jurors expressed the benefits in terms of: “early detection”, “preventing your death” and “extended life”. This woman said she would want to know what her chances of not having breast cancer were and of receiving a negative result.

Members of the jury also wanted to include information on the process of breast screening in order to encourage women to attend, i.e., that it wasn’t going to be too painful, that you would be looked after well by a nurse, in order to de-mystify the process and make it seem less scary. One juror said that the leaflet should express:

‘It is a benefit for you to come to the screening but your chances of having breast cancer are small.’

7.6 Potential harms (overdiagnosis) of breast screening

Jurors talked about the need to strike a balance between telling women about the possibility of overdiagnosis and encouraging them to attend screening. One juror was concerned that the information about overdiagnosis could put people off attending, while others were strongly of the view that any leaflet should be transparent - “the more transparency the better”- and upfront about the risk of overdiagnosis. These differing views tended to be determined by individual women’s different information preferences, the ‘realists’ and those preferring limited information and reassurance.

One table thought it needed to be mentioned that over-diagnosis could occur and an estimated figure for how much this was needed to be included, something like: “we recommend treatment, even though your cancer might not grow”.

That there was more than one kind of cancer was very novel information for some. As a result, they felt this information was important to include in the leaflet and as a way to explain overdiagnosis and the harms of breast screening. One woman said: “The thing is you always associate cancer with death, before this I just thought cancer was cancer”. Another said that the leaflet needed to include information that “there are different types of cancer, and not all of them will kill you, some you can live with, all cancers are different”.

7.7 Emerging themes

- **Expressing benefits and harms in numbers and words** – there were emerging messages from this discussion session that the benefits and harms of screening should be explained, with some jurors starting to debate and express preferences for the term “risk” to “harm”. Summary figures and round numbers were preferred because they were easier to understand.

- **Information on the benefits of early detection** – some jurors started to make suggestions that the leaflet include information about how breast screening could lead to early detection of breast cancer, which would mean a woman could have less radical treatment and have better outcomes in terms of treatment. However, one woman felt that
since coming to the jury, she was unclear about whether early detection would lead to less severe treatment. "If possible, I would like to know, that earlier diagnosis leads to less drastic treatment".

7.8 Understanding complex health issues, uncertainty and complex information

On the afternoon of Day 2, jurors listened to presentations from Professor Angela Coulter on communicating complex issues to the public. Options for communicating quantitative information were presented by Professor David Spiegelhalter. The afternoon witness presentations concluded with Roger Felton presenting specific options for communicating the benefits and harms of breast screening in a leaflet. The objective of these witness sessions was for jurors to understand the challenges associated with communicating complex information, including information on breast screening, for jurors to understand the ways in which complex issues can be communicated to the public and to introduce the ways in which the information about the benefits and harms of breast screening could be communicated.

These witness sessions were followed by extended juror table discussions focussed on jurors emerging recommendations about expressing benefits and harms.

Communicating complex health issues

Witness 7: Professor Angela Coulter - Director of Global Initiatives at the Informed Medical Decisions Foundation, Boston, and Senior Research Scientist at the Department of Public Health, University of Oxford.

- Communicating complex health issues.
- Challenges and principles of expressing complex issues to the public.
- Options for communicating benefits of breast screening using words (e.g. communicating absolute risks in screened and unscreened women, absolute risk reductions, numbers needed to screen).
- Options for communicating the concepts of overdiagnosis and DCIS.
- Options for communicating the risk of overdiagnosis using words (e.g. absolute risks, numbers needed to screen).
- Options for communicating uncertainty about the size of benefits and harms (whether it is statistical or because of imperfections in the research data).

Communicating uncertainty and complex information – communicating numbers

Witness 8: Professor David Spiegelhalter - Winton Professor for the Public Understanding of Risk, and Professor of Biostatistics, at the University of Cambridge

- Option for communicating quantitative information about benefits and harms of screening to the public using graphics (including addressing challenge of communicating data that only make sense over time because the benefits only accrue over time, i.e. 200 women have to be screened for 20 years, every 3 years, to save one life by the time they are 80.
- Options for communicating scientific and statistical uncertainty.
Communicating information in the leaflet: look and feel

Witness 9: Roger Felton - Managing Director of Felton Communication Ltd.

- Specific options for communicating the benefits and harms of breast screening, including:
  - Use of colour - how colours and hues should relate to the audience and subject matter.
  - Importance of typography - readability, size, space - related to audience.
  - Alternative formats - look, feel, words per page and practicality.
  - Structure - scan reading and navigation.
  - Image styling - overall illustration styling and content.
  - Breast screening image - show alternative photographs and illustrations of an actual breast screening image.

7.9 Overview of discussion - community complex health issues

The jurors reflected positively that Professor Angela Coulter’s presentation had presented information based on a woman’s individual perspective and many echoed the view that:

    I understood more from her than from anyone else.’

One juror said they felt that this presentation, and the way in which the information about the benefits and risks of breast cancer screening were presented: “addressed every woman’s uniqueness” and felt this presentation acknowledged that “everybody wants different levels of detail and has different attitudes towards the risks and harms”.

At this point, this table of jurors had a discussion about why the figures used in the presentation were the numbers of women ‘invited to screening’ and not those who had attended screening. There was a strong feeling from the table that to understand the outcomes of screening, it was better to have figures for women who attended screening.

Some jurors liked the way Professor Coulter had expressed benefits in terms of:

    Out of 1,000 women invited for breast screening, 17 will die of breast cancer by the time they are 80.
    Out of 1,000 women not invited for breast screening, 21 will die of breast cancer by the time they are 80.

In one juror’s words:

    ‘This seems to be the clearest indicator that there is actually a benefit to be gained. It is clearer to understand than the other ones with numbers. They are worded so awkward sometimes that some people won’t understand it...’

Some jurors did not like the language of “X number fewer will die” which was used as an option to express the benefits in Angela Coulter’s presentation:

    ‘I don’t know why but I find this quite confusing, it’s too complicated. Fewer is a strange word, it doesn’t sound right.’

On probing, the main reasons for disliking “fewer” was because it was not seen as using positive language, it was difficult to understand the meaning of the statement and, in one juror's words it didn’t ‘hit home’ as hard as other statements of benefit.
The women also had a conversation about whether the figures used in the presentation and whether the denominator should be 10,000 or 1,000 in the leaflet. Jurors liked the use of 1,000 in Angela’s presentation as they felt that smaller numbers made concepts easier to understand than facts presented as ‘out of 10,000’.

Some jurors discussed the scales picture in Angela’s presentation. Some of them liked it a lot, as a way of weighing up the pros and cons whilst others said it made it look as though “Your life is in the balance”.

In regards “lives saved” and “deaths prevented” in one juror’s words:

‘You need to mention death to bring home the importance of screening.’

7.10 Juror questions

The questions jurors had focussed on figures and Professor Coulter’s approach to simplifying information.

- **Invited versus attended** - there were some questions about the usefulness of figures based on the number of women invited to screening and the number of women attending screening. Jurors expressed an early preference for figures based on the number of women attending screening as this was meaningful for them from a patient perspective.

- **Figures** - one table asked: if the screening programme is for women aged 50-70, why use figures for women aged 80? Professor Coulter responded by explaining that the benefits of the screening programme in relation to mortality accrue beyond the target age range of the screening programme. And what does this mean for what figures will be used in the leaflet? How will this be explained?

7.11 Overview of discussions - Communicating uncertainty and complex information – communicating numbers

Jurors responded positively to Professor David Spiegelhalter’s presentation, describing the information presented as clear and there were few questions of clarification. In general terms, jurors liked the fact that the numbers presented were out of either 250 or out of 1,000. Many jurors liked the presentation of information under the title: “250 ways things may turn out for you” as this made the information personal and easy to understand. Some liked the way this infographic showed the randomness of outcomes and felt that it depicted that it could be you or could not be you who have treatment for breast cancer. Some other jurors expressed a preference for the words used in the Cancer Research UK infographic (but not the graphics themselves). Some jurors also noted that it was important to stay consistent in the way numbers were used (e.g., 1/10 or 1/100). Some jurors talked about liking icon arrays and the infographics as ways of presenting this information about breast cancer screening. Some jurors preferred words to numbers: “too many numbers gets very confusing”. Jurors liked the comparison – side-by-side in table format – of figures of how many died, were overdiagnosed and what happened to those who attended versus those who didn’t as this brought together the summary figures which many women found useful.

Other jurors expressed a preference for Professor Spiegelhalter’s formulation stating: Each time 1,000 women have a mammography, 959 get the ‘all clear’, 41 are called back, 33 have no cancer, and 8 have cancer. When probed, jurors explained that they liked this expression of benefits because it provided information on benefits which contained figures for women getting a normal result. In one juror's words this:
‘Means they are doing something good… so for me when I get this reading, this is the benefit for me, it is positive. Because the number “959 get the all clear” — it is good news and reassuring, so even if they overdiagnose, it is only 41 that are called back then — only 8 are found to have cancer, so you don’t have to get worried, or agitated before the screening.’

The jury as a group tended not to like the pie chart infographic which “shows the proportion of 250 women invited for screening every three years…” some felt it looked like a breast which “had something wrong with it”.

7.12 Juror questions

There were a few questions from the Jury. One was in relation to the word ‘treatment’ used on one of the graphs — they wanted to know what this referred to. Overall, they felt that the graphics would need more words to help make the information presented clear. One table of jurors asked for examples of existing good practice, Professor Spiegelhalter responded that the process being used to develop the new breast cancer screening leaflet was ‘historic’.

7.13 Overview of discussions - Communicating information in the leaflet: look and feel

The jury were quick to express top of mind preferences for the look and feel of any leaflet in response to the options presented by Roger Felton. In summary these were: that any leaflet should be hand-bag sized, that photos be ‘up-to-date’ and not in black and white and that images used should ensure representation of BME groups.

7.13.1 Juror questions

The group had a limited number of questions about this presentation, one of which was what is the budget for the leaflet?

7.14 Initial discussions on how information about benefits and harms should be expressed.

Following these witness sessions, jurors spent time on their tables discussing how information about benefits and harms should be expressed.

Jurors again expressed a preference for the statement: breast cancer screening prevents 1,300 deaths. They viewed this as a simple, positive way of expressing the benefits and saw this as a big number which would create impact in terms of telling women about the benefits of breast screening:

‘That is quite clear and obviously we know a lot more about the overdiagnosis, but getting women to that first stage [of going to breast screening], it is like ‘oh that is good, that is good to know.’

‘It’s pretty clear, the word ‘prevent’ and 1,300 is a nice big number.’

There were mixed preferences for which denominators were most useful for expressing information about benefits and harms. Some jurors did not like the use of 250 as a denominator, preferring 1,000 as it was a “round number”:

‘I would prefer numbers I understand, I can’t picture millions of people but I can understand 1,000.’
Other jurors preferred the denominator of 250 as this number of women was easy to visualise:

‘We all probably know 250 women.’

‘Even someone who doesn’t have an O-Level can visualise 250 and one life in 250 – we are talking about women, not all highly educated, some are – especially some of the Asian communities…we’re talking about a spectrum of women.’

Some jurors reflected at this point that: “the first time to hear about the harms was today.” During the discussions, the women started talking about whether being overdiagnosed was a ‘harm’. There was a strong feeling among some jurors that they would rather be overdiagnosed than not diagnosed and that having treatment which could be unnecessary was preferable to dying from breast cancer.

Jurors’ working explanations of “overdiagnosis” at the end of Day 2

Jurors were asked to “describe overdiagnosis to a woman on the bus” in order to sense check understanding of the concept. Responses included:

- In some cases, the screening might show something that needs to be further investigated. Need to explain what happens with follow up to screening – may or may not be cancer, could develop into cancer, treatment which may not be needed. This situation is sometimes referred to as overdiagnosis.
- Overdiagnosis is a diagnosis, something has been found, it’s not a ‘faulty’ diagnosis. It might be unimportant and non life-threatening. But it might be important and dangerous. No one can tell. Therefore the choice of action is tricky…you can’t blame anyone, it’s impossible to do the right thing…
- The ‘calcium’ could be cancerous, but it might not hurt you. Might not come out of the duct in your lifetime. If you don’t go to screening, you may live happily without the cancer killing you. Are you happy to live with cancer within you? You decide.
- Overdiagnosis is cancer, it is not an error that they’ve made and it’s up to you to talk to the doctor to find out the best action for you to take but you’ve got to make that decision in the end.
- It’s the detection of cancer after screening which might be – invasive or just DCIS which might need treatment or not need treatment but you will need to talk with your consultant for further information or treatment.
- Means we have found some lump that looks like cancer it may not develop into anything serious or it will develop into something serious...
- After breast screening, we found something which needs investigation and its looks like cancer and after that we found a lump which looks like cancer …it may develop into something serious or it may not develop into anything so you are given the choice to go further.
- Following your breast screening there is a possibility that you could be diagnosed with DCIS which is benign but at the same time you need to seek further advice and support on the way forward.
- As a result of your breast screening the doctor might misinterpret the result in that he confirms you have BC but then to add to the bad news you are then told that there is no way at this point of knowing if you will die so treatment is necessary that may not be
They have found a cancer, but it is of the type that can go one of two ways – the doctor wants you to take the responsibility of the dilemma out of his hands and he will go with whatever your decision is. So that there is no come back on him.

The final session on Day 2 asked jurors to start to consider how mortality benefits, overdiagnosis and uncertainty should be expressed in words, numbers and pictures. A thematic summary of responses is provided below:

- **Understanding need for information on benefits and harms**
  - Most jurors felt that women should be told that they can be overdiagnosed - the message that: “you can have treatment you may not need.”
  - At the same time jurors noted that screening does not provide a guarantee, the message that: “despite screening, we might not find cancer.”
  - Others considered it important to include information that explains that screening alone cannot tell what form of cancer you have.
  - Some also thought that it was important to tell women that cancer can be found between screenings.
  - Others felt it important for women to know what the different results of screening might be, what would require you to come back (recall) and why more tests might need to be done.
  - Some participants started to talk about preferring the language of “risks” to “harms”.

- **Tone** – an emerging recommendation from the jury was around making information in the leaflet not too frightening or off-putting. The group identified the challenges of presenting this information in a concise way in a leaflet because they felt that they had greatly benefited from the conversations they had had in the jury. Some jurors tended to feel that ‘having conversations’ was the best way to convey this kind of information. Some jurors thought it would be useful to have case studies in the leaflet or elsewhere, in the words of one juror:
  ‘Women listen to other women’s views.’

- **Language** – jurors generally liked positive language to express benefits such as ‘prevents’ and they felt this would be helpful to ‘get women through the door’. Some jurors felt that they had been very blasé about breast cancer screening before they attended this event and so it was important to use the right kind of language to encourage women to attend. Another juror (who actively choose not to attend Breast Screening despite a history of breast cancer in her family) said:
  ‘There is not enough information to say how serious breast cancer is.’

- **Myth-busting** – some suggested that there is a need for the leaflets to have a ‘myth busting’ information in – i.e. clear information about the process which cleared up any of the myths which go around abut the process of screening.

There was a one day break for the Jury before they reconvened for a half day consensus building session on Thursday 22nd November.
8. Day 3

8.1 Reaching consensus

The third and final day of the jury focussed on providing time for jurors to examine the words, numbers and graphics presented by the expert witnesses on Days 1 and 2 of the Jury and to reflect on their own notes and thoughts in order to make recommendations.

Specifically, the aim for the final day was to facilitate the Jury – as a group – to make recommendations on:

- How to describe the mortality benefit associated with breast screening using words and the size of the benefit using graphics;
- How to describe the risk of overdiagnosis associated with breast screening using words and graphics;
- The level of detail on overdiagnosis needed for an informed decision;
- Whether ductal carcinoma in situ should be described and the level of detail;
- How to set out the mortality benefit and risk of overdiagnosis against each other in such a way that women can make an informed choice; and
- How to describe the scientific uncertainty around current estimates of mortality benefit and overdiagnosis.

The discussions and consensus recommendation process on the final day was framed in terms of moving from a position of jurors giving their individual views, to the Jury - as a group of informed citizens - making recommendations on how best to express benefits and harms of breast screening in words, numbers and pictures.

At the start of the day jurors were made aware of the ‘listening’ to juror discussions that had already taken place and the fact that they had already expressed some views about the leaflet and its contents, namely:

- The need for key breast cancer statistics on: numbers attending screening, numbers diagnosed number of normal results, risk factors.
- The need for information about the process of screening.
- That too many numbers are off putting, percentages are off putting and figures about ‘life years saved’ were seen as unhelpful in making an informed decision.
- Equalities considerations and cultural sensitivities.
- Tone: seriousness.
- Framing that attending screening is a personal and very individual choice.

Discussions on Day 3 were facilitated through a combination of group discussions on tables, plenary led feedback and discussion sessions and key pad voting to support the consensus building process.

Key pad voting was used as a tool to support consensus building and to check and reflect the range of views on selected issues. The consensus methodology is described below and the areas of consensus and difference for each of the jury’s objectives are presented in the Executive Summary and Recommendations on pages 1 to 6 of this report.
8.2 How to describe the mortality benefit associated with breast screening using words and the size of the benefit using graphics

Jurors were asked to consider: "How do you think the **benefits** of breast screening should be expressed – in words, numbers and graphics - to help women make an informed choice about cancer screening?"

Jurors worked at their tables to consider and agree on examples of ways of expressing benefits which had been presented by expert witnesses on Days 1 and 2. These were provided in paper format under the headings “Background” and “Benefits” and jurors were encouraged to use them as a resource pack which they could use in any way they wished, for example, by cutting and pasting parts together, changing words and amending them.

**8.2.1 Table feedback**

Images from each tables’ selected ways of expressing benefits in words, number and graphics are provided below along with results from key pad voting on the issues of:

- Whether benefits would be best expressed as ‘deaths avoided’ or ‘lives saved’.
- Preferences for pie charts or icon array graphics.

One table liked the statement that ‘of 1000 women who attend breast screening, 5 fewer will die of breast cancer by the time they are 80’ because it focused on women ‘attending’ rather than ‘invited’ to screening. However, they also felt that 5 was too low a number to encourage women to go for screening.
Another table selected the statement “Number needed to screen to prevent one breast cancer death”, the group wanted this number to reflect those attending screening. This was selected alongside summary figures on diagnosis, overdiagnosis and cancer deaths prevented, again with these figures reflecting attendance to screening and also reflecting the number of women with normal results:
A third table selected a statement expressing the 1,300 cancer deaths prevented figure, with an additional focus on ‘early detection’. This group liked the wording used by Cancer Research UK to describe the benefits of screening, but not the diagram which they found confusing.
Figure 6: Blue table benefits in words

Key pad voting was used to understand the Jury’s overall view on whether benefits were best expressed as ‘deaths avoided’ or ‘lives saved’. There was a preference for ‘lives saved’ – see Figure 7 below.
Figure 7: Keypad vote on “deaths avoided” versus “lives saved”

Language

Q8. How do you prefer to express the data?

1. In terms of deaths avoided
2. In terms of lives saved
3. Both
4. Neither
5. Don’t know

Base: 25 jury members

There were different preferences for graphics. However, the jurors expressed opinions about some of the approaches they had seen.

- Pie charts were broadly rejected because they were felt to be not easily understood. Examples of comments illustrate this well: “(these pie charts) are misleading as the bases are different numbers,” and “what is the white bit in the middle?” Jurors wanted the “normal results” figures to be clearly described in words on these graphics.
- Bar chart options were also generally not favoured while further written descriptions to explain what graphics and charts show in words were recommended by some.
- It was notable that no jurors or tables selected any of the line graphs presented by witnesses indicating that these were difficult to understand/not meaningful for the women.

Key pad voting showed a preference for “icon arrays”.

Figure 8: Keypad vote on preferences for pie charts versus icon rays

Graphics – icon array described as people not dots

Q7. Which of these graphics do you prefer?

1. 

2. 

Base: 25 jury members
Some jurors’ spontaneous response to this voting session was to express a preference as a group for the icon array which depicts individuals as outlines of ‘people’ or ‘women’ rather than dots. Jurors felt the dots were “impersonal” – in the words of some that it: “looked like a colour blindness chart”, or “battleships”. So the vote was re-taken on the basis that the dots were instead people.

8.3 How to describe harms: the risk of overdiagnosis associated with breast screening using words and graphics and DCIS

Jurors were asked to consider at their tables and then as a group: “How do you think the overdiagnosis associated with breast screening should be expressed – in words, numbers and graphics - to help women make an informed choice about cancer screening?”

Jurors worked at their tables to consider and agree on examples of ways of expressing benefits which had been presented by expert witnesses on Days 1 and 2. These were provided in paper format under the heading: “Harms”.

8.3.1 Table feedback

Images from each tables’ selected ways of expressing risks in words, number and graphics are provided below along with results from key pad voting on the issues of:

- Whether overdiagnosis is better expressed as overdiagnosis or overtreatment.
- Preferences for the language used to express ‘harms’.

One table selected words describing overdiagnosis as: “detection and treatment of cancers in women in whom the cancer may not have become symptomatic…” editing this to be expressed in terms of “overtreatment” rather than “overdiagnosis” alongside “my risk of being overdiagnosed due to breast screening”.

Classification: restricted external  OPM page 37
This table also like the summary of disadvantages expressed as:

Disadvantages:

- Detects many cancers/DCIS that may never have become a problem in patient’s lifetime (overdiagnosis).
- Impossible to predict which of their cancers will be life-threatening. Therefore, many patients are treated (over-treatment) with physical and psychological consequences.

The table discussed that these statements were important to express together in order to explain the impact on a woman of overdiagnosis/overtreatment.
Many jurors continued to find DCIS difficult to understand. They were given information about DCIS and came to understand it through understanding the difference between non-invasive and invasive cancer. Jurors considered these terms a better way to describe the topic and explain the issues.

Another table talked about what an effective explanation of ‘overdiagnosis’ would be. They liked the definition: “Breast cancer screening detects many cancers/DCIS that may never have become a problem in a patient’s lifetime (over diagnosis)” This table also spoke about the definition which expressed: “overdiagnosis is a difficult concept for both the public and health professionals”. Some of the table liked the definition which was on this slide, others liked it but didn’t agree with the first bullet point about the lack of certainty amongst health professionals.

**Figure 10: Red table: Harms**
Key pad voting was used to understand the Jury’s preferred term to express “overdiagnosis”. As Figure 11 illustrates, the keypad voting resulted in the jurors expressing a preference for the use of the term “overtreatment”.

Figure 11: Keypad vote on “overdiagnosis” or “overtreatment”

<table>
<thead>
<tr>
<th>Graphics</th>
<th>Q2. Which of these words do you prefer?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Overdiagnosis</td>
<td>![4 votes]</td>
</tr>
<tr>
<td>2. Overtreatment</td>
<td>![21 votes]</td>
</tr>
</tbody>
</table>

Base: 25 jury members

There was considerable table debate about the use of the term “harms” over the course of the Jury. Jurors were agreed in their rejection of the term “harms”. One juror expressed the view that harms sounded like it was “inflicted on purpose”. Key pad voting was used to poll the Jury on their language preference around harms, which found preferences split across “risks”, “disadvantages” and “downsides”, as illustrated in Figure 12 below.

Figure 12: Keypad vote on preferences for language around “harms”

<table>
<thead>
<tr>
<th>Leaflet options</th>
<th>Q3. Which of these words do you prefer?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Cons</td>
<td>![1 vote]</td>
</tr>
<tr>
<td>2. Harms</td>
<td>![1 vote]</td>
</tr>
<tr>
<td>3. Minuses</td>
<td>![0 votes]</td>
</tr>
<tr>
<td>4. Risks</td>
<td>![10 votes]</td>
</tr>
<tr>
<td>5. Downsides</td>
<td>![4 votes]</td>
</tr>
<tr>
<td>6. Drawbacks</td>
<td>![1 vote]</td>
</tr>
<tr>
<td>7. Disadvantages</td>
<td>![7 votes]</td>
</tr>
<tr>
<td>8. None of the above</td>
<td>![0 votes]</td>
</tr>
<tr>
<td>9. Don’t know</td>
<td>![1 vote]</td>
</tr>
</tbody>
</table>

Base: 25 jury members
8.4 How to set out benefits and harms alongside each other

Jurors were then asked to consider at their tables then as a group: “How would you hold alongside one another the benefits and harms of breast screening in words, numbers and graphics?” and to: “Imagine you were speaking to a woman on the bus. How would you express the benefits and harms of breast screening together in the same sentence or two?”

8.4.1 Table feedback

The idea of presenting information on both benefits and harms/risks was understood by the jurors as important in the context of being able to make an informed choice; many jurors had a clear and strong preference for presenting benefits and ‘harms’ side-by-side and this was reflected in their selection and presentation of information.

There was some consensus on what to present around benefits and harms but less consensus around the how, especially the use of graphics, suggesting the testing of specific options is still needed. As Figure 13 illustrates below, keypad voting confirmed a spread of views on the best way to set out benefits and risks but also demonstrated the jurors’ tendency to select graphics/tables which present benefits and risks alongside each other.

Figure 13: Keypad vote on preferences for expressing benefits and harms together or separately

<table>
<thead>
<tr>
<th>Language</th>
<th>Keypad vote on preferences for expressing benefits and harms together or separately</th>
</tr>
</thead>
<tbody>
<tr>
<td>Q10. Which do you prefer?</td>
<td></td>
</tr>
<tr>
<td>1. Express benefits and harms separately</td>
<td>4</td>
</tr>
<tr>
<td>2. Express benefits and harms together</td>
<td>8</td>
</tr>
<tr>
<td>3. First express the benefits and harms separately, and then express them together</td>
<td>12</td>
</tr>
<tr>
<td>4. Don’t know</td>
<td>0</td>
</tr>
</tbody>
</table>

Base: 24 jury members

Each table was asked to formulate an agreed statement in response to the question “Imagine you were speaking to a woman on the bus. How would you express the benefits and harms of breast screening together in the same sentence or two?”

These were:

The benefits of going for breast screening is that it saves about 1,300 lives each year in the UK. It is also known that just over 1 per cent of women will experience overtreatment following their diagnosis.
Citizens’ Jury on information for women about breast screening

Breast cancer screening could lead to early detection of a possible life threatening condition, but it might lead to you being diagnosed with a condition that might not have impacted on you in your natural life span if it wasn’t treated.

A third table of jurors preferred to engage in a conversation, rather than condense their thoughts into a single sentence. They felt the conversation should be informative, rather than persuasive, and include:

- Reason to go for breast screening: i.e., that older women are more likely to have breast cancer, screening will determine if you have cancer or not.
- That there is a choice about whether or not to go to screening.
- You should look at the leaflet to find out more about screening, and it will also tell you where to go if you need information.
- Attending screening is not a simple decision; screening is beneficial, but there are risks. You should read about the benefits and risks (pros and cons) when making a decision that’s right for you.
- If you do go and they find you have breast cancer, there are many treatments, so don’t be scared.
- Some jurors felt strongly that women should be told that the benefits outweigh the risks.

There was some agreement across the Jury that the “250 ways things might turn out for you” Figure 14 – presented by Professor Spiegelhalter was a helpful approach, but there was disagreement about which option(s) were best. About half like the icon array that groups the possible outcomes in a single block; the other half of the group preferred the display that emphasised the randomness (women highlighted in pink). All mentioned that these icon arrays were missing the number of women who receive normal results and as mentioned, most preferred the icon arrays using silhouettes of women, rather than dots. In relation to the dot icon array specifically, what the women liked most were the explanatory notes at the top and bottom.

Figure 14: Infographic presented by Professor David Spiegelhalter
There was some disagreement between jurors about the usefulness of the icon array illustrating randomness through highlighted pink silhouettes of women, Figure 15. Some liked the way in which it displayed how ‘random’ the outcomes could be in any given population of 250 women but criticised for others as being confusing. In particular it was felt that the pink fuzzy arrows were not clear enough. One juror pointed out that the statement “1 would have died if not screened” could be misread as “I would have died…” they suggested that “1” is spelt out as “one”.

**Figure 15: Infographic presented by Professor David Spiegelhalter**

Some jurors suggested the leaflet encourage a conversational approach to information provision, something which could be reflected in the tone of the leaflet. They placed importance and value on being able to talk with someone about the benefits and harms or an indication in the leaflet about whom to speak with for more information (pre-screening).

### 8.5 How to describe scientific uncertainty

The jury discussed uncertainty about screening outcomes and medical interventions and also voted on what mattered most; reassurance, accuracy or both.

**Figure 16** shows a majority preference for language and information that both reassures and is accurate:
Figure 16: Keypad vote on preferences for information to “reassure” or accuracy

**Language**

Q16. Which matters most?

1. To reassure: 3 votes
2. To be accurate: 7 votes
3. They are equally important: 15 votes
4. Don’t know: 0 votes

*Base: 25 jury members*

8.6 Discussions about figures presented referring to women ‘attended’ or ‘invited to screening’

There was a debate amongst jurors over whether it would be useful to use statistics based on the number of women invited to screening versus the number of women attending screening. Figure 17 shows the near consensus preference for using attendance figures.

Figure 17: Preferred language to express data

**Language**

Q9. How do you prefer to express the data?

1. In terms of the number of women invited for screening: 0 votes
2. In terms of the number of women attending screening: 23 votes
3. Both: 2 votes
4. Neither: 0 votes
5. Don’t know: 0 votes

*Base: 25 jury members*

Jurors considered ‘attended’ figures as the most ‘accurate’ and meaningful for them in terms of actual women screened, as opposed to the figures of ‘invited to screening.’ Some jurors felt it was also important to collect information on who didn’t turn up and the reasons why this could be.
8.7 Discussion about which denominator to use

Jurors were asked about which denominators which were meaningful for them and keypad voting asked for jurors' individual views on whether the consistency of the denominator was important. Figure 18 describes jurors' preferences.

Figure 18: Keypad vote on preferences for denominators

Q12. What matters most?

1. To use the same denominator throughout the leaflet
   - 17

2. To use the preferred denominator wherever possible, even if this means that it will vary at different points of the leaflet
   - 8

3. Don't know
   - 0

Base: 25 jury members

8.8 Other emerging issues and suggestions from the jury

There were additional discussions around ensuring the accessibility of the leaflet - the outcomes of which are reported in the section on recommendations set out on pages 1 to 6.

Consensus recommendations and areas of disagreement/lack of consensus for each of the jury objectives are presented in the Executive Summary and Recommendations in pages 1 to 6 of this report.
Appendix A: Detailed agenda

Informed Choice about Cancer Screening

Citizens’ Jury on information for women about breast screening

19th, 20th and 22nd November 2012

A review of the benefits and harms of population breast screening, commissioned by Cancer Research UK and the Department of Health, has recently been published (October 2012). The review summarised the size of the effect of breast screening on breast cancer mortality and set out the risk of overdiagnosis. Overdiagnosis refers to cancers detected through screening which would never have caused problems or shortened life, but for which women will be offered treatment.

The review recommended that information about benefits and harms should be made available to women invited for breast screening in a transparent and objective way so that they can make an informed decision about attending.

Informed Choice about Cancer Screening is leading the development of a new invitation letter and leaflet sent to women when they are invited for breast screening, which will include information about both benefits and harms of breast screening.

This Citizens’ Jury will gain women’s perspectives about how to present this information to women being invited to attend screening to enable them to make an informed choice.

The objectives of the Jury are to seek recommendations on how to present information in the leaflet, in particular:

- How to describe the mortality benefit associated with breast screening using words and the size of the benefit using graphics;
- Whether ductal carcinoma in situ should be described and the level of detail.
- The level of detail on overdiagnosis needed for an informed decision.
- How to describe the risk of overdiagnosis associated with breast screening using words and graphics.
- How to set out the mortality benefit and risk of overdiagnosis against each other in such a way that women can make an informed choice.
- How to describe the scientific uncertainty around current estimates of mortality benefit and overdiagnosis.
Agenda

Day 1 – Monday, 19th November

Overall aims for day 1:

- To ensure the jurors understand the aims and objectives of the deliberative citizens’ jury and the intended outcomes
- To ensure the jurors understand the process of the jury
- To ensure that the jurors understand their roles and those of the witnesses, observers and facilitators
- To provide the jurors with sufficient knowledge about breast cancer and breast screening to allow the jurors to make specific recommendations
- To provide jurors with an insight into the decisions women face after a diagnosis of breast cancer and how they made those decisions

<table>
<thead>
<tr>
<th>Timings</th>
<th>Session details</th>
</tr>
</thead>
<tbody>
<tr>
<td>8:00-9:00</td>
<td><strong>OPM venue set up and meet and greet</strong></td>
</tr>
<tr>
<td></td>
<td>OPM to lead:</td>
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<td></td>
<td>- 8:15 OPM facilitator briefing</td>
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<td>- Set-up registration desk (OPM)</td>
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<td></td>
<td>- Final check of power-point, video and audio with Dr Alison Chapple 8:30 (OPM)</td>
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<td>- Final check of interactive voting (OPM)</td>
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<td>- Venue liaison (OPM)</td>
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<td>- Meet and greet participants on street and guide to registration in venue (OPM)</td>
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<td>- Meet and greet witnesses (OPM)</td>
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<td>- MHP to liaise with all journalists</td>
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<td>9:00-9:30</td>
<td><strong>Arrival and coffee</strong></td>
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<td>9:30-9:45</td>
<td><strong>Welcome and introduction to jury / purpose of the day</strong></td>
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<td>9:30 – Independent moderator Joanne Rule introduces:</td>
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<td>- 9:30 to 9:35 - <strong>Professor Amanda Ramirez</strong> (Director, Informed Choice about Cancer Screening) to welcome attendees and explain:</td>
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<td>- Who are ICCS - Why has the work been commissioned and what will it do? (including concept of informed choice and Marmot review)</td>
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<td>- Role as observers for the rest of the event.</td>
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<td>- 9:35 to 9:45 - <strong>Joanne Rule</strong> to explain:</td>
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<td>- Aims and objectives of the jury:</td>
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<td>- Gain women’s perspectives about how to present information about the</td>
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</table>
benefits and harms of screening to women being invited to attend screening, to enable them to make an informed choice

- Central role of jurors: Importance of your opinions, lots of new information, ask lots of questions!

- **Purpose of today:**
  - To allow you to understand the aims and objectives of the citizens’ jury and the intended outcomes
  - To allow you to understand the process of the jury
  - To make sure that you understand your role and those of the witnesses, observers and facilitators
  - To provide you with sufficient knowledge about breast cancer and breast screening to allow you to make specific recommendations
  - To provide you with an insight into the decisions women face after a diagnosis of breast cancer and how they made those decisions

- **Purpose of day 2 (tomorrow):**
  - To help you understand the benefits and harms associated with breast screening
  - To help you understand the different ways that that information about breast screening can be communicated

- **Purpose of day 3 (Thursday):**
  - For you to develop recommendations on how to present information on the benefits and harms of breast screening

- **Roles:** You, Independent moderator – Joanne Rule, OPM / table facilitators,Observers, Witnesses

- **Ground rules:** Respect each other, We’re interested in the range of different views, Everyone has a voice and is listened to

  - So be careful not to interrupt when someone else is talking! And please switch off mobile phones. Ask questions when something is not clear

There are no stupid questions – and you’ll be doing someone else a favour. Respect the timetable, Please come back from breaks on time, We will finish sessions and the day on time

And provide you with the information you need to help you through the day

- **Health and Safety:** toilets / fire exits and alarm

<table>
<thead>
<tr>
<th><strong>09:45 – 10:30</strong></th>
<th><strong>Warm up session: ‘getting people talking’ and understanding baseline views</strong></th>
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<tbody>
<tr>
<td><strong>Session aims:</strong></td>
<td>• To help jurors feel at ease and comfortable working together</td>
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<td>• To generate and address clarification questions about purpose of the jury and/or agenda for the two and a half days</td>
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</table>
| **How the session will work:** seed
9:45 to 10:05 - Facilitated warm-up table discussions (20 mins)
- Get jurors to introduce self: what they do, family, where they live
- Ask for permission to record using table recorders – explain this is so we can capture what is said today and will be used for no other purpose than this. Files will stored securely by OPM and be safely destroyed after 2 years.
- Facilitator to pose two questions to group:
  - Do you have any questions about the Jury and your role?
  - What do you know about breast cancer screening?
  Facilitators to record discussion using paper template on table – each table discussion in the Jury will have a template for facilitators to write down key themes and quotes as well as recording discussions on audio recorders)

10:05 to 10:15 - Plenary question and answers (10 minutes) - Chaired by Joanne Rule
- Jurors and/or facilitators to feed back questions from their tables relating to the purpose / aims of the jury or agenda. Informed Choice about Cancer Screening representatives and Joanne Rule to answer.
- OPM to take notes during plenary
- Facilitator to STOP RECORDING

10:15 to 10:30 Plenary interactive voting (15 mins): To let you know who is in the room
- Joanne Rule to explain how to vote with ppvote keypads

Warm up questions for practice:
- How did you get here today? / Favourite colour?

Questions to capture and reflect back:
- Age (ranges: 47-54, 55-64, 65-73 and over 73)
- Ethnicity (white british, white other, south asian, black caribbean/african, other non-white, Mixed, other, would rather not say)
- Are you: working/not in paid work/retired
- What area of London are you from? (Central, North East, North West, South East, South West)
- Have you been invited to breast screening? (Yes/No/Don’t know)
- Have you attended breast screening? (Yes/No)
- On a scale of 1-10, where 1 is not at all important and 10 is very important, how important are each of these factors when you make a decision about your care and treatment? (one slide for each question)
  - Doing my own research
  - Discussing with family and friends
  - A recommendation from a health professional
  - My family’s medical history
Understanding the potential benefits and risks of different options
• The seriousness of the condition/issue.

ALL – help people to use the voting handset (particularly, older people, disabled people and / or people with sensory impairments)

10:30 – 10:45
Coffee break
Ice-breaker activity for coffee break to help jurors get to know women not on their tables and build sense of group belonging: “Find someone with same hobby as you”.
Jurors in breakout room

10:45 – 1:00
10:45 to 10:50 - Joanne Rule introduces witness session
Witness session 1: Understanding breast cancer
Learning objectives:
• For jurors to understand breast cancer, types and stages, risk factors, treatment and outcomes through witness presentations
• To allow jurors to ask questions and gain clarification from expert witnesses
• For jurors to understand the rationale behind Breast Screening
• To explore jurors initial views on what and how much information about breast cancer should be provided in the invitation to attend screening

How the session will work:
• The session has been split to cover witness evidence on the following topics with time built in for jurors to consider questions in their tables and time for them to put these questions to the witnesses.

Witness presentations
• 10:50 to 11:15 - Understanding Breast Cancer: Professor Malcolm Reed (25 mins)
  What is breast cancer?
  – How common is breast cancer? –epidemiology, including risk factors, and, survival
  – Two main routes to diagnosis (screening and symptomatic presentation)
  – Symptoms of breast cancer – clinical presentation
  – How diagnosed – cover the triple assessment
  – Types of breast cancer
  – Stages of breast cancer (including DCIS) and why this matters, in relation to treatment options and survival

11:15 to 11:30 Facilitated table discussions (15 mins)
• Facilitator to RECORD SESSION
• [If necessary facilitator to draw jurors’ attention to copies of witnesses presentation in their packs – if jurors require information in other formats]
- What was important?
- What was difficult to understand?
- What would you like to know more about?
  - Facilitator to encourage jurors to note questions for clarifications on post-its, and record discussion using template on table.

### 11:30 to 11:40 Plenary – Chaired by Joanne Rule
Each table asks witnesses for clarification based on the questions considered above (10 mins)

- **11:40 to 12:00 - How is breast cancer treated? Understanding treatment and decision-making: Dr Alison Jones – with Professor Malcolm Reed covering surgical management** (20 mins)
  - How is breast cancer treated - introduction by Alison Jones:
  - Malcolm Reed: Overview of surgical treatment of breast cancer (keeping it as simple as possible)
  - Alison Jones: Non-surgical management, adjuvant therapy, neo-adjuvant therapy
  - Management of advanced disease (do not need much detail) – Alison Jones
  - Shared decision-making about breast cancer treatment in particular for DCIS and stage 1 – Alison Jones

### 12:00 to 12:10 - Facilitated table discussions (10 mins)
- **Facilitator to RECORD SESSION**
- Facilitator to draw jurors’ attention to copies of witnesses presentation in their packs, and ask:
  - What was important?
  - What was difficult to understand?
  - What would you like to know more about?
  - Facilitator to encourage jurors to note questions for clarifications on post-its, and record discussion using template on table.

### 12:10 to 12:20 - Plenary – Chaired by Joanne Rule
Each table asks witnesses for clarification on the questions above (10 mins)
- **12:20 to 12:35 - What is the NHS Breast Screening Programme and why has there been a review?** Professor Malcolm Reed (15 mins)
  - Introduce the NHS Breast Screening Programme and its rationale (emphasising early detection not prevention)
  - Benefits and harms of screening (concise information – what these are rather than quantitative information).
  - Why we have had a review of the effectiveness of breast screening
- **12:35 to 12:45 - Facilitated table discussions (10 minutes)**
Facilitator to RECORD SESSION
Facilitator to draw jurors’ attention to copies of witnesses presentation in their packs, and ask:
- What was important?
- What was difficult to understand?
- What would you like to know more about?
Facilitator to encourage jurors to note questions for clarifications on post-its, and record discussion using template on table.

12:45 to 12:55 Plenary – Chaired by Joanne Rule
Each table asks witnesses for clarification on the questions above (10 mins)

12:55 to 1:00 Summary plenary question and answers (5 minutes) – Chaired by Joanne Rule
- Opportunity for summary of key points of clarification provided by witnesses and opportunity for jurors to ask any other questions.
- OPM to take notes during plenary
- Facilitator to STOP RECORDING

1:00 – 1:45 Lunch – For observers and witnesses in Churchill Room and for jurors in Large Common Room
OPM to greet witnesses arriving for the second half of the day

1:45 – 3:15 1:45 to 1:50 Joanne Rule introduces session
Witness session 2: Understanding breast screening
Learning objectives:
- For jurors to understand the process and experience of breast screening
- For jurors to understand overdiagnosis and its implications
- To allow jurors to ask questions and gain clarification from expert witnesses
- To explore jurors’ initial views on what and how much information about breast screening should be provided in the invitation to attend screening

How the session will work
The session has been split to cover witness evidence on the following topics with time built in for jurors to consider questions in their tables and time for them to put these questions to the witnesses.

Witness presentations
- 1:50 to 2:10 - How the breast screening programme works: Patsy Whelehan (20 mins)
  - How the breast screening programme works
  - What is the process of breast screening, starting from invitation, including recall
  - What is the experience of breast screening for women
  - Illustrated patient experience by drawing a map of a woman’s journey
Citizens’ Jury on information for women about breast screening

2:10 to 2:20 - Facilitated table discussions (10 minutes)

- Facilitator to RECORD SESSION
- Facilitator to draw jurors’ attention to copies of witnesses presentation in their packs, and ask:
  - What was important?
  - What was difficult to understand?
  - What would you like to know more about?
- Facilitator to encourage jurors to note questions for clarifications on post-its, and record discussion using template on table.

2:20 to 2:30 - Plenary – Chaired by Joanne Rule

Each table asks witnesses for clarification on the questions above (10 mins)

- 2:30 to 2:55 - Issues related to screening: Dr Mike Michell (25 mins)
  - Problems related to screening - overdiagnosis, DCIS, false positives, false negatives, and psychological distress

2:55 to 3:05 - Facilitated table discussions (10 minutes)

- Facilitator to RECORD SESSION
- Facilitator to draw jurors’ attention to copies of witnesses presentation in their packs, and ask:
  - What was important?
  - What was difficult to understand?
  - What would you like to know more about?
- Facilitator to encourage jurors to note questions for clarifications on post-its, and record discussion using template on table.

3:05 to 3:15 - Plenary – Chaired by Joanne Rule

Each table asks witnesses for clarification on the questions above and any other questions

3:15 to 3:30 Coffee break – Lead facilitator leads an ‘energiser’ if necessary jurors in breakout room

3:30 to 4:40 3:30 to 3:35 Joanne Rule to introduce session

Session 3: Understanding patient experiences

Learning objectives:

- For jurors to hear about different patient experiences of breast cancer and breast screening and its management
- For jurors to understand how patients have made decisions about attending breast screening and breast cancer treatment options after diagnosis

How the session will work:

- Jurors have heard about breast cancer and breast cancer screening from
The aim of this session is to hear about women’s experience of breast screening, different outcomes and different views about the information available.

Some of the information may be new or upsetting. For some jurors this may be the first time they have heard about DCIS or overdiagnosis, some may have family or friends who have experienced this – participants may react to the information in different ways. Point out that a representative from Breast Cancer Care will be on hand to support any jurors who need to take some time away from the discussions.

3:35 to 3:45 Plenary Dr Alison Chapple presents healthtalkonline videos

3:45 to 4:15 Videos - Topics broadly cover: “positive” experience, reassuring, false positive, fear of screening, painful experience of mammogram, right not to know, overdiagnosis and not happy with information, diagnosis, DCIS and decision making

4:15 to 4:40- Table discussion: Jurors will spend time considering each example. Facilitators explore with their tables:
- Listening to these experiences, what information about screening would have been helpful for these women beforehand or during the process?
  Probe: for “positive” experience, reassuring, false positive, fear of screening, painful experience of mammogram, right not to know, overdiagnosis and not happy with information, diagnosis, DCIS and decision-making

Facilitators note: This session needs to be facilitated very sensitively. For some jurors this may be the first time they have heard about DCIS or overdiagnosis, some may have family or friends who have experienced this – participants may react to the information in different ways, become upset or angry. A representative will be on hand to support any jurors who need to take some time away from the discussions.

4:40 – 4:55

4:40 to 4:55 Joanne Rule leads summary of day

Summary review of information heard on Day 1

Session aims:
- To explore jurors’ initial priorities for what information should be provided in the invitation to attend screening

Joanne Rule to facilitate in plenary

Thinking about what you have heard so far, what information about breast cancer and breast screening is important for you?
- What information would you like to receive when you are invited for breast screening?
- What makes you say that?
- Probe if necessary about different subjects of information:
  - Explaining why there is a Breast Screening Programme
  - Types and stages of breast cancer
  - DCIS + overdiagnosis.
  - What else?
<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
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<tbody>
<tr>
<td>4:55 to 5:00pm</td>
<td><strong>Thanks and close</strong>&lt;br&gt;&lt;li&gt;Joanne Rule to:&lt;br&gt;- Remind jurors about next day and provide brief overview of the agenda&lt;br&gt;- Tell jurors that they are welcome to talk to their family and friends about what they have heard today&lt;br&gt;- Thank participants for their contributions and enthusiasm&lt;br&gt;<strong>Facilitators</strong> to distribute thank you payment of £75 in exchange for voting handset. Explain that the rest of payment will be provided on Thursday.</td>
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<tr>
<td>5:00pm</td>
<td><strong>Informed Choice about Cancer Screening/OPM Debriefing session</strong>&lt;br&gt;What do we need to take note of for tomorrow’s session?&lt;br&gt;What have we learnt?&lt;br&gt;Reflect on whether to mix tables for Day 2</td>
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Day 2 – Tuesday, 20th November

Overall aims for day 2:

- To revisit and clarify issues as agreed in debriefing session that have been raised in the first day of the jury
- To help jurors understand the findings of the Marmot review: benefits (especially mortality including scientific uncertainty) and harms (especially overdiagnosis including scientific uncertainty) associated with breast screening
- To help jurors understand the different ways that information about breast screening can be communicated, including the challenges associated with this
- To identify jurors’ preferences for communicating information about the mortality benefits and overdiagnosis and scientific uncertainty associated with these

<table>
<thead>
<tr>
<th>Timings</th>
<th>Session details</th>
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<tr>
<td>8:30-9:30</td>
<td><strong>OPM venue set up and meet and greet</strong></td>
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<td>- 8:45 OPM facilitator briefing</td>
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<td>- Set-up registration desk (OPM)</td>
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<td>- Final check of power-point (OPM)</td>
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<td>- MHP to liaise with all journalists</td>
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<td>9:30-10:00</td>
<td>Arrival and coffee</td>
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<td>10:00-10:10</td>
<td><strong>10:00 to 10:02 - Welcome back and review of objectives</strong></td>
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<td>• Joanne Rule to:</td>
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<td>- Recap of yesterday’s agenda</td>
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<td>- Key information priorities identified by jurors yesterday</td>
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<td>- Provide overview of agenda for the day</td>
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<td>- Revisit principles for taking part today: no right or wrong answers; please respect the views of others even if they hold an opinion different to your own, don’t be afraid to ask questions; interested in everyone’s views, etc</td>
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<td>- Remind jurors of their central role: Importance of their opinions; will be learning a lot of new and quite complicated information and should ask lots of questions</td>
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<td>- Other practicalities: Toilets / fire exits and alarm</td>
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<td><strong>Plenary: introduce R4 Today programme audio clip from 30th October - runs 8 minutes 10:02 to 10:08</strong></td>
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<td>10:10-11:30</td>
<td><strong>10:10 to 10:15 Joanne Rule introduces witness session</strong></td>
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<td><strong>Witness session 4: Understanding the evidence from the Marmot review: Professor John Dewar</strong></td>
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**Learning objectives:**

- For jurors to understand the potential benefits and harms of breast screening, **over time** as presented by the Marmot review (especially mortality and overdiagnosis)
- For jurors to understand the uncertainty around estimates of benefits and harms of breast screening, as presented by the Marmot review
- To introduce jurors to the importance of communicating the mortality benefits and overdiagnosis risks of screening in a way that promote informed choice
- To allow jurors to ask questions and gain clarification from expert witnesses
- To identify jurors’ initial priorities for information for how information sent to women invited to attend breast screening should be presented

**How the session will work:**

The session has been split to cover witness evidence on the following topics with time built in for jurors to consider questions in their tables and time for them to put these questions to the witness.

- **Professor John Dewar** to present the findings from the Marmot review in discrete chunks and explain why it was conducted, with time built in for jurors question and answers

**10:15 to 10:45** **Professor John Dewar - Part 1: About the review and the mortality benefits (deaths avoided) of breast screening (30 mins)**

- About the Marmot Review – the purpose, scope, the types and range of evidence the panel looked at
- The evidence reviewed about the benefits of screening and what the panel concluded. Suggest important to emphasise the time taken for a woman to accrue the benefits.

**10:45 to 10:50 - Rapid facilitated table discussions (5 mins)**

- Facilitator to RECORD SESSION
- Facilitator to ask:
  - What was important?
  - What was difficult to understand?
  - What would you like to know more about?
Facilitator to encourage jurors to note questions for clarification on post-its, and record discussion using template on table.

**10:50 to 11:00 - Plenary – Chaired by Joanne Rule**

Each table asks witnesses for clarification on the questions above (10 mins)

**11:00 to 11:15** **Professor John Dewar - Part 2: Overdiagnosis (15 mins)**

**11:15 to 11:20 - Rapid facilitated table discussions (5 mins)**
- Facilitator to RECORD SESSION
- Facilitator to ask:
  - What was important?
  - What was difficult to understand?
  - What would you like to know more about?
- Facilitator to encourage jurors to note questions for clarification on post-its, and record discussion using template on table.

**11:20 to 11:30 - Plenary – Chaired by Joanne Rule**
Each table asks witnesses for clarification on the questions above (10 mins) **INTRODUCE Q&A RESPONSES**

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<thead>
<tr>
<th>Time</th>
<th>Activity</th>
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<tbody>
<tr>
<td>11:30 to 11:45</td>
<td>Tea and Coffee break – staggered with jurors in breakout room</td>
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<tr>
<td>11:45 to 12:10</td>
<td><strong>11:45 to 12:00 Professor John Dewar - Part 3: Summarising the main conclusions of the Review (15 mins)</strong></td>
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<td><strong>12:00 to 12:05 - Rapid facilitated table discussions (5 mins)</strong></td>
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<td></td>
<td>- Facilitator to RECORD SESSION</td>
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<td>- Facilitator to draw jurors attention to copies of witnesses presentation in their packs, and ask:</td>
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<tr>
<td></td>
<td>- What was important?</td>
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<td>- What would you like to know more about?</td>
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<td>- Facilitator to encourage jurors to note questions for clarifications on post-its, and record discussion using template on table.</td>
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<td><strong>12:05 to 12:15 - Plenary – Chaired by Joanne Rule</strong></td>
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<td>Each table asks witnesses for clarification on the questions above (10 mins)</td>
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<td>12:10 – 1:00pm</td>
<td><strong>12:10 to 12:20 Joanne Rule introduces session</strong></td>
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<td><strong>Facilitated table discussion to consider Marmot evidence</strong></td>
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<td>Joanne Rule to introduce in-depth table discussion sessions to consider Marmot evidence presented and discussed in last session in more detail and building on information heard on Day 1 (jurors can refer to handouts of Day 1 presentations and table discussion summaries on pin boards if necessary)</td>
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<td><strong>12:20 to 12:35 - Mortality benefits (deaths avoided by) of breast screening (15 mins)</strong></td>
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<td>Considering information from Day 1 on breast cancer and breast screening and information from Professor Dewar on mortality benefits of breast screening, tables consider in detail:</td>
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<tr>
<td></td>
<td>- Thinking about what you have heard so far, what information about</td>
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</table>
the benefits of breast screening would you like to receive when you are invited for breast screening? What makes you say this?
  – Is there anything else you need to find out about in order/ want to be repeated to understand this?

- Facilitator to encourage jurors to note questions for clarification on post-its, and record discussion using template on table.

12:35 to 12:50 – Potential harms (overdiagnosis) of breast screening (15 mins)
Considering information from Day 1 on breast cancer and breast screening and information from Professor Dewar on potential harms (especially overdiagnosis) of breast screening, tables consider in detail
  – Thinking about what you have heard so far, what information about the harms of breast screening would you like to receive when you are invited for breast screening? What makes you say that?
  – Is there anything else you need to find out about in order/ want to be repeated to understand this?

- Facilitator to encourage jurors to note questions for clarification on post-its, and record discussion using template on table.

12:50 to 1:00 - Joanne Rule to facilitate: All jury plenary session final Q&A with Professor Dewar and table feedback
  - Invite headline feedback from tables
  - Is there anything else you need to find out about in order/ want to be repeated?
  - OPM to take notes during plenary (Zoe Khor)

1:00-1:45
Lunch – For observers and witnesses in Churchill Room and for jurors in Small Common Room
OPM to greet witnesses/observers arriving for the second half of the day

1:45 – 3:30
1:45 to 1:50 - Joanne Rule to introduce witness session and concept of informed choice
Witness session 5: Communicating the benefits and harms of breast screening
Learning objectives:
- For jurors to understand the challenges associated with communicating complex information, including communicating information on breast screening
- For jurors to understand the ways in which complex issues can be communicated to the public
- To introduce ways in which information about the benefits and harms of breast screening can be communicated – both verbally and pictorially
### How this session will work:

**Witness presentations**

- **1:50 to 2:10 – Professor Angela Coulter on communicating complex health issues**
  - Challenges and principles of expressing complex issues to the public
  - Options for communicating benefits of breast screening using words (e.g. communicating absolute risks in screened and unscreened women, absolute risk reductions, numbers needed to screen)
  - Options for communicating the concepts of overdiagnosis and DCIS
  - Options for communicating the risk of overdiagnosis using words (e.g. absolute risks, numbers needed to screen)
  - Options for communicating uncertainty about the size of benefits and harms (whether it is statistical or because of imperfections in the research data)

- **2:10 to 2:15 - Quick facilitated table discussions (5 minutes) – (dependent on how interactive witness presentation is - may not be required)**
  - Facilitator to RECORD SESSION
  - Facilitator to draw jurors’ attention to copies of witnesses presentation in their packs, and ask:
    - What was important?
    - What was difficult to understand?
    - What would you like to know more about?
  - Facilitator to encourage jurors to note questions for clarification on post-its, and record discussion using template on table.

- **2:15 to 2:20 - Plenary – Chaired by Joanne Rule**
  Each table asks witnesses for clarification on the questions above (5 mins)

- **2:20 to 2:45 - Professor David Spiegelhalter on communicating uncertainty and complex information – Communicating numbers (25 minutes)**
  - Option for communicating quantitative information about benefits and harms of screening to the public using graphics (including addressing challenge of communicating data that only make sense over time benefits only accrue over time, i.e. 200 women have to be screened for 20 years, every 3 years to save one life by the time they are 80.
  - Options for communicating scientific and statistical uncertainty

- **2:45 to 2:50 - Quick facilitated table discussions (5 minutes) – (dependent on how interactive witness presentation is - may not be required)**
  - Facilitator to RECORD SESSION
  - Facilitator to draw jurors’ attention to copies of witnesses presentations
<table>
<thead>
<tr>
<th>Time</th>
<th>Activity</th>
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<tbody>
<tr>
<td>2:50 to 2:55</td>
<td>Plenary – Chaired by Joanne Rule</td>
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<tr>
<td></td>
<td>Each table asks witnesses for clarification on the questions above (5 mins)</td>
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<td></td>
<td><strong>2:55 to 3:10 - Roger Felton on communicating look and feel (15 minutes)</strong></td>
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<td></td>
<td>– Specific options for communicating the benefits and harms of breast screening, including:</td>
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<tr>
<td></td>
<td>Use of colour - how colours and hues should relate to the audience and subject matter</td>
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<tr>
<td></td>
<td>Importance of typography - readability, size, space - related to audience</td>
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<tr>
<td></td>
<td>Alternative formats - look, feel, words per page and practicality</td>
</tr>
<tr>
<td></td>
<td>Structure - scan reading and navigation</td>
</tr>
<tr>
<td></td>
<td>Image styling - overall illustration styling and content</td>
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<td></td>
<td>Breast screening image - show alternative photographs and illustrations of an actual breast screen</td>
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<tr>
<td>3:10 to 3:15</td>
<td>Quick facilitated table discussions (5 minutes) – (dependent on how interactive witness presentation is - may not be required)</td>
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<td></td>
<td>Facilitator to RECORD SESSION</td>
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<td></td>
<td>Facilitator to draw jurors attention to copies of witnesses’ presentation in their packs, and ask:</td>
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<tr>
<td></td>
<td>- What was important?</td>
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<td></td>
<td>- What was difficult to understand?</td>
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<td></td>
<td>- What would you like to know more about?</td>
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<td></td>
<td>Facilitator to encourage jurors to note questions for clarifications on post-its, and record discussion using template on table.</td>
</tr>
<tr>
<td>3:15 to 3:20</td>
<td>Plenary – Chaired by Joanne Rule</td>
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<td></td>
<td>Each table asks Roger for clarification on the questions above (5 mins)</td>
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<tr>
<td>3:30 to 3:45</td>
<td>Tea and Coffee break – staggered with jurors in breakout room</td>
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<tr>
<td>3:45 to 4:50</td>
<td><strong>3:45 to 3:50 - Joanne Rule introduces session and concept of informed choice.</strong></td>
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</tbody>
</table>
Session aims:

- To give jurors the space to reflect on witness sessions and discuss the different ways in which the benefits and harms of breast screening can be expressed.
- To allow jurors to understand the different ways that the benefits and harms of breast screening can be expressed.

How this session will work:

3:50 to 4:20 - Facilitated table discussions: mortality benefits (deaths avoided by) of breast screening – how do you think the mortality benefits of breast screening should be expressed in words, numbers and pictures? (30 minutes)

- Facilitator to RECORD SESSION

Discussion 1: How should information about benefits be expressed in words and numbers? (15 mins)

- Facilitator to draw jurors’ attention to previous speaker presentations expressing benefits in words and numbers.
  - Breast screening prevents about 1,300 breast cancer deaths per year
  - Women invited for breast screening have a 20 per cent reduced chance of dying from breast cancer compared with what it would be without a screening programme.
  - For every 10,000 women aged 50 invited to screening for the next 20 years 43 breast cancer deaths (0.43%) would be prevented
- Facilitator to emphasise that people may have differing views and that we are interested in all views.
- Facilitator to pose the following questions for discussion:
  - What information do you think women would like to see included in the leaflet? What makes you say that?
  - What information do you think women would most like to see included? What makes you say that? What is most important?
  - Given that not all information can be included in a leaflet where should people be able to get more detailed information?
  - Is there any information that you think should not be included? What makes you say this?

Discussion 2: How should information about benefits be presented in pictures? (15 mins)

- Facilitator to draw jurors’ attention to previous speaker presentations on the different ways in which benefits can be illustrated:
  - Bar charts
  - Crowd icon array
  - Army icon array
  - Images / pictures
Citizens’ Jury on information for women about breast screening

Facilitator to emphasise that people may have differing views and that we are interested in all views.

Facilitator to pose the following questions for discussion:

- Which of these illustrations/images do you find most helpful in communicating the benefits associated with screening? What makes you say this?
- Are there any that you particularly did not like? What makes you say this?

4:20 to 4:50 - Facilitated table discussions: overdiagnosis associated with breast screening – how do you think the harms of breast screening should be expressed? (30 minutes)

Discussion 1: How should information about overdiagnosis be expressed in words and numbers? (15 minutes)

Facilitator to draw jurors' attention to previous speaker presentations expressing overdiagnosis in words and numbers.

- About 4000 women are overdiagnosed through breast screening every year
- 19 per cent of breast cancers diagnosed in women aged 50 to 70 invited for screening would not have caused any problem if left undiagnosed and untreated.
- For every 10,000 women aged 50 invited to screening for the next 20 years 129 cases of breast cancer, invasive and non-invasive would be overdiagnosed.

Facilitator to emphasise that people may have differing views and that we are interested in all views.

Facilitator to pose the following questions for discussion:

- What did you understand by the term over-diagnosis as you’ve heard it used so far?
- How would you describe what is meant by overdiagnosis to another woman?
- What information do you think women would like to see included in the leaflet? What makes you say that?
- What information do you think women would most like to see included? What makes you say that? What is most important?
- Given that not all information can be included in a leaflet where should people be able to get more detailed information?
- Is there any information that you think should not be included? What makes you say this?

Discussion 2: How should overdiagnosis be presented in pictures? (15 minutes)

Facilitator to draw jurors’ attention to previous speaker presentations on the different ways in which benefits can be illustrated:
Citizens’ Jury on information for women about breast screening

<table>
<thead>
<tr>
<th>4:50 – 5:00pm</th>
<th>Thanks and close</th>
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<tbody>
<tr>
<td></td>
<td>Joanne Rule to:</td>
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<td></td>
<td>– Remind jurors about Thursday and provide brief overview of the agenda and how important it is</td>
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<td>– Tell jurors they are welcome to talk to their family and friends about what they have heard today</td>
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<td></td>
<td>– Ask jurors to submit any final points of clarification to witnesses (OPM to follow these up on Wednesday)</td>
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<td>– Thank jurors for their contributions and enthusiasm</td>
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**Wednesday 20th November:** OPM work to summarise what jurors have heard previously: witness presentations, ppvoting and participant discussions and key questions – for presentation at the start of Day 3, follow up with jurors any outstanding clarification questions.

**Day 3 (half day) – Thursday, 22nd November**

Overall aims for day 3:

To develop recommendations on how to present information on:

- how to describe the concept of reduced mortality using words and the size of the benefit using graphics
- whether ductal carcinoma in situ should be described and the level of detail
- the level of detail on overdiagnosis needed for an informed decision
- how to describe the risk of overdiagnosis associated with breast screening using words and graphics
- how to set out the mortality benefit and risk of overdiagnosis against each other in such a way that women can make an informed choice
- how to describe the scientific uncertainty around current estimates of mortality benefit and overdiagnosis

- Bar charts
- Crowd icon array
- Army icon array
- Images / pictures

Facilitator to emphasise that people may have differing views and that we are interested in all views.

Facilitator to pose the following questions for discussion:

- Which of these illustrations/images do you find most helpful in communicating the benefits associated with screening? What makes you say this?
- Are there any that you particularly did not like? What makes you say this?
<table>
<thead>
<tr>
<th>Timings</th>
<th>Session details</th>
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<tbody>
<tr>
<td>8:00 – 8:45</td>
<td><strong>OPM venue set up</strong></td>
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<td>- 8:15 OPM facilitator briefing</td>
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<td>- Set-up registration desk (OPM)</td>
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<td>- Final check of power-point and interactive voting (OPM)</td>
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<td>- Meet and greet witnesses (OPM)</td>
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<td>- MHP to liaise with all journalists</td>
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<tr>
<td>8:45 – 9:15</td>
<td>Arrival and coffee</td>
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<td>9:15 – 9:30</td>
<td><strong>9:15 to 9:30 Joanne Rule: Reviewing information provided</strong></td>
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<td><strong>Consensus building objectives:</strong></td>
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<td>- Recap on key concepts useful for final day: benefits, harms, overdiagnosis.</td>
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<td>- Move jurors from individuals to group of citizens making recommendations on how best to express benefits and harms of benefits of breast screening in words, numbers and pictures.</td>
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<td></td>
<td><strong>How this session will work – Joanne Rule:</strong></td>
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<td></td>
<td>- Introduces the purpose of the final day.</td>
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<td>- Concept of moving to consensus view on recommendations</td>
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<td><strong>Joanne Rule</strong> to reflect that ICCS are working on how to express issues around psychological impact, breast screening process, and pain in the leaflet separately, that are not the focus of the jurors recommendations today.</td>
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<td></td>
<td>Joanne also reflects back listening that has been done already around:</td>
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<tr>
<td></td>
<td>- Key breast cancer statistics need to be included on: numbers attending screening, numbers diagnosed, number of normal results, risk factors</td>
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<td></td>
<td>- Screening process information</td>
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<td></td>
<td>- Numbers: too many numbers are off putting, percentages are off putting and acknowledge that life years saved figures are unhelpful in making an informed decision</td>
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<td>- Equalities considerations and cultural sensitivities</td>
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<td>- Tone: seriousness</td>
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<td>- Framing that attending screening is a personal and very individual choice</td>
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<td><strong>Lead facilitator:</strong> Calls for any questions or clarifications from jurors.</td>
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<tr>
<td>9:30 – 10:45</td>
<td><strong>9:30 to 9:35 Joanne Rule introduces table discussion and activity session</strong></td>
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### Objectives:
Allows jurors to think and visualise information in terms of the leaflet.

Using evidence heard from the previous two days on benefits and harms and overdiagnosis in words, numbers and pictures tables work with stimulus materials to start to ‘mock up’ how they – as a group – would like to see information on benefits and harms expressed in the leaflet.

How do we best express the benefits and harms of breast screening?

#### 9:35 to 9.55 Table discussion 1
- How do you think the **benefits** of breast screening should be expressed – in words, numbers and graphics - to help women make an informed choice about cancer screening?

#### 9:55 to 10:10 Tables feedback and explore in the room via Lead facilitator

#### 10:10 to 10:30 Table discussion 2
- How do you think the **overdiagnosis** associated with breast screening should be expressed – in words, numbers and graphics - to help women make an informed choice about cancer screening?

#### 10:30 to 10.45 Tables feedback and explore in the room via Lead facilitator

### 10:45-11:00 Coffee break – can also be flexible according to discussions - jurors in breakout room

### 11:00 – 12:55

11:00 to 11:05 - Joanne Rule introduces session

We are now moving into the stage of exploring whether or not we can reach consensus by beginning to hold benefits and harms against each other as if in a set of scales.

**Plenary:** How would you hold alongside one another the benefits and harms of breast screening in words, numbers and graphics?

11:05 to 11:25 **Tables discuss** this question and work together with their resources to set out how they would do this on an A2 sheet using the resource materials provided in session 1 and in the light of having listened to each other in the before break plenary.

11:25 to 11:35 **In plenary - tables** present their A2 sheets in plenary and these are displayed

11:35 to 11:40 **Plenary:** Joanne Rule introduces session.

Imagine you were speaking to a woman on the bus. How would you express the benefits and harms of breast screening together in the same sentence or two?

11:40 to 12 noon. **Tables work to draft** a sentence or two that they broadly agree on and write it out on a flipchart sheet

12.00 to 12:05 **In plenary - tables** present their statements which are then displayed.
12:05 to 12:55 – Plenary consensus building led by Joanne Rule:

Lead Facilitator explores areas of agreement and disagreement and the extent to which the above sentence or two can become a consensus statement; and the extent to which consensus can be reached about graphics based on work before and after coffee.

Lead Facilitator then explores key tensions which have either emerged on the day or which remain unresolved. To cover:

- Preference between different types of graphics for benefits and harms (pie charts/icon arrays/other)
- Whether benefits and harms should be shown separately or included in one infographic
- Preference on how to describe reduced mortality specifically in terms of ‘lives saved’ or ‘deaths avoided/prevented’
- Preference basing proportions who experience benefits and harms on denominators of those who attended or those invited to screening

12:55 to 1:00pm

Next steps, thanks and close

- **Professor Amanda Ramirez** (Informed Choice about Cancer Screening) to:
  - Thank jurors for contribution
  - Reflect on recommendations produced
  - Explain how recommendations will feed into leaflet design – including timescales for design
  - Explain how jurors can keep in touch with Informed Choice about Cancer Screening
  - Explain when and how jurors can access the report from the citizen’s jury to be produced by OPM

- **Joanne Rule** to:
  - Invite jurors to complete evaluation forms
  - Thank jurors for their contributions and enthusiasm
  - Thank you payments in exchange for voting handset

1:00pm

Lunch served for all in Churchill Room
Appendix B: Expert witness biographies

Monday, 19 November
Witness Session 1: Understanding Breast Cancer

Professor Malcolm Reed - Professor of Surgical Oncology and Head of the Department of Oncology, University of Sheffield

Professor Reed is the Foundation Professor of Surgical Oncology at The University of Sheffield having being appointed in 1999. He is a practicing surgeon with a major interest in breast cancer and soft tissue sarcoma.

He is currently head of the Department of Oncology at the University of Sheffield, a member of the Government Advisory Committee on Breast Cancer Screening a Member of the Audit Committee, Association of Breast Surgeons and was President of the British Association of Surgical Oncologists (2007 – 2009). Professor Reed has a long-standing research interest in breast cancer including studies in tumour micro-environment and genomic instability. He is an investigator in a number of large national clinical trials in breast cancer. Over the past 10 years, Professor Reed has received funding from CRUK, YCR, NIHR and a number of other sources.

Dr Alison Jones - Consultant Medical Oncologist and Senior Lecturer at the Royal Free and University Hospitals London

Appointed in 1993 as a Consultant, Alison initially treated a wide range of tumours including breast cancer, lymphoma and lung cancer but over the last 10 years has specialised in breast cancer. She has been active in clinical trials from Phase I to Phase III and served on steering committees and data monitoring committees for several trials. She has been a member of Cancer Research U.K. Trials Advisory Committee (CTAAC), was Vice Chair of the committee for 5 years. She is Immediate Past Chair of the Association of Cancer Physicians and has chaired the Joint Council of Clinical Oncology UK.

She has further researched interests in issues of survivorship, pregnancy and fertility in young women and pharmacogenomics of anthracycline induced cardiotoxicity in breast cancer survivors. She also is interested in the introduction of new treatments into practice and is a member of the London Cancer Drugs Group with respect to this.

Monday, 19 November
Witness Session 2: Understanding Breast Screening

Patsy Whelehan - Senior Research Radiographer (Breast imaging), Division of Cancer Research, Medical Research Institute, University of Dundee

Patsy Whelehan qualified as a diagnostic radiographer from Westminster Hospital School of Radiography in 1987. In 1997 she moved to Addenbrooke’s Hospital in Cambridge to specialise in mammography. Having completed her postgraduate mammography qualification through the Jarvis breast screening training centre and Kingston University, she continued her studies alongside her clinical work and gained a qualification in mammography image interpretation, followed by a master’s degree in radiography in 2003. In 2004 she moved to King’s College Hospital in London to lead the national breast screening training centre there. During this time she was involved in design and delivery of academic and clinical mammography training and assessment. She later became the superintendent
radiographer in addition to the training role, and took on the part-time post of regional quality assurance radiographer for breast screening in London.

Patsy has lectured extensively to radiographers and other health care professionals on various aspects of mammography and breast imaging, in the UK and overseas. She has also spoken to women's groups about breast awareness. She has undertaken quality assessment visits in Germany for the European Reference Organisation for Quality Assured Breast Screening and Diagnostic Services (EUREF). She is currently a member of the Department of Health Advisory Committee for Breast Cancer Screening and of the NHS Breast Screening Programme's radiography quality assurance group, and is a trustee of Symposium Mammographicum, a charity supporting breast imaging education.

Patsy has a longstanding interest in research and since 2009 has been fortunate to hold a post at the Medical Research Institute within the University of Dundee, where she is a co-investigator and project manager for clinical research projects in breast imaging. Her own main research interest is in understanding women's experiences of mammography and how to improve them through advances in radiographic practice.

Dr Mike Michell - Consultant Radiologist, King’s College Hospital, Director, South East London Breast Screening Programme and King’s National Breast Screening Training Centre.

Michael Michell has been Consultant Radiologist at King’s College Hospital NHS Foundation Trust since 1986, and has been the Director of the South East London Breast Screening Programme and National Breast Screening Training Centre since 1998.

He is a national expert in all aspects of screening and diagnosis of breast disease and leads a team of seven Consultant Radiologists who are responsible for screening and further assessment for over 50,000 women per annum.

He has successfully incorporated new technology such as image guided vacuum biopsy techniques and digital breast tomosynthesis into routine practice. Educational courses for both technicians and specialist clinical breast radiologists are run at King’s to national quality assurance standards.

Michael Michell has served on the Department of Health Advisory Committee on Breast Cancer Screening, as Lead Radiologist for the London Breast Screening Quality Assurance Reference Centre, the Higher Risk Screening Working Group, and currently serves on the Department of Health Improving Outcomes a Strategy for Cancer Committee. He continues to promote and develop Breast Radiology through research and education.

Monday, 19 November

Witness Session 3: Understanding Patient Experiences

Dr Alison Chapple, Medical Sociologist, Department of Primary Care Health Sciences, University of Oxford

Alison Chapple is a medical sociologist. She was an undergraduate at The London School of Economics, obtained an MA in Health Research at Lancaster University, and completed a PhD at the University of Manchester. Since joining the Department of Primary Care Health Sciences at the University of Oxford in 2000, Alison has been part of the Health Experiences Research Group, which conducts the research for the award winning website Healthtalkonline (www.healthtalkonline.org), which is run by the DIPEx Charity. Alison has conducted interviews with people for various sections of the website, including sections on prostate cancer, testicular cancer, lung cancer, pancreatic cancer, the PSA test for prostate
cancer, screening for bowel cancer, bereavement due to suicide and bereavement due to traumatic death. She is now interviewing people who are living with a long term urinary catheter. She has published articles in academic journals on all of these subjects.

Tuesday, 20 November

Witness Session 4: Understanding the Evidence from the Marmot Review

Professor John Dewar - Consultant Clinical Oncologist and Honorary Professor at Ninewells Hospital

Professor John Dewar worked as a Consultant Clinical Oncologist and Honorary Professor at Ninewells Hospital and Medical School for 25 years, until his retirement from clinical work earlier this year. His main clinical interests have been the management of patients with breast cancer and, in particular, clinical trials. The latter have been concerned with both radiotherapy (START, TARGIT) and systemic therapy (ATTom, TACT, Scottish chemo-endocrine, POETIC etc.) and he has been Chair of the Scottish Breast Cancer Trials Group. He has been concerned with audit of treatment and guideline development, and he chaired the first group on the management of breast cancer for the Scottish Intercollegiate Guidelines Network (SIGN). More recently he has also served on the expert group, set up by Professor Sir Michael Richards to review breast screening in England.

Tuesday, 20 November

Witness Session 5: Communicating the Benefits and Harms of Breast Screening

Professor Angela Coulter - Director of Global Initiatives at the Informed Medical Decisions Foundation, Boston, and Senior Research Scientist at the Department of Public Health, University of Oxford.

Angela Coulter is a health policy analyst and researcher who specialises in patient and public involvement in healthcare. She is Director of Global Initiatives at the Informed Medical Decisions Foundation, Boston, and Senior Research Scientist at the Department of Public Health, University of Oxford.

A social scientist by training, Angela has a doctorate in health services research from the University of London. From 2000 to 2008 she was Chief Executive of Picker Institute Europe. Previous roles included Director of Policy and Development at the King’s Fund, and Director of the Health Services Research Unit at the University of Oxford. She is a Senior Visiting Fellow at the King’s Fund in London, holds Honorary Fellowships at the UK Faculty of Public Health and the Royal College of General Practitioners and is a Trustee of National Voices.

Angela has published more than 250 research papers and reports and several books including The Autonomous Patient, The European Patient of the Future (with Helen Magee), winner of the Baxter prize, The Global Challenge of Healthcare Rationing (with Chris Ham) and Hospital Referrals (with Martin Roland). She was the founding editor of Health Expectations, an international peer-reviewed journal on patient and public involvement in health care and health policy. Her latest book, Engaging Patients in Healthcare, was published by Open University Press in August 2011 and was highly commended in the latest BMA awards. In January the Donabedian Foundation at Barcelona University awarded her the 2012 Donabedian International Award in healthcare quality for her work on patient-centred care.
Professor David Spiegelhalter - Winton Professor for the Public Understanding of Risk, and Professor of Biostatistics, at the University of Cambridge

David Spiegelhalter is Winton Professor for the Public Understanding of Risk, and Professor of Biostatistics, at the University of Cambridge. His background is in medical statistics, particularly the use of Bayesian methods in clinical trials, health technology assessment and drug safety. He led the statistical team in the Bristol Royal Infirmary Inquiry and also gave evidence to the Shipman Inquiry.

In his post he leads a small team (UnderstandingUncertainty.org) which attempts to improve the way in which the quantitative aspects of risk and uncertainty are discussed in society. He works closely with the Millennium Mathematics Project in trying to bring risk and uncertainty into education. He gives many presentations to schools and others, advises organisations and government agencies on risk communication, and is a regular columnist on current risk issues. He presented the BBC4 documentary 'Tails you Win: the Science of Chance", and in 2011 competed in Winter Wipeout.

He was elected FRS in 2005 and awarded an OBE in 2006 for services to medical statistics.

Roger Felton - Managing Director of Felton Communication Ltd.

Roger graduated from art college in London in 1982 with a BA Hons in Graphic Design. He joined Saatchi & Saatchi Advertising and worked in the creative department until 1989, when he started his own agency. For the past 23 years, Felton Communication has worked on all forms of creative communications from branding to advertising and brochures to websites from all manner of clients across both the private and public sectors.

Over the last decade the agency has focussed on the not-for-profit sector and worked with organisations including the Women's Sport and Fitness Foundation, Living Street's Walk to School, Lambeth and Southwark Housing and Terrence Higgins Trust. The agency has won numerous design effectiveness and creative awards as well as a BMA Patient Information Award every year since 2003.