

## **Inside View Moderator Notes**

### **Background**

This DVD is a recording of a live performance which was funded by the Wellcome Trust to stimulate and inform debate about prenatal screening during early pregnancy. It aims to raise questions about some of the social, ethical and cultural issues and to allow them to be explored from the perspectives of both health professional and pregnant women.

The performance draws on the findings of a research project on the Social Implications of Prenatal Genetic Screening. This was funded by the ESRC within the Innovative Health Technologies Programme (L21825042). This project collected questionnaires from several hundred women in two different locations both before and after birth. It also carried out interviews with women during pregnancy and after childbirth. It recorded consultations within two maternity clinic sites and interviewed the staff working there. The project provided a wealth of rich narrative data, from health professionals, women and their partners about prenatal screening, which was used to develop this performance.

The moderator notes and suggested further discussion material in this pack arises from the questions raised during the development of this performance and discussions which took place following each of the live performances. It is not intended to be exhaustive, but to indicate areas that could be developed into discussion.

## **Synopsis**

The performance follows Sandra Dee's journey through a one-stop shop prenatal screening clinic. It begins with Sandra's joyful discovery that she is pregnant, before switching to see her in her kitchen about to leave for the clinic. She is busy trying to drink sufficient fluids to have the full bladder required by the clinic. Her mug is described as lopsided, but it is the imperfections that make it her favourite. She hears the voice of her Grandmother describing how control is not always a good thing. The next scene is in Sandra's car on route to the clinic, she is listening to a radio programme celebrating the wonders of medicine today and its drive to eliminate adverse illnesses.

When Sandra arrives at the clinic she appears uncertain about how to proceed, and has to follow a map to get through the booking visit. She first has a booking visit in which the screening tests are described to her. Although the information is being given, it is clear that she is not really taking it all in, and she is confused about the processes involved. She does not have time to discuss the many issues. Back in the waiting area she tries to come to terms with the implications of screening. Next she moves to the phlebotomy room and meets Felicity the phlebotomist who tries to reassure her about the process, and distracts her whilst taking the bloods. The blood is then sent to the lab, and a mini lecture describes the testing process that it is undergoing. Back in the waiting area, Sandra meets another pregnant woman. This woman (Woman 2) represents pregnancy as a set of consumer choices in which pregnant women and their partners can select the perfect baby. Sandra's Grandmother's voice counteracts with the view that choice can be problematic. Sandra is then called into the scanning room and meets the Sonographer. For Sandra, like most pregnant women, the scan is where the pregnancy become 'real', the visual image of the foetus confirming that her baby exists. The Sonographer outlines the dilemma of scanning. Whilst women are often busy building connections to their baby, their role is to screen for possible problems. Sonographers may diagnose something problematic, but they are not the professionals who can discuss this in depth with the women.

Following the results of the scan and blood test, the Midwife Counsellor explains to Sandra that she is at higher risk of having a baby with Down's Syndrome. This is obviously devastating news. Sandra is upset, confused and having difficulty taking the information in. She is offered CVS (a diagnostic test which can give definite results), but this carries a chance of miscarriage. If she takes up the offer of CVS, and she is carrying a Down's Syndrome baby, she could then decide whether or not to have a termination. Finally we see Sandra back at home. She hears the radio discussing the problems of raising a child with a disability but also her Grandmother's point of view pointing out that in the past women just loved and accepted the baby they gave birth to. She reflects on what is an anomaly, the problems you cannot screen for and the agony of having to decide. The performance ends without knowing her decision.

## **Characters**

Sandra Dee

Sandra's Grandmother

Felicity the phlebotomist

Woman 2 (yellow jacket)

Sonographer

Midwife Counsellor

## **Using the material**

The pack has been designed to be used after the performance has been seen in its entirety, but for some groups, it might be appropriate to raise some questions before viewing.

The pack introduces six areas for discussion with an outline of some of the points raised by the performance and some starter questions for discussion. The themes are overlapping so the divisions put forward here may not suit all groups. There are six themes with relevant questions for discussion that link to the performance. These are the nature of choice, scanning and screening, what is an anomaly, understanding risks, clinic experiences, and new health technologies, In addition, the performance can be used to address ethical issues, communication in the clinical setting, and the organisation, resourcing and structure of the clinic.

There are also other areas themes and questions and moderators are encouraged to see this pack as a starting point rather than a definitive guide to using the performance.

## The nature of choice

In today's health service, patients are increasingly asked to make complex decisions based on the information provided by health professionals. The performance raises many issues about the nature of choice in pregnancy.

Woman 2 strongly believes that choice is her right. She has accepted all the screening and diagnostic tests as she believes that the information they will give her will enable her to choose better. This would include choosing to undergo termination if her foetus was found to have a disability.

Sandra's Grandmother shows how that in the past women had fewer choices, but in some ways this made their lives easier. They did not have to agonise over making the right decision. Pregnant women today have to make many decisions; they have lost the right not to choose.

Sandra is grateful that maternity care today gives her the opportunity to see her developing foetus, and that it has improved the chances for babies to survive. However, at the end of the performance, Sandra is left having to choose between further testing which carries a risk of miscarriage against continuing with a pregnancy unsure of if the developing foetus has an anomaly. If she opts for further testing, and the diagnosis is confirmed then she will have to choose between continuing the pregnancy or having a termination. Sandra is bewildered at having to make such a critical decision. Women and their partners have different views concerning what is thought of as serious enough to warrant a termination shaped by their previous life experience. There is a lack of clarity and consensus and much diversity.

1. What do you understand by the term 'informed choice'?
2. To what extent is having choices in prenatal screening beneficial?

3. How can health professionals optimise the information-giving part of their role in the antenatal clinic whilst working with limited time available for each woman?

### Scanning and Screening

Ultra-sound scanning has become a routine part of pregnancy care, although different areas do vary in the number and timing of scans they do. In general, women and their partners welcome the chance to see their developing foetus and the visual confirmation of pregnancy, which often comes before the baby is felt moving, is seen by most as making the pregnancy 'real'. Health professionals often have concerns that women only see this social side of scanning, and rarely consider how the scan is primarily a screening tool to provide development checks on the foetus. Research has shown that women do understand that scanning is screening, but prefer not to think about the more positive side.

In the performance, Sandra is desperate to see her baby, and resents not being able to see the screen properly to begin with. When she does see the developing foetus, this does finally confirm the pregnancy for her and develops the connections she feels towards the foetus. However having made this connection, the high risk result of the scan means that it makes the need for her to make decisions about the possible future of the pregnancy harder. Also, as the performance makes clear existing screening programmes are limited so they can rule out certain anomalies but can never guarantee the health of the developing foetus.

1. Why is seeing the image of the foetus so important in confirming the pregnancy?
2. Women emphasise scanning and health professionals emphasise screening, do you think that each side fully understands the position of the other?

3. Do you think it is harder for women to make decisions which might affect the future of the pregnancy following a scan. If so, what if anything, could be done to help.

### What is an anomaly?

The performance concentrates on the screening test for Down's syndrome, but it raises wider questions about the nature of anomalies and disabilities. Sandra is told that she has a higher risk of having a baby with Down's syndrome. She is offered further diagnostic testing to get confirmation, but this carries a risk of miscarriage. If Down's syndrome was confirmed, she would then be offered a termination. Down's syndrome is a varied condition and while some people with Down's syndrome grow up and live independently, others are more severely affected. The extent of ability or disability of a foetus with Down's syndrome cannot be fully assessed in the womb.

Woman 2 believes that screening exists to prevent the birth of babies with disabilities. She wants and expects a perfect baby, and feels that disabilities are no longer necessary or acceptable. The radio programme at the end suggests that a child with Down's syndrome can only be understood as a burden on their parents and a significant cost to society.

In thinking about her choices, Sandra thinks about the nature of difference and disabilities. She thinks about how some things are valued because they are different, her favourite mug is handmade and contain imperfections, but this makes it individual. She considers how some anomalies, such as having very small or large feet, are not considered so significant that they are viewed as abnormal or a disability. She thinks about the other things that could happen, for example, that there are no screening tests for the risks of becoming a serial killer. Sandra wonders how it is decided what is and is not 'normal', or indeed if 'normal' is possible in world of different individuals.

1. What type and level of difference/disability should be considered as problematic?



2. Does testing for disabilities imply that people with disabilities are less valued and births should be prevented if possible?

## Understanding Risks

Screening tests produce a risk assessment which can be presented either as a ratio (1 in 250) or as a percentage (2%). We know from research that understanding risk in pregnancy is a very complex matter, and influenced by many factors. These include personal circumstances, experiences of others known to us and moral beliefs. In some cases, the presentation of the numbers can make people feel differently. For example, some people might feel that a 1:100 is a high risk, yet if they were told that it was 99% certain things would be OK then they would see this differently.

In the performance, Sandra is given two different risk assessments. First, she is told her risk of Down's syndrome is 1:280 and as such she is deemed to be at higher risk. This higher is arrived at through a combination of her age, the nuchal translucency measurement taken from the ultrasound scan and the results of the maternal blood test which measured certain hormones (free  $\beta$ -hCG and PAPP-A). Sandra is also told that if she wants to find out for certain then she can choose to undergo Chorionic villus sampling (CVS) which carries a 1:100 risk of miscarriage. In this particular scenario, the risk of miscarriage is higher than the risk of Down's syndrome. In addition, if she declines the diagnostic test, she will continue the pregnancy knowing that she is at higher risk.

1. What factors do you think someone in this position would need to consider?
2. How easy do you think it is for most people to weigh up the different risk assessments?
3. What do you think it would be like to continue with a pregnancy knowing your foetus has been deemed at higher risk for a condition such as Down's syndrome, but not actually knowing for sure?

## Clinic Experiences

Maternity appointments within the UK health service are often quite short given the large amount of medical history and routine examinations that they are trying to cover. Much of the information is given out in leaflets as midwives rarely have time to explain everything in person.

In the performance, Sandra's first booking visit to the hospital includes seeing a midwife for a full medical history, routine blood tests, ultrasound scan, and then a session to get the results of the tests. Although she has read the leaflets, it is clear that she does not always fully understand everything, nor does she always feel able to ask questions. Although the screening tests are optional, they are presented as part of the normal routine. Although Sandra is told that the tests are screening for anomalies, the results still come as a shock. She is given some time to decide what to do, but it is also clear that the length of time she has to make her decision in is quite short.

1. Do you think Sandra's experience of maternity services as rushed and slightly confusing is a common one?
2. To what extent do you think people understand that the tests offered are optional?
3. Do you think people should think about the different possibilities before they attended the clinic?
4. If you did think about the possibility of being given a higher risk result beforehand, to what extent do you think you would be able to successfully guess how you would feel, and what decision you would take?

## New Health Technologies

Medical technologies such as ultrasound scanning which were originally developed to help with difficult maternity cases can become routinised and offered to all pregnant women. Often this is beneficial, for example, by detecting a potential problem in an otherwise normal pregnancy leading to a better outcome for both mother and foetus. However, sometimes the problematic issues, particularly if they involve ethical decisions are not fully thought out until after the technology is in place. Moreover, screening or testing for anomaly may mean that other things are discovered which women did not really know that they were being tested for. Sometimes the technologies are introduced without sufficient attention into how the new service will impact on pregnant women and their partners or how the test and any results can be properly explained.

In the performance, Sandra attends a one-stop-shop for maternity booking and screening, so the screening tests and results are given in the same appointment. This technology produces the results much faster and earlier in pregnancy which means that Sandra could choose CVS rather than amniocentesis, and if she elected to go for termination, the procedure is easier the earlier it is carried out. However, getting the results so soon means that Sandra has less time to think about the issues as she only becomes aware of the full implications of the screening during her appointment.

1. What advantages and disadvantages can you think of in having the development of faster, early and more comprehensive screening during pregnancy?
2. What issues should be considered before screening technologies are:
  - i. Developed
  - ii. Introduced
3. Should there be limits on the conditions we try and detect during pregnancy and for what reason?

### **Additional references from the ESRC research study**

Williams, C. Sandall, J. Lewando Hundt, G. Grellier, R. Heyman, B, Spencer, K. (2005) 'Women as 'moral pioneers'?: experiences of first trimester nuchal translucency screening', **Social Science and Medicine**, 61: 1983-92.

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Lewando Hundt G. et al 2006. Navigating the troubled waters of prenatal testing decisions pp. 25-39 in **New Technologies in Health Care: Challenge, Change and Innovation** Ed. A. J.Webster Palgrave Basingstoke

### **Additional general references**

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