

ADVISORY COMMITTEE ON CERVICAL SCREENING (ACCS)

**Extraordinary Meeting to re-examine current policy on
cervical screening for women aged 20-24 years taking
account of any new evidence and to make recommendations
to the National Cancer Director and Ministers**

**1pm to 5pm, Tuesday 19th May 2009, Department of Health, Room LG26/27,
Wellington House, 133-155 Waterloo Road, London SE1 8UG**

MINUTES

Present

Members

Professor Henry Kitchener (Chair)
Dr Joan Austoker (Researcher, University of Oxford)
Ms Frankie Brown (Royal College of Nursing)
Dr Laurence Brown (Royal College of Pathologists)
Mr Geoffrey Curran (Institute of Biomedical Sciences)
Dr Karin Denton (Royal College of Pathologists)
Ms Kay Ellis (National Association of Cytologists)
Dr Shaun Firth (BMA General Practice Committee)
Dr Surenda Kumar (BMA General Practice Committee)
Mrs Moira Morris (Lay member)
Dr Catti Moss (Royal College of General Practitioners)
Dr Sue Moss (Researcher, Institute of Cancer Research)
Professor Peter Sasieni (Biostatistician and Epidemiologist, Wolfson Institute)
Dr Peter Smith (British Society for Clinical Cytology)
Dr Christopher Sonnex (Royal College of Physicians)
Mrs Susan Vryenhoef (National Association of Cytologists)
Dr Jane Woyka (Royal College of General Practitioners)

NHS Cancer Screening Programmes

Professor Julietta Patnick (Director)
Mr Richard Winder (Deputy Director)

National Screening Committee

Dr Anne Mackie (Director)

Department of Health

Mrs Jane Allberry (Cancer Policy Team)
Mr Matthew Capper (Cancer Policy Team)
Mr Tim Elliott (Cancer Policy Team)
Dr Kevin Smith (Screening and Specialised Services Team)
Dr Ursula Wells (Research and Development)

Observers

Dr Margaret Boyle (Northern Ireland)
Dr Hilary Fielder (Wales)
Mr Tony O'Brien (Republic of Ireland)

Invited Guests

Ms Rachel Bennett (Patient, Jo's Trust)
Professor Jack Cuzick (John Snow Professor of Epidemiology, Wolfson Institute)
Dr Rosie Loftus (GP, Macmillan Cancer Support)
Mr Robert Music (Director, Jo's Trust)
Dr Siobhan Quenby (Obstetrician, Liverpool Women's NHS Foundation Trust)
Dr Angela Raffle (Consultant in Public Health, Bristol)
Dr Steven Reid (GP, Lytham St Annes)
Professor Mike Richards (National Cancer Director)
Ms Di Riley (National Cancer Intelligence Network)
Ms Tessa Shewan (Patient, Jo's Trust)
Mr Patrick Walker (Gynaecologist, Royal Free Hospital)
Ms Sarah Woolnough (Cancer Research UK)

Apologies

Ms Melissa Crowley (Patient, Jo's Trust)
Ms Paula Lloyd (National Cancer Action Team)
Ms Margaret Middleton (Institute of Biomedical Sciences)
Mr Mahmood Shafi (Royal College of Obstetricians and Gynaecologists)

1. Welcome and introductions
 - 1.1 Professor Kitchener welcomed everybody to the meeting, and attendees introduced themselves.
 - 1.2 Professor Kitchener reiterated the objective of the meeting – to re-examine current policy on cervical screening for women aged 20-24 years taking account of any new evidence and to make recommendations to the National Cancer Director and Ministers. He stated that the NHS Cervical Screening Programme was recognised and respected internationally. Its success was based on high coverage, policy based on evidence and quality assurance.
2. Background – Professor Mike Richards, National Cancer Director
 - 2.1 Professor Richards said that England had a very successful screening programme that was saving thousands of lives. The decision of the ACCS to clarify the age of starting screening at age 25 in 2003 was based on the best available scientific evidence, which was later confirmed by recommendations by the International Agency for Research on Cancer (IARC), part of the World Health Organisation.
 - 2.2 Recent publicity surrounding the death of Jade Goody from cervical cancer, and campaigns to lower the screening age by Jo's Trust and the family of Claire Walker, a 23 year-old from County Durham who died of cervical cancer, led to questions of whether this was still the right policy. There was also Parliamentary interest. Ministers therefore decided that the policy should be formally reviewed, taking into account any new evidence.
 - 2.3 Following the meeting, the ACCS would make recommendations to ministers, who would make the final decision on the policy.
 - 2.4 Professor Kitchener asked attendees to show discretion regarding the outcomes of the meeting until ministers had made their decision.

3. Epidemiological data (National Cancer Intelligence Network)
- 3.1 Ms Riley presented data on trends in the incidence of cervical cancer in England and the non-English UK countries between 1995 and 2006, and acknowledged the help of Cancer Research UK and the Trent Cancer Registry in putting the data together. Ms Riley also presented data on premature births at less than 36 weeks gestation.
- 3.2 Ms Riley concluded that there was no clear evidence of an increase in the incidence of cervical cancer following the change to the screening age limit in England in 2004. Further work could be undertaken in linking screening cases with registry cases and Hospital Episode Statistics (HES) to explore further. Ms Riley acknowledged that the data only went up to 2006, and said 2007 data would be available in August 2009.
4. Evidence for and against screening in women aged 20 to 24
- 4.1 Professor Sasieni gave a presentation based on his paper *Effectiveness of screening in young women*, which had been previously circulated. He summarised the presentation as follows:
- Cervical cancer was rare in young women
 - There was no evidence that screening worked in women age 20-24 because women who developed cervical cancer under the age of 25 were as likely to have been screened as unscreened
 - The data suggested that there was very low progression potential in young women
 - There was considerable harm (and cost) of screening aged 20-24
 - No sufficiently robust new evidence had been published since June 2003
 - Current evidence suggested that the harms of screening women aged under 25 outweigh the benefits
- 4.2 Responding to a query about the Swedish study (Andrae et al 2008), Professor Sasieni said that due to the definitions use in the study, screen-detected cancers were unlikely to have been counted as screened.
- 4.3 Dr Raffle questioned whether screening in the under 25s was really in the best interests of young women.
- 4.4 Dr Fielder said that saying there was no evidence that screening worked in women aged under 25 was very bold, and said Wales had similar data to the Swedish data. Professor Sasieni responded that confidence levels around the level of protection were between 0% and 65% for the Welsh data. Professor Sasieni also said that the evidence could be interpreted as being not strong enough for Wales to change its policy of screening at age 20 years but also not strong enough for England to change its policy of screening at 25 years.
- 4.5 Professor Sasieni said that there appeared to be no evidence that the change in policy had led to lower coverage in the age group 25-29 years. Dr Fielder said that the coverage in this age group seemed to be falling more rapidly in England than in Wales since 2004.
- 4.6 Dr Sue Moss asked about selection bias, and could this differ between age groups. Professor Sasieni said that those at the highest risk of cervical cancer were the least likely to be screened.

- 4.7 Mr Music gave a presentation on the case for screening at age 20, which had been circulated prior to the meeting. Mr Music's main points in his presentation were:
- Jo's Trust wants women in England to be afforded the same level of protection as the rest of the UK
 - There was concern at anecdotal evidence of an increase in cancers/younger cancers- did we want to risk the potential for a ticking time bomb?
 - The risk of pre-term labour was based on association and not causation and did not account for what stage or week in pregnancy early delivery took place. Women would rather have a baby at, say, 36 weeks gestation than not be able to have babies at all. Women could make their own decisions about treatment/risks after they are screened – rather than denied screening – about informed consent. Screening did not cause harm
 - Many young women over 25 are undergoing radical treatment for cervical cancer that could have been avoided if the abnormalities had been detected earlier, when minor/less invasive treatment would have been effective
 - There was a cohort of women aged 18-25 who were unprotected by either screening or vaccination, and we needed to bridge that gap for a time limited period
 - The ongoing reduction in the age of sexual debut in England had led to earlier transmission of HPV, resulting in a need to reduce the screening age to counter this
 - This was an opportunity to improve the health of young women in England
 - There was enormous public support for the age to be reduced with over 200,000 signatures on recent petitions and a Harris survey in Metro highlighting that 91% of women in England wanted the age reduced
- 4.8 Ms Bennett read out a statement summarising her experience of discovering she had developed cervical cancer aged 21. The statement is at Annex A.
- 4.9 Dr Reid spoke, having submitted a submission to the review which had been circulated earlier. Dr Reid said he was concerned about screening starting at age 25, and the focus should be on the incidence of cancer in those aged 25 to 29 as a result. Dr Reid questioned whether CIN3 was any less aggressive in women aged under 25. Ostor and Melnikov had shown progression from CIN3 to invasive disease in 12% and 25% of cases respectively.
- 4.10 Professor Kitchener said a case series from Dr Susan Davidson, Consultant Clinical Oncologist at Christie Hospital, between 2001-02 to 2008-09, had 19 cases in women aged 25 or under. Seven had occurred despite previously screened (six within the previous three years) and four were screen detected. There had been six cases with diagnostic delays of greater than four months, five by GPs and one by hospital gynaecologists.
- 4.11 Dr Reid said his data from Blackpool showed 6 cases of cervical cancer in the age band 25-29 in the 12 months April 2008-09 compared with no cases in that age band in the 12 months April 2007-08, and anticipated this would become a trend as a consequence of the 20-24 age band not being screened since 2004. If CIN3 were less aggressive in women aged under 25, would an ethics committee ever agree to research being undertaken, as Green et al had done in New Zealand? Dr Reid finished his talk with a paradox – what

was the difference between a woman aged 24 years and 11 months and a woman aged 25 years and 1 month?

- 4.12 Professor Sasieni commented that cervical screening was not an appropriate course of action for a woman presenting with symptoms. Probably half of women under 25 with cervical cancer had symptoms, whilst the other half were screen detected.
- 4.13 Dr Quenby spoke about premature births, saying that they were increasing and were the most common reason for babies to die or be born severely disabled. There was no evidence that treatment for cervical incompetence could prevent premature births. Professor Sasieni had shown in his presentation that there was one premature birth for every 275 women screened. Dr Quenby said that in her clinic she saw women on a weekly basis who had a premature birth associated with Large Loop Excision of the Transformation Zone (LLETZ). Premature birth voluntary sector organisations were very concerned about this. Inequalities were also increased as women from deprived groups were more likely to have a pre-term delivery. The review needed to take a wider view.
- 4.14 Mr Walker said that there was a cohort of treated women at risk of pre-term delivery, but most were not. The first time treatment success rate for CIN was about 85% with up to 15% of women requiring a second treatment in the next six to ten years. If the age range of screening was lowered again for the 20-24 year age group there would be a risk of second treatment before the age of first pregnancy, which was now 32. This age was higher than previously, and therefore the issue of second treatments needed to be considered. Multiple treatments were a high risk for pre-term deliveries. Treatment failure was more common in younger women with large lesions.
- 4.15 Mr Walker also expressed concern at the 62 day waiting time standard for treatment, which led to more “see and treat” episodes at colposcopy. Professor Kitchener said that this should not have the undesirable effect of inappropriate treatments. Professor Richards was very clear that the 62 day standard was for women who were fit and ready for treatment, and gynaecologists could choose to delay treatment where appropriate.
- 4.16 Dr Kumar said that symptomatic patients were totally different from screening in a presumably healthy population. He suggested that earlier sexual activity may have some significance in early cervical cancers.

5. The impact of recent publicity on the awareness of cervical cancer and uptake of cervical screening

- 5.1 Professor Patnick gave her presentation, which had been circulated previously. Her presentation was summarised as follows:
- Samples received in laboratories had increased slightly at the time of Jade Goody’s diagnosis of cervical cancer in August 2008, but increased two-fold in the weeks leading up to her death in March 2009
 - Hits on NHS Cancer Screening Programme’s website, Jo’s Trust website and NHS Choices had increased dramatically in March 2009, but there were signs that activity had started falling by April 2009
 - A Populus opinion poll undertaken on 30th March 2009 showed that: 45% of women thought cervical cancer was the second most common cancer after breast cancer; 33% of women aged over 35 claimed never to have

received information about cervical screening from the NHS; 30% of women could not name a symptom of cervical cancer; the four most common reasons for non-attendance at screening were: pain, forgetting to go, embarrassment and lack of time

- Cervical screening coverage had been falling in each age cohort, with the youngest cohort, those born 1970-74, the least likely to be screened
- The Improvement Foundation were undertaking work on the analysis of the causes of poor uptake in the 25-34 age group across six sites. This work included systems and processes, barriers to uptake, and awareness and promotion of the service. The project analysis period had been extended by 6 months to avoid the spring 2009 period when publicity was at its highest. Comparison areas would be sought

6. Impact of vaccination against HPV 16/18 on cancer incidence and abnormalities in women aged 20-24 in England

6.1 Professor Cuzick gave a presentation based on his paper *Impact of vaccination against HPV 16/18 on cancer incidence and abnormalities in women aged 20-24 in England*, which had been previously circulated. He summarised the presentation as follows:

- HPV 16/18 was relatively more common in lesions in young women
- Full benefit to age 30 of vaccination would take 16 years – all ages would take much longer, 50% benefit around 2016
- Catch up – minimal effect on cancers in women under 30 years of age
- Positive Predictive Value (PPV) for CIN2+ of screening would be reduced in vaccinated women by approximately 2.5 fold
- Registry was essential to tailor screening to vaccination

7. Discussion

7.1 To begin the discussion, Professor Kitchener summarised the issues raised so far:

- Benefits versus harms
- Delays in primary care for referring women presenting with symptoms
- Poor awareness by women of the value of cervical screening
- The reasons women did not accept their invitations to be screened
- Promising progress with the HPV vaccine programme. The high uptake of the HPV vaccine in the school based programme should reduce the incidence of CIN 3 by at least 50%

7.2 Dr Brown commented on Professor Sasieni's epidemiological paper, saying that although CIN3 did not progress in all cases, all CIN3 would be excised. Professor Kitchener agreed, saying we did not know which CIN3 would progress. CIN2 was also treated. Professor Cuzick said in countries where there was no screening, the cancer rate was never as high as the CIN3 rate in this country might predict. Dr Raffle explained that epidemiological evidence showed a major gap between point prevalence and cumulative incidence. This was recognised in the 1970s by Archie Cochrane and George Knox, and the only possible explanation was that the majority of CIN regressed. Pathologists tended not to be familiar with the population data so tended to assume that progression was the norm. Professor Sasieni said it was not possible to model cervical cancer rates without allowing the rate of progression from CIN3 to vary across age groups.

7.3 Professor Kitchener raised the issue of the delay in diagnosis in women with symptoms. Were GPs not examining women? Irregular bleeding was

common, but was a cardinal symptom of cervical cancer. Dr Catti Moss said that if women presented to primary care with irregular bleeding, they were first tested for chlamydia and other infections. Dr Denton clarified that cytology was not a useful test in women with symptoms, and the issue of cytology screening for under 25s had no bearing whatsoever on the diagnosis and management for symptomatic women.

- 7.4 Dr Catti Moss raised the scenario of a 23 year-old woman who said she wanted to be screened, and the GP thought she may be at high risk. Dr Catti Moss did not agree that screening should start from age 20 for all, but what about women wanting to be screened voluntarily? If refused, she may never attend screening again. We should do as little harm as possible, but we were dealing with real people.
- 7.5 Dr Denton said that in Bristol they had worked very hard with primary care colleagues to ensure they were well informed. This was difficult, but it was a question of education. Courses were available nationwide but not well attended. A cervical screening test was absolutely pointless in symptomatic women and risked providing false reassurance.
- 7.6 Dr Sonnex said there was a national guideline that women with symptoms should be referred to a genito-urinary medicine practitioner¹. Dr Kumar said the 23 year-old should be asked why she was requesting a cervical screening test. Was there a hidden symptom? Other members of the primary care team could also help. Women with symptoms should be seen by a gynaecologist.
- 7.7 Dr Woyka felt strongly that education was key. We were missing a huge opportunity with girls being vaccinated with HPV to enhance the awareness of cervical cancer and screening. If the screening age were lowered back to 20, only half of women aged 20-24 would attend and these would be the women least at risk. The coverage of the HPV vaccine was very good, but the relationship between cervical cancer, HPV and screening needed to be taught in schools. Dr Firth said that even vaccinated girls did not know why they were being vaccinated as they did not read the leaflet. Dr Austoker agreed, saying that girls thought the vaccine would stop them dying from any cancer.
- 7.8 Dr Raffle said that when cervical screening first started, it was only for women aged over 35. Ante-natal care had led to screening being done in younger women. In Bristol, they had a leaflet for GPs setting out the facts that screening in the under 25s does more harm than good. This was an opportunity to explain, and had nothing to do with cutting costs.
- 7.9 Ms Bennett agreed strongly that education was key. It took her eight months to go and see her GP, and she was not aware of HPV or cervical cancer. These issues should be covered in sex education lessons, which mainly focused on STIs and pregnancy. Girls do not understand what HPV and cervical cancer are.
- 7.10 Professor Kitchener asked Ms Bennett whether increasing awareness would impact on apathy. Ms Bennett firmly believed that if young women knew the risks and chances of getting cervical cancer, they would attend screening.

¹ Colposcopy and Programme Management: Guidelines for the NHS Cervical Screening programme. NHSCSP Publication No.20 – ISBN 1 84 4630 14 5 April 2004

Education should be from an early age – “it is just something that you do”. Professor Kitchener asked how young women could be made more receptive to the awareness messages. Ms Bennett said it should be taught in schools, with reminders later in life, especially the risks of losing fertility and dying. Ms Shewan said that even her mother did not really understand what screening was all about, so it was difficult to communicate. Communication and education had to come from somewhere. Ms Ellis said that her service sent information out, but it was not read. Ms Shewan said that leaflets and letters did not work. Telephone calls may be better.

- 7.11 Mr Walker said the review was an opportunity to re-emphasise the point of screening and cervical cancer symptoms to both women and clinicians. There was probably capacity to do colposcopies on symptomatic women providing all other potential problems had been ruled out. Starting screening at age 25 seemed about right, but what about women who fell through the net? Was it possible to start screening eight years after a woman first had intercourse? If people were to identify themselves, would it be feasible as part of a national programme? Women aged 25 and over would be invited, whilst those aged 20 to 24 could access screening if they were high risk. If the age remained at 25, more effort had to be made in increasing the coverage in women aged 25 to 34.
- 7.12 Ms Brown said that school nurses were best placed to provide advice and education, but there was a real issue about them being cut to save costs.
- 7.13 Dr Woyka suggested a GCSE in healthy living, as children did not really learn about themselves and their own health in biology lessons. They knew all about drugs and contraception, but nothing about themselves.
- 7.14 Dr Sue Moss said that from her cohort data, younger women delayed longer to respond to their screening invitations, at around seven months. Could the first invitation be sent out at age 24?
- 7.15 Professor Cuzick asked whether we could identify a group of women where the benefits outweighed the risks. The onus would be on the service to get the evidence. Case control for women with cancer should be nationwide, but we should not overreact unless there was evidence of a rise of incidence. Professor Kitchener agreed, saying that monitoring and surveillance should continue so a potential “ticking time bomb”, if it existed, could be identified as soon as possible.
- 7.16 Dr Kevin Smith said that the UK National Screening Committee were responsible for all screening programmes, not just cancer screening programmes. He said he was really shocked by the harm ratio in screening younger women, which was stark. There needed to be real benefits before screening was offered universally again to women aged under 25.
- 7.17 Dr Fielder said that a review of possible harms to screened women aged 20 to 24 was already underway in Wales. The published evidence had not taken into account possible confounding factors such as deprivation or smoking. Research linking cervical screening with birth outcome in Wales would provide more evidence.
- 7.18 Dr Denton said that the issue of harm through the psychological affects of an abnormal result also needed to be taken into account. If a third of women

aged 20 to 24 would be identified with an abnormal result the adverse effects would be huge. Professor Cuzick agreed, saying such psychological affects would stop women attending for screening in the future.

- 7.19 Professor Sasieni said that education would be good, but would be complicated. According to the Populus poll, women were over estimating their risk of cervical cancer yet still were not attending screening. The HPV vaccine was also an issue, as those who were not vaccinated would be the ones we needed to screen. Smoking was also an issue. Presenting information in an unbiased way was difficult, especially if we were to allow women aged under 25 to opt in.
- 7.20 Ms Shewan said that saying 30% of women aged under 25 would have an abnormal result with the anxiety that entailed assumed that they would know what an abnormal result meant. Professor Kitchener said that the psychological harm to women being screened was clearly documented in the literature, and he saw a significant proportion in his clinic. A lot of these women thought they had cancer.
- 7.21 Mr Walker said that 90% of abnormalities were mild and would regress, and questioned what should be done with the large number of women with low grade abnormalities. Dr Raffle said that professionals and users needed to learn from each other. It had been pressure from women in the 1970s and 1980s which had forced health professionals to recognise the anxiety and distress caused to healthy women, and to move towards giving more balanced informed choice based on information of the benefits and harms. . A study in Wales and Bristol had also shown no difference in anxiety experienced by women who had a nurse explain their abnormality and those that did not. Dr Kumar said there was harm in false reassurance.
- 7.22 Dr Fielder asked if the English Advisory Committee on Cervical Screening only offered advice to English ministers. Professor Kitchener said that it did. Dr Kevin Smith said that the UK National Screening Committee would consider the English recommendations.
- 7.23 Dr Sonnex asked whether the system could be tailored to accommodate those women under 25 who presented and had early intercourse, smoked and their parents had cervical abnormalities. It was acknowledged that all national screening programmes had age limits in order that they are practical to deliver and that they are seen to be consistent and fair. There was a real danger of stigmatising women if the first age was to be based on sexual activity, smoking and family history, and the system likely to be unworkable. Dr Woyka said that we needed to bear in mind the 18 year-olds who were being vaccinated and would be eligible for screening in two years time. Professor Kitchener agreed the vaccine impact would be considerable.
8. Recommendations to ministers
- 8.1 Professor Kitchener turned to ACCS members to decide on what recommendations were made to ministers. He summarised the discussion as follows, which members agreed with:
- The harm/benefit ratio was real – there were a small number of cancers detected in women aged under 25, some of whom had already been screened. There was a far larger group where harm was done in terms of future pre-term deliveries and anxiety
 - There were clear concerns about the falling coverage

- Awareness and education were issues
 - There were issues about symptomatic disease and delays in referral
 - The HPV vaccine would be very important with large benefits and protection against cervical cancer, although this may hit screening coverage. Catch-up messages were therefore an issue
- 8.2 Professor Kitchener outlined three potential options:
- No change – screening started at 25, with heightened efforts to increase coverage. There was also the potential for the first invitation to be sent out at age 24½
 - Screening started at age 20
 - An informed choice system to allow women who presented as high risk or GPs determine to be high risk to be able to be screened
- 8.3 Mr Walker said there was a difference in refusing to process samples, and promoting the fact that samples taken in women aged under 25 would still be processed. Further discretion may be considered. Dr Loftus said that there would be different responses from different GPs, so guidelines would have to be very clear. Mrs Vryenhoef said that if such a system were promoted, women would attend for screening in considerable numbers.
- 8.4 Professor Patnick said there were a number of points to consider. One was increasing inequalities – it was unlikely that women from more deprived areas who had intercourse at an early age would attend for screening, more the young women from middle class areas who were less at risk would attend. Getting the right information for an opt-in scheme would be very difficult, especially in educating GPs. Other programmes had found it very hard to get such messages across (eg breast screening in women aged over 70, the Prostate Cancer Risk Management Programme). She reminded attendees of the fact that in the Populus poll 33% of women aged over 35 claimed never to have received any information about cervical screening from the NHS. We had to operate in the real world.
- 8.5 Mr Music said that, from a public perspective, if there was to be an opt-in proposal it would need to be very carefully managed, with education as the key. Jo's Trust would have a key role to play in the education process.
- 8.6 Professor Kitchener said that if there were to be an opt-in proposal, 22 year-olds with CIN2 would end up in colposcopy clinics. There would need to be very clear guidelines to avoid harm.
- 8.7 Mr Walker said that in the USA, screening began at age 20 or three years after intercourse. Could the English programme formally start at age 25, or eight years after first intercourse? Professor Patnick responded that the USA did not have a population screening programme. The great success of the English programme was the call/recall system. Screening in the USA came at a very high cost.
- 8.8 Ms Brown said that having choice for women aged under 25 would be chaos, and it would be very tough for practice nurses to have that decision put on to them. Dr Raffle agreed, saying that screening did not work in women aged under 25. Papers published on trying to identify high risk women had said it would lead to chaos.

- 8.9 Ms Woolnough said that we would have to be very careful about the messages about harm. If there was harm in women aged under 25, what about women aged 25½? Communication was very important.
- 8.10 Professor Sasieni said that we should not make women aged under 25 who had had cervical cancer feel uncomfortable or guilty. Screening may not have prevented their cancer.
- 8.11 Professor Richards thanked all those attendees who had presented what was the best available evidence, and summarised the discussion as follows:
- There was a huge commitment to improving the health of young women
 - Symptom awareness amongst both women and GPs was key, and algorithms/guidelines should be revisited. The GP Research Database should be examined to see what the problems were
 - Cases of women with cervical cancer should be audited to learn lessons which could save lives
 - Education of the public was difficult, but should be tried with the help of behavioural psychologists and social marketing
 - Clear messages about the harms and benefits of screening at different ages should be set out
 - There was a major commitment to improve coverage in women aged 25 to 34, and monitor the length of the “Jade Goody effect”
 - Trends should be closely monitored, linking to HES data and modelling the impact on the NHS
 - There was no compelling evidence that screening should begin at age 20, but there was significant evidence of both physical and psychological harm
 - Informed choice would be very hard, with a lot of work undertaken to consider this option. Could polyclinics offer better information? Could models of service be developed?
 - The time lag between women aged 25 receiving and responding to their invitations suggested that the screening age be lowered to age 24½
- 8.12 Professor Kitchener asked ACCS members if any were in favour of lowering the screening age back to 20. The ACCS were unanimous that the screening age should not be lowered to age 20.
- 8.13 Coming on to the option of an informed choice opt-in, Dr Denton said that if discretion were allowed it would be abused. The issue of very high risk women was considered (eg child sex abuse victims, child prostitutes, immuno-suppressed transplant patients, those with LiFraumini Syndrome), and it was suggested that these women could be managed clinically on an individual basis. Professor Kitchener asked ACCS members if they were in favour of an informed choice opt-in. The ACCS were against this option, but Dr Woyka was unable to agree with this. As a doctor whose duty is to the individual patient, she felt she must be able to offer screening to patients considered appropriate to screen by virtue of age and the onset of sexual activity.
- 8.14 The ACCS supported the lowering of the age of first invitation to screening to 24½.
- 8.15 Professor Kitchener asked Mr Elliott about next steps. Mr Elliott said that he would write up the minutes of the meeting, including the recommendations of

the ACCS (see Annex B), from which a submission would be written to ministers on which they would make a decision. This was likely to be in early June 2009.

8.16 Professor Kitchener thanked all attendees, and in particular Jo's Trust.

9. Any other business

9.1 There was none.

10. Date of Next Meeting

10.1 This had already been set for Thursday 25th June 2009.

Tim Elliott
Team Leader: Cancer Screening and Male Cancers
May 2009

Statement as read out by Rachel Bennett (see paragraph 4.8)

Good morning.

When I was 21 and in my final year of university, I began bleeding during intercourse. I was quick to dismiss it, and convinced myself I was being paranoid and it would subside on its own. Eventually I got over my embarrassment of having to talk about my nether region to my doctor, and asked for some advice. She stated that everything looked OK, but wanted me to visit the hospital anyway as she believed I may have pre-cancerous cells in my cervix. After constant reassurance from the doctors and a colposcopy, I was told that it couldn't be cancer yet due to my age but they wanted me to have an operation to remove the abnormal cells in case they developed into cancer later in life. I was informed at the time that there was only a small chance of the cells turning cancerous, and that an operation to remove these cells may affect my future fertility a minute amount, but regardless I felt that the risk of potential cancer was a valid reason to opt for removal. However, soon after the operation was complete, they discovered I in fact was worse off than they had predicted. I had stage 1b1 cervical cancer.

I was lucky. I truly believe that. If I didn't have symptoms, If my GP hadn't sent me to hospital instead of brushing me off because I was under 25, or if the doctors at the hospital hadn't decided to give me the choice of having these cells removed, then chances are I wouldn't have my whole life still ahead of me.

I do not see myself as a unique case though. Through Jo's Trust I've spoken to numerous women under 25 who are also having symptoms, and who are not allowed a smear test simply because of when they are born. I was lucky that I lived where I was immediately sent to hospital, but this isn't the case for the whole of England. Even so, had I been old enough to be screened, chances are it would have been caught much earlier, and dealt with before I needed to go through the treatment and the trauma. I cannot stress enough how important these screening programmes are. Women who's cancer is more advanced than my own face infertility and even death, which is especially sickening to think that this is a young woman's cancer. These are the women who have not had the chance to have their own children, nor to live their lives. These women should be a priority, especially now that young women are becoming sexually active even earlier. All sexually active women need screening, as all are at risk, and therefore it is unfair to deny any women their right for a smear.

To conclude, I was given the choice. I was told of the risks involved in the operation that removes pre-cancerous cells. It was my decision to make, and I firmly believe I would not still have my fertility if it wasn't for those doctors deciding that it wasn't their place to determine my fate. Women under 25 want to be screened, and they want to be given the right to choose whether or not to have their smears, whether or not to go through with the operations if the smears come back positive for abnormal cells. All we want is our right for a smear and our right to decide our own fate, instead of just being dismissed because of when we were born. Thank you for your time.

Extraordinary Meeting of the Advisory Committee on Cervical Screening to re-examine current policy on cervical screening for women aged 20-24 years taking account of any new evidence – 19th May 2009

Recommendations to the National Cancer Director and Ministers

1. Symptomatic patients

It is becoming increasingly clear that a significant proportion of young women with cervical cancer actually present with symptoms and there may be a significant delay prior to referral. They should not have had a cervical screening test, but should have been referred directly for investigation. Cervical screening tests may have delayed their diagnosis.

Actions

- (i) Development of a new algorithm or guidance on the management of young women with gynaecological symptoms (e.g. pain/bleeding on intercourse, bleeding in between periods). This will need to involve primary care, GU medicine, gynaecology and cervical screening experts.
- (ii) Analysis of rates of attendance in primary care for gynaecological problems amongst young women (e.g. via GP Research Database or EMIS).
- (iii) Audit of all young women diagnosed with cervical cancer – how many had symptoms; duration of symptoms; referral routes.
- (iv) Awareness campaign for GPs and practice nurses.
- (v) Modelling of impact of new algorithm on workloads (e.g. GU medicine; colposcopy).

2. Asymptomatic patients

We need clarity about the magnitude of harms and benefits of cervical screening at different ages. We also need to increase coverage in women over 25 years.

Actions

- (i) Develop easily understood tables setting out harms and benefits at different ages – including psychological morbidity, colposcopy rates, treatment rates (plus re-treatment), premature births etc. and cancers detected, lives saved.
- (ii) Maintain start of screening age at 25²
 - Do not reintroduce call and recall at 20 and 23

² Dr Woyka did not sign up to this recommendation as she felt she must be able to offer screening to the individual whose age of sexual debut makes them suitable to screen before 25

- Do not allow 'screening on demand' in women under 25
- Send out invitations before 25th birthday (perhaps 24½) so that women are screened by 25
- 'exceptional cases' (eg child sex abuse victims, child prostitutes, immuno-depressed transplant patients, those with LiFraumini Syndrome) should be clinically managed on an individual basis, and allowed screening subject to prior authorisation (i.e. GP phoning up to request lab processes sample)

(iii) Continue and consider expanding work of Improvement Foundation to increase uptake in over 25s.

(iv) Work with colleagues in social marketing to consider how best to get messages to this age group.

3. Further monitoring/research so a potential "ticking time bomb" can be identified as soon as possible. We need to consider:

- Case control study for all cases of invasive cervical cancer
- Linkage of screening, cancer registry and HES data on pre-birth deliveries