Hysterectomy – Not Clear Cut!

Proceedings of
Women’s Health Victoria’s Forum

02 July 2001

Edited by:
Kim Johnstone and Marilyn Beaumont
Women's Health Victoria's Forum (3rd : 2001 : Melbourne, Vic.).


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ISBN 0 9577744 6 X.


618.145309945
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Introduction

The proceedings from the forum, Hysterectomy – Not Clear Cut!, are aimed at keeping Women's Health Victoria’s (WHV’s) members and stakeholders connected with important women's health issues arising from our environmental scanning work, which is a key component of WHV’s clearinghouse of women's health information. These proceedings have been prepared based on a transcript of the forum. Figures and tables throughout have been created from slide presentations used by the speakers.

Women's Health Victoria is a state-wide women's health information service. In our work, we undertake continual scanning of women's health issues and status and experience of the health system through a variety of ways to identify women's health issues for public discussion. Throughout the last year or so, a number of issues have emerged which relate to hysterectomy. These issues were brought together for public discussion in the forum held 02 July 2001.

We would like to acknowledge the two generous financial donations we received to enable us to put the forum on. The first from the funds remaining from the windup of the Victorian Hysterectomy Support Group, which has assisted us in publishing the forum proceedings, and the second from the Victorian Department of Human Services for the expenses of our guest speaker, Beth Reid.

Women's Health Victoria has identified the need to consider a number of key issues around women’s experience of treatment options and outcomes relating to hysterectomy (a summary of these was provided to forum participants in the fact sheet shown on the next page). These include variable rates of hysterectomy between urban and rural women, and between women with and without private health insurance; the cost of hysterectomy and other alternatives, both to service providers and to individual women; the income generated from hysterectomy, for example, Medicare rebates for hysterectomy versus alternative measures, gynecologists’ income generated from hysterectomy; barriers to women receiving what they consider to be best-practice care; and the availability of information on choices for women.

The issues that we wanted to address were what drives practice and whether there is a need for change. The evening was structured with Professor Beth Reid providing a keynote address on the major findings and implications from the Relative Utilisation Rates of Hysterectomy Research carried out by her Department at the University of Sydney for the Commonwealth Department of Health and Aged Care. This was followed by short presentations from Dr. Sonia Grover, University of Melbourne, Dr. Alison Lilley, Royal Women's Hospital and Jane Widdison, Royal Women's Hospital. The content from the speakers was the catalyst for the discussion that followed.

Regrettably we had an apology from one of our speakers, Sharyn Cook, who couldn’t be with us due to a serious farm accident her daughter had. She told us that the points she would have wished to raise are the need for community education and information about the range of options for rural women; informed choice; the need for doctors to offer more information on options; finding ways to make options available to rural women; and support for transport and accommodation when rural women have to travel to the metropolitan or provincial centres for test treatment or surgery.

In addition to the papers presented and the discussion that took place at the forum, these proceedings include an article from a woman with recent experience of hysterectomy. We look forward to this resource being used to continue to inform practice change.
Thank you to Women’s Health Victoria for inviting me to speak here. I'm very excited to be able to accept this invitation because we did this work some time ago and I'm very excited that something might be really going to happen about variation in hysterectomy rates in Victoria. The report on which this talk is based is available from the Commonwealth Department of Health and Aged Care.

I think the reason for starting with this presentation is because we've become used to evidence-based practice and evidence-based everything. We've got evidence-based teaching in my university now, we are not expected to change teaching practices unless we have got good evidence for making the change and for monitoring what we are doing. Obviously this began in health. The point with my presentation is to present the evidence for some of the issues identified by Women’s Health Victoria that led to the holding of this forum. How can we be confident in making some of these statements?

A lot of people were involved in this research. Their names and their jobs are outlined in Table 1 so that you have a feel for who the team was and their backgrounds.

Table 1: Relative Hysterectomy rates – the research team

<table>
<thead>
<tr>
<th>Researchers</th>
<th>Beth Reid, Chris Aisbett, Lauren Jones, Michael Mira, Liselot Muhlen-Schulte, George Palmer, Leslie Reti, Rosemary Roberts</th>
</tr>
</thead>
<tbody>
<tr>
<td>Backgrounds</td>
<td>Health information managers, medical practioners (gynaecology and general practice), sociologist, health economist, statisticians</td>
</tr>
</tbody>
</table>

The research problem that we began with was that we know that there are wide variations between geographic areas in admission rates and procedure rates and we've known about this
evidence for a long time but we don’t know why these variations exist. One of the main reasons that we think that it exists is there are differences in clinical practices. There are also supply issues; for example, you are going to see from my findings tonight that there are more hysterectomies in rural areas than there are in city areas. That may have to do with a shortage of beds relatively in city areas compared with country areas, to some degree. There are also differences in underlying morbidity. There are differences in rates of illness in different parts of the country, we don’t expect that they would be the same. We also know that socioeconomic status has something to do with the use of resources.

The one thing I've learned about the answers to this, and I've been doing this research since the early 1990s, is there will never be just one cause for variation. That's the one thing that I'd like you to take home. I see journal articles and newspaper articles about variation in admission rates and procedure rates and sometimes at the end of the article they say once we know the cause we will be able to do something about it. There is not one single cause; all of these things are operating to a certain degree and to different degrees at different points of time so it's not simple.

There are also a variety of factors that influence your individual health and what may happen as a result of that. There is quite a lot of chance in health. There are some things that you can't do very much about:

- your genetic inheritance, who your parents are
- the social class we were born into (although we might want to try and work hard to change it later)
- the educational and occupational opportunities that we have in life (the sort of hand that gets dealt to us, later in life sometimes we can control that a bit)
- the doctor that you choose (we often don't have very good information about who the practitioners are in an area and what the differences would be, but if we shopped around and spent a lot of time going to one general practitioner for one thing and another one at another time we would lose the continuity of care)
- where you live
- the number of available doctors and beds.

The objective of our study was to determine if high or low rates for hysterectomy could be linked to the diagnosis codes recorded in the hospital separation data. We knew that there would be wide variations in hysterectomy rates but what we wanted to know was could those variations in hysterectomy be traced back to the reason why the hysterectomy was done, the diagnoses that had been recorded in the hospital separation data. These are data that are collected for every person discharged from every hospital all throughout Australia, public and private. Every time there is a piece of paper or a computer record, this information is gathered so we've got rich data. One of the problems has been that we haven't been very good at using that in the past.

The data came from 1996/1997. It's a bit old now but the problems of variation and hysterectomy has been discussed in the past and will be discussed in the future; it's not a problem that is new or only occurred in 1996/1997, it's been there for a long time. We did this study in New South Wales, the ACT and Victoria. This was a pilot study intended to show the Commonwealth Department of Health and Aged Care, who funded the study, that the methodology would work and that you could trace the variations back to the diagnoses and do something with the objective that they gave us. It was the Department that selected hysterectomy.

As I said before, the data include both public and private hospitals. We took all the hysterectomy records, it didn't matter what kind of hysterectomy the person had, but then we discarded all the ones where there was a cancer diagnosis. We didn't include those at all for obvious reasons. We were interested then in what were the diagnoses that were recorded on the discharge records for each of those women. One of the things that came up first was that
93 per cent of the records had more than one diagnosis; there isn't just one reason for hysterectomy. Furthermore there was no basis for identifying a single indication for the hysterectomy. When you look at previous literature about this variation in hysterectomy rates, results are written up as if there was one reason for doing the hysterectomy. No one talks about this problem and I think the fact that we do is unique for our work. I believe that people who have been doing that in the past have not realised that there are all these other codes on the discharge records and they've assumed that the principal diagnosis was the one that they should trust. I'm here to tell you that's not right.

There were four codes that were present, either singly or in combination on 93 per cent of the records. The 93 per cent in the two places is just a coincidence, they don't have anything to do with each other. The four codes are not going to surprise anybody in the room if you've got a health background or if you're a woman who has had these sort of problems. They're fibroids, prolapse, menstrual disorders and endometriosis. If you take those four and put them in all the four combinations, there are 16 possible combinations. Each of the diagnoses was present in eight of the combinations and absent in eight of the combinations.

In terms of the methodology, we took all of the records and assigned them to the statistical local area of the women's residence. This means the variations don't necessarily have anything to do with the hospital where the procedure was done. It was what is called a population based study; it's where you live, not where you have the hysterectomy that mattered for us in this research.

One of the problems about this sort of research is that some of the work in the past, if it's been done on variation in procedure and admission rates, has not recognised the fact that where you have very small numbers you will get a greater impact of random variation. What we did to avoid this was take any statistical local area where there were less than 40 hysterectomies and amalgamated them with adjacent areas. There are maps inside the final report that show you how we rolled things up. A colleague of mine, Lawrence McMahon, has written in this area and calls this the doughnut method. If there's a town, you often find there is quite enough in the town for you to have the town centre as the hole of the doughnut, you don't have to roll that up with anything. But around the town centre you roll all of those up into one area and then around that again into another area. What we try to do is minimise the impact of distance from the hospitals being the factor. When we did the amalgamations we got 163 areas for New South Wales, Victoria and the ACT. All together there were 99 urban and 64 rural areas.

We adjusted the rates for age using the indirect method. Of course, there will be some areas where the average age of the women is quite young and there are more hysterectomies being done in comparison to in a retirement population, where for example, women have had hysterectomies in the past and are not candidates for hysterectomies now. We also kept the urban and rural data separate. The age adjusted data mean it doesn't matter that there were differences in the number of women living in an area or the age of those women.

We didn't take into account the high rate or the low rate of hysterectomy in the past in each local area. Some colleagues of mine at Sydney University have published some of that sort of work but it wasn't done for this study.

What the adjusted data showed was a big difference in the hysterectomy rate between urban and rural women. As shown in Table 2, this was true in Victoria and NSW.
Table 2: Hysterectomy rates per 1,000 women, Victoria and NSW

<table>
<thead>
<tr>
<th></th>
<th>Victoria</th>
<th>NSW</th>
</tr>
</thead>
<tbody>
<tr>
<td>Urban</td>
<td>3.44</td>
<td>3.25</td>
</tr>
<tr>
<td>Rural</td>
<td>4.23</td>
<td>4.27</td>
</tr>
</tbody>
</table>

Our null hypothesis was that if the variation in hysterectomy rates was just all random variation in the data and didn't mean anything (it wasn't statistically significant) then what you would see is no difference between the expected rates and the observed rates. We had to reject the null hypothesis because of the results shown in Table 3.

Table 3: Distribution of hysterectomy rates, urban and rural data NSW, Victoria & ACT

<table>
<thead>
<tr>
<th>Rate categories</th>
<th>Expected number (%) of areas under the null hypothesis</th>
<th>Observed number (%) of areas</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extremely high rates</td>
<td>0.025 (0.02%)</td>
<td>15 (9%)</td>
</tr>
<tr>
<td>High rates</td>
<td>4.05 (2.5%)</td>
<td>18 (11%)</td>
</tr>
<tr>
<td>Rates within the expected range</td>
<td>154.85 (95%)</td>
<td>92 (56%)</td>
</tr>
<tr>
<td>Low rates</td>
<td>4.05 (2.5%)</td>
<td>26 (16%)</td>
</tr>
<tr>
<td>Extremely low rates</td>
<td>0.025 (0.02%)</td>
<td>12 (7%)</td>
</tr>
<tr>
<td>Total</td>
<td>163</td>
<td>163</td>
</tr>
</tbody>
</table>

Under the null hypothesis we expected to see less than one extremely high rate. If there had been one then the variation would have been due to random variation in the data rather than other factors. Under the null hypothesis we also expected to see about four in the high category, 155 of them within the expected range and so forth. What we found instead though was 15 in the extremely high category instead of one, instead of four in the high category we found 18 and only 92 instead of 154 in the expected range. So you can see this variation is not random fluctuation in the data, something else is happening here.

Table 4 shows where the high and low use areas in Victoria are. Remember the low rates aren't because there are no women in those areas in the right age group because we have adjusted these data for differences in age.

Table 4: Areas in Victoria with atypical adjusted hysterectomy rates

<table>
<thead>
<tr>
<th>Extremely high</th>
<th>High</th>
<th>Low</th>
<th>Extremely low</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brimbank – Keilor</td>
<td>Brimbank – Sunshine</td>
<td>Boroondara – Hawthorn</td>
<td>Glen Eira – Caulfield</td>
</tr>
<tr>
<td>Cardinia</td>
<td>Hobsons Bay – Altona</td>
<td>Darebin – Northcote</td>
<td>Port Philip</td>
</tr>
<tr>
<td>Frankston – West Melton</td>
<td>Hume – Broadmeadows</td>
<td>Glen Eira – South</td>
<td>Yarra</td>
</tr>
<tr>
<td>Wyndham</td>
<td>Hume – Sunbury</td>
<td>Melbourne</td>
<td>Wangaratta – Benalla</td>
</tr>
<tr>
<td>Baw Baw</td>
<td>Maroondah – Ringwood</td>
<td>Stonnington – Malvern</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Mornington Peninsula – East</td>
<td>Stonnington – Prahran</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Whittlesea</td>
<td>Whitehorse – Nunawading E</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Echuca</td>
<td>Moe – Morwell</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Gr. Shepparton – Pt A</td>
<td>Queenscliffe – Bellarine</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Sale + Wodonga</td>
<td>South Banwon – Inner</td>
<td></td>
</tr>
</tbody>
</table>

When we did the work of looking at comparing the groups with and without each of the diagnoses what we found was that only one of the four diagnoses had an impact on the variation. You do this simply by repeated tests where you take out all the groups where there is, for example, the diagnosis of menstrual disorders and then put them back in again. You can see from Table 5 that for menstrual disorders, once we took the records with menstrual
disorders out, the observed number of 15 areas with extremely high rates shrank to three. The number in the expected range also went up to closer to what we were expecting. The observed number of low rates went from 26 down to 18, and the extremely low rates went from 12 down to six. What was noteworthy was that it was only for this diagnoses that we saw that pattern.

Table 5: Results after removing the menstrual disorders, urban and rural data

<table>
<thead>
<tr>
<th>Rate categories</th>
<th>Expected number (%) of areas</th>
<th>Observed number (%) of areas all records</th>
<th>Observed number (%) of areas no menstrual disorder records</th>
</tr>
</thead>
<tbody>
<tr>
<td>Extremely high rates</td>
<td>0.025 (0.02%)</td>
<td>15 (9%)</td>
<td>3 (2%)</td>
</tr>
<tr>
<td>High rates</td>
<td>4.05 (2.5%)</td>
<td>18 (11%)</td>
<td>18 (11%)</td>
</tr>
<tr>
<td>Rates within the expected range</td>
<td>154.85 (95%)</td>
<td>92 (56%)</td>
<td>118 (73%)</td>
</tr>
<tr>
<td>Low rates</td>
<td>4.05 (2.5%)</td>
<td>26 (16%)</td>
<td>18 (11%)</td>
</tr>
<tr>
<td>Extremely low rates</td>
<td>0.025 (0.02%)</td>
<td>12 (7%)</td>
<td>6 (4%)</td>
</tr>
<tr>
<td>Total</td>
<td>163</td>
<td>163</td>
<td>163</td>
</tr>
</tbody>
</table>

When we took the records out for fibroids, for prolapses, and for endometriosis, the number of areas with extremely high and low rates didn't decrease. That is the crucial finding that shows that it's really menstrual disorders that are responsible for the variation. Because it was menstrual disorders, we thought there would be an effect if you just look at it by age because we all know once you have had menopause you are not really at risk for a menstrual disorders problem.

Figure 1 compares the women aged less than 49 to the women over 50. This is a surrogate age for menopause because we don't really know when any of these women had menopause, we didn't have that data. When you do this comparison what you see is that the extremely high and low rates are only seen among women under 50, there are no extreme results once you get over 50. This shows that it's not hysterectomies in women over 50 that are the problem. This variation is a young woman's problem so that's what makes it much more an area of urgent concern.

Figure 1 : Impact of age on the distribution of rate categories, urban data
We then looked at all the women in the under 50 age group to see whether there was any one particular age group of women which accounted for the variation. We did this by repeated testing with five year age bands and kept testing them until we saw a result. The result occurs for the 30 to 44 year age group. Those women are where the extreme results are. When you take those women out and look at all other ages for the less than 50 year old women, the extremes are just tiny (see Figure 2). It’s clearly the 30 to 44 year age group that we need to be looking at.

Figure 2: Distribution of rate categories for the ≤ 49 age group, urban data

What this research shows is a way of targeting. If we are writing guidelines that want to address variation then if you just wrote guidelines for the management of menstrual disorders in 30 to 44 year old women you would have some chance of addressing this problem. If you tried to write guidelines for the whole of hysterectomy it’s a much bigger task and you won’t necessarily do anything about the variation. The main thing that comes from this research is that you’ve got to target the work done in this area.

The other thing that I wanted to show you was a strong link with socioeconomic status. We used the socioeconomic status that is collected in the census to create a socioeconomic index. We compared the socioeconomic index with the hysterectomy rates and we found a strong inverse relationship in socioeconomic status and hysterectomy rate for urban areas. We didn’t do this in rural areas because of lack of homogeneity where you have very wealthy people living in the next farm besides someone who is doing it very tough. Whereas in urban areas we know, especially from price of housing for example, that you get much less variation in socioeconomic status. The results showed very low $p$ values which means that the variation is not chance, this is something real that’s going on.

To summarise:
- The extreme variation in hysterectomy rates was driven by hysterectomy for menstrual disorders in 30 to 44 year olds
- Women in disadvantaged areas were at a much greater risk of hysterectomy.

Both of those things make me concerned that people who are already disadvantaged by not having good educational and economic opportunities are possibly being disadvantaged further.
We had some limitations in our study. We were limited to readily obtainable hospital discharge data, we didn't have any data from general practice. The socioeconomic results also reflect what is called an ecological fallacy. This is, we didn't know the socioeconomic status of the woman who had been operated on, all we knew was that they came from an affluent or less affluent area. Despite the ecological fallacy it's a very strong result. The $p$ value is very, very small and it's consistent with a lot of other findings that show that there is more ill-health, more operations and more admissions in disadvantaged areas. If it had gone the other way then you would feel less confident about the result. Our work was just a pilot study of one procedure, and therefore our methodology is yet to be proven across a lot of other procedures.

There are a number of things that I think should result from this research. There could be further research in the menstrual disorders' management of 30 to 44 year old women in both the high and low use areas. I wouldn't do it everywhere else, just in high and low use areas and compare what's going on. We need to look carefully and see whether we can determine whether women in the low socioeconomic areas are being offered the same choice of alternatives. Are they getting the information that they need to make the decisions, that is, the same information as women in high socioeconomic areas? We also need to develop guidelines to address these variations. When we do this we need to target the way we write this information to meet the needs of those women. It needs to be plain language information for women who have had some sort of educational disadvantage or economic disadvantage, and the two things go together.

Since I launched this work a lot of women have come and talked to me about their problems, sent me e-mails and written me letters. What I realise is going on behind all of this work is a myriad of different stories and lots of different perspectives. Not all of these factors are important all the time, some factors are more important for some women and others not. And I'm not about demonizing hysterectomy; if a hysterectomy is warranted then that can be the right choice for some women. What you have to consider though, is if we have got as much variation as we've shown, surely there is something wrong. If it was just due to differences of morbidity and those sorts of things then it would be much closer to the results that you would see just by chance alone, but the differences are so great that I think we do need to follow through and do additional research.
**Hysterectomy – not clear cut**

Dr. Sonia Grover  
Royal Women’s Hospital

Sonia is an obstetrician at the Royal Women’s Hospital. She is involved in the young mothers clinic and also has an interest in the health issues of immigrant women. Sonia also works as a gynaecologist at the Royal Children’s Hospital and Centre for Adolescent Health and has considerable involvement in the menstrual and contraceptive needs of women with intellectual disabilities. She is working to encourage the least invasive means of managing clinical problems.

Sonia has past and current involvement in a number of research projects all involved around “reducing or avoiding unnecessary surgery”. Last year she worked on an NHMRC project assessing the educational strategies to reduce the rate of D&Cs in women younger than 40 and comparing the effectiveness of the education of gynaecologists versus general practitioners.

The challenge (for medicine) that we have to meet this century, I think, is to have a look at reviewing some of the established practice. Hysterectomy has been a straightforward procedure to undertake when there have been problems, but maybe it's time to look at the evidence and to take on board some of the newer things that are available for us to offer to women. As health professionals, the onus is on us to look at the evidence to support what we are doing but also to look at what else is available for us to offer women. I think we also need to be much clearer about our need to give information to women. I was talking to an endocrinologist in a pediatric context the other day who was saying that in his 25 years of practice the key thing that has changed is that you now have to give people information. I think I started my clinical practice at a time where information has always been part of what I thought was my job but clearly there has been a remarkable change in the last 20 to 25 years. The bottom line for me is that we should be avoiding unnecessary surgery if at all possible.

I am going to focus on menorrhagia but a lot of the points that I will raise in fact can equally be raised and put to question with regard to management for fibroids. We need to look at the evidence around medical management options for menorrhagia, we need to know a little more about our surgical options and surgical complication rates. What Table 1 shows is that there are a range of different non-surgical approaches to reduce menstrual loss that are available. These range from non-steroidal medications that reduce menstrual loss by 30 per cent, with 50 per cent of women reducing their menstrual loss from what we would define as being menorrhagia, through to things like the Levonorgestrel IUD, known as Mirena. This has been available overseas for 10 to 15 years, has been available in Australia for three to four years, and more readily available in the last year. This intervention reduces menstrual loss by 94 per cent and practically 100 per cent of women will get some benefit.

This is a new option so what we might have been doing five years ago to manage menorrhagia needs to be reconsidered in the light of current evidence and information. But some of the other approaches have been around for some time and have been used to greater or lesser extents. Things like Danazol have been around for some time but scarcely used here in Australia, and maybe because of legitimate reasons, such as side-effects. Transexamic Acid has been used in Scandinavia for 30 years. Their hysterectomy rate seems to be at about 10 per cent whereas the hysterectomy rates here in Australia would mean somewhere between 30 to 40 per cent of women end up with a hysterectomy. Some of that is not menorrhagia
related but one would have to wonder whether the use of Transexamic Acid is one of the factors that contributes to a reduced rate of hysterectomies. As Table 1 shows there is a 50 per cent reduction in menstrual loss in association with the use of these tablets.

**Table 1: Medical Management Options for Menorrhagia**

<table>
<thead>
<tr>
<th>Drug</th>
<th>Mean reduction in blood loss (%)</th>
<th>Women benefiting – proportion with MBL &lt;80ml/cycle (%)</th>
<th>Specific benefits</th>
<th>Adverse Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>Levonorgestrel IUS(1) (Mirena)</td>
<td>94%+</td>
<td>100%+</td>
<td>contraception, no requirement to take tables</td>
<td>menstrual cramps, expulsion of system, intermenstrual bleeding</td>
</tr>
<tr>
<td>Oral Progesterone (days 5-25)(2)</td>
<td>87%</td>
<td>86%</td>
<td>cycle regularity</td>
<td>bloating, mood swings, PMS</td>
</tr>
<tr>
<td>Danazol</td>
<td>50%</td>
<td>76%</td>
<td>no bleeding</td>
<td>weight gain, acne</td>
</tr>
<tr>
<td>Transexamic acid</td>
<td>47%</td>
<td>56%</td>
<td>non-hormonal</td>
<td>nausea, diarrhoea</td>
</tr>
<tr>
<td>OC pill(3)</td>
<td>43%</td>
<td>50%</td>
<td>contraception, relief of dysmenorrhoea</td>
<td>nausea, breast tenderness, headache</td>
</tr>
<tr>
<td>NSAIDs(4)</td>
<td>29%</td>
<td>51%</td>
<td>relief of dysmenorrhoea and headaches</td>
<td>nausea, diarrhoea, headache</td>
</tr>
<tr>
<td>Oral progesterone (luteal phase)</td>
<td>4%</td>
<td>18%</td>
<td>cycle regularity</td>
<td>Bloating</td>
</tr>
</tbody>
</table>

(1) IUS = Intra-uterine system. Based on only one randomized controlled trial.
(2) Based on only one randomized controlled trial.
(3) OC = Oral contraceptive. Based on only one randomized controlled trial.
(4) NSAIDs = Non-steroidal anti-inflammatory drugs.

As I have mentioned, some of those approaches do have side-effects. Somebody has now attempted to score how women feel about these based on utilisation. Women have been asked to make step wise decisions about what they would do regarding treatment if they were offered a tablet they had to take every day compared to one they didn't? How do they feel about one that causes some side-effects versus other side-effects? Women are taken through a logical sequential weighing up of one thing versus another. The utilisation score ends up with the treatment Mirena ranking wonderfully as it lasts for five years and it reduces menstrual loss by 94 per cent. Something like Danazol, although it's quite effective at reducing menstrual loss, gets rated poorly on the utilisation score because it has got unacceptable side-effects. Women have given us this utilisation score by being asked, what did you think about the weight of benefits versus side-effects?

We have already had the issue raised of variation between different areas. I asked the drug representative who is responsible for Mirena (Levonorgestrel intrauterine systems) about differences in uptake between states. As you can see in Table 2, there is a considerable variation between the states in a five month period. This could be attributed to differences in populations. However, when you look at the number of women between the ages of 30 and 50, the age of most women using Mirenas, it is clear that there is some variation in the utilisation of this method of managing menorrhagia.
Another way of trying to look at the uptake of a new, less invasive alternative to managing menorrhagia is that up until this year we had to register to use Levonorgestrel IUS in Australia. It wasn’t particularly difficult to register. The College of Obstetricians and Gynecologists had to fill in a form to say I was a member and I had to fill in a form to say I would use it for the appropriate indicated reasons. It wasn’t particularly hard to fill out but for some reason this poses substantial challenge to a number of gynecologists who chose not to register to use it. The data in Table 2 are from two years into the Special Access Scheme, so it no longer applies. As it stood last year it is clear that there is a substantial variation in gynecologists taking up this new non-invasive means of managing menorrhagia.

A further issue is that of surgical complications. We need to put it in balance with what we know and what we tell our patients about complication rates when we do operations. It’s all very well for us as individuals to think we don’t really have many complications when we operate. But if I have a complication every five years, it actually adds up in terms of the total numbers of operations I’m doing. And women want to know what their risk of complications are, but people don’t keep tallies. The accepted rates of complications following hysterectomy are shown in Table 3. Although we have these known published rates of complications occurring when we do hysterectomies, and the rates don’t differ greatly between abdominal and vaginal hysterectomies, we don’t know very much about the laparoscope assisted vaginal hysterectomies and their complication rates. We don’t know what the complication rates are when comparing the groups. If I was a woman who had to have a hysterectomy, I would like to know which procedure has got which rate of complication and which rate of blood transfusion.

### Table 2: Utilisation of uptake of Levonorgestrel IUS\(^{(1)}\) between states

<table>
<thead>
<tr>
<th>State</th>
<th>Utilisation by women</th>
<th>Utilisation by practitioners</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Number of users Jan 2001 – May 2001</td>
<td>Number of O&amp;G practitioners registered for authorised prescriber status two years into SAS(^{(3)}) scheme 2000</td>
</tr>
<tr>
<td>New South Wales</td>
<td>707</td>
<td>56</td>
</tr>
<tr>
<td>Victoria</td>
<td>575</td>
<td>46</td>
</tr>
<tr>
<td>Queensland</td>
<td>535</td>
<td>61</td>
</tr>
<tr>
<td>South Australia/Northern Territory</td>
<td>236</td>
<td>N/A(^{(4)})</td>
</tr>
<tr>
<td>Western Australia</td>
<td>258</td>
<td>N/A</td>
</tr>
</tbody>
</table>

(1) Intra-uterine system.
(3) Special Access Scheme.
(4) Not Available.

We have got less invasive surgical approaches than hysterectomy. There have been several randomised trials comparing the ablative techniques with hysterectomy. Ablative techniques have shorter stay in hospital and need less recovery time, so there seem to be lots of advantages. There hasn’t been so much work comparing Mirenas to these surgical approaches so again, there is a bit of a gap in knowledge. Women, when they’ve been asked about what they think of the outcome of the procedures, haven’t necessarily been quite as happy with endometrial libations because some of them have had to come back to theatre and somewhere between 20 and 30 per cent have ended up having hysterectomies down the track. So it's not quite as good as we sell when we are saying this is a less invasive technique.
I would also ask the question as to whether or not we could be doing something even less invasive.

We also need to keep in mind that just putting someone in hospital carries risks. The 1995 Quality in Australian Health Care Study showed that operative procedures were the most frequent category of adverse events (50%), of which 44 per cent were assessed to be preventable. I like to think that my patients never run into problems, however, I have to accept that problems do occur and maybe if there are ways of keeping her out of hospital it might be to her benefit.

A key question is, are women being given the information and the options regarding hysterectomy procedures? Certainly in the UK when women on a long waiting list for hysterectomy were given the chance to have a Mirena put in without their name coming off the waiting list, it was found that 65 per cent of the women took their names off the waiting list within a few months of having a Mirena put in because they felt they no longer needed the surgery. I have to ask, is this happening in Victoria? I reviewed 50 consecutive records for women on a waiting list for major surgical procedures associated with menorrhagia. Two-thirds did not have any documented evidence of having been offered Transexamic Acid, simple oral medication, or a Mirena. I would like to be brave enough to say that I don't think women in Victoria are necessarily being given the information to take up less invasive options.

So women need to be given the information. I think they need to be given information about the various complication rates honestly and truthfully. But that requires us to do a bit more work because we don't have local information and we don't know the transfusion rates with the relative procedures.

One of the problems within the public health system is that we need time to explain things to women and to give them choices. Within the health system that may not always be what is available. Maybe that is one of the differences between socioeconomic groups, that some people can access private care and buy time to get the explanations and choices and people in the public system aren't getting the time to go through the choices as well as they would like to.
Hysterectomy service variations – provider behaviour

Dr. Alison Lilley
Royal Women's Hospital

Alison is currently the Director of Anaesthesia at the Royal Women’s Hospital in Melbourne. Apart from a medical degree and specialist qualification, she also has an MBA, a Masters in Public Policy and Management and has just completed a minor degree in Health Economics.

Through her clinical work at the Royal Women’s Hospital Alison has become interested in the process of medical clinical decision-making. For example, why is it that the medical decisions made are not based on evidence-based medicine but rather on various other factors which result in some procedures and operations being performed on women that are not necessarily best practice? Why is the practice in one country or hospital different from that in another? How can we do it better for the women of this State? To help unravel these issues, this year Alison has commenced a PhD at the Key Centre for Women’s Health.

This paper provides just a brief outline of some of the possible influences on provider behaviour. We've certainly heard a lot about the variations. Professor Reid's study highlights the extraordinary differences in hysterectomy utilisation. Women with the same benign condition can have markedly different treatment, depending on their geographic or socioeconomic position in Australian society.

Australia is not alone with this, of course. Differences have been known both between and within countries. Between countries we see in America a rate of 6.9 per 1,000 women compared to the UK rate of only 2.8 per 1,000.¹ It's hard to imagine that American women suffer from more fibroids, menorrhagia or endometriosis than the average English woman. So the question that comes to my mind when I see a huge variation of results of any sort is, what is the correct figure? What is too much or too little?

A study reported in the Journal of the American Medical Association in 1993, was the results of a panel of eight physicians who analysed the records of 712 women. It was a second opinion study and what they were looking at was the appropriateness of the operation work that was done. Overall they found that only 58 per cent of women received hysterectomies for what they called appropriate reasons. Twenty five per cent had hysterectomy for uncertain reasons and 16 per cent for inappropriate reasons.²

This raises the question, how do we benchmark appropriate hysterectomy rates? I haven't got the answer, perhaps the gynecologists have. Professor Lilford decided he would sidestep the answer and the question. He suggested, “there is no ‘correct’ hysterectomy rate, but ‘correct’ practice is to make explicit the trade-offs between the operation and the increasing number of alternatives.”³

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So, what are the factors that influence clinical practice? I believe there are three prime factors (see Figure 1). One is a belief in the benefit of the service and that belief affects both the provider and the consumer. The provider has to believe that what he or she is doing is a good thing and the consumer has to believe that it's worth going through. The second factor is that both the provider and the consumer live within a culture. The consumer lives within their own social culture, and the provider lives not only within his or her own social culture but within their own professional culture as well. Finally and very briefly, there are, of course, some economic factors. For the provider, how much is this going to cost? Can I afford to provide this service? Can I make a living out of providing this service? And for the consumer, can I afford to have this service?

Figure 1: Factors influencing hysterectomy practice

I have chosen to concentrate on the provider side of the equation. In medicine, belief in the benefit of any service is theoretically supported by the 'Holy Grail', evidence-based medicine. This paradigm plays into the myth of the physician as pure scientist. There are a number of quite clear, formal steps that we take when we are deciding to use evidence-based medicine for our practice. These are:
1. Formulate clear clinical questions
2. Search the literature
3. Evaluate for validity and usefulness
4. Apply evidence-based policy to individual patients.

It means that we as doctors can be objective and very scientific about the decisions that we make. If we follow all this assiduously it will lead to, in capital letters, the 'Only True and One Answer'.

It's a great idea. It's the way we like to make decisions about most of the things in our life. So if it's so fantastic why is the golden Grail so often only proved to be a plastic cup? If you have a look at some of these factors the answer is that it is just too hard. It's hard, it's complex, it's time consuming and the end point is sometimes too uncertain. It requires education, you need to be able to understand biostatistics and epidemiology. You need to have the time to go to the library, to go to meetings, to listen to what people have to say. You also need to be able to evaluate it all. And finally, there is just not enough good evidence.

Professor Cindy Farquar was over in Melbourne recently from the National Women's Hospital in Auckland (New Zealand). She takes part in the Cochrane database there. One of the biggest problems she has in trying to delineate information for the Cochrane database on gynecological problems is that there is just not enough good, solid research. For example, as Sonia alluded to, and so has Cindy Farquar, there is hardly any research that compares medical and surgical techniques in the dealing of menorrhagia. This creates a problem for the average provider in deciding what to do that's in the best interests of the patient.

But even if the best evidence is available it doesn’t necessarily change practice. In the UK Wyatt et al. provided evidence-based medicine to 25 different obstetric units to see if they
They gave them the resources they needed and sent obstetricians with the best Cochrane-based evidence there to talk to the leading opinion makers of the units. Despite targeting of senior medical staff, after two years, 46 per cent of those units were still not managing according to current Cochrane-based data. This means that despite all those resources evidence-based medicine is still too hard, there is something in the system that is holding this back. Is it the fact that the public health system is too overworked and can’t handle information or is there something else?

One of the questions I have is how can we improve the uptake of evidence-based medicine? Yes, it is a great idea and there is some good evidence out there, it's terrific if we actually utilise it but it is hard to take up. Some of the economic issues inhibiting take up include:

- Small area variations – physician uncertainty
- Target income model
- Monopoly markets
- Price discrimination
- Supplier-included demand (Romemer's Law)
- Transfer pricing.

Finally, I reach the issue of surgical culture, which might be a little controversial. How do doctors make clinical-practice decisions? I started with this question to myself on a particular day in an operating theatre somewhere in Australia, where I anaesthetised a woman undergoing hysterectomy because she had depression. Then I followed up by anaesthetising a woman for an endometrial ablation, and who the consultant gynecologist actually said would be far better treated with a Levonogestrel IUD, but it was good practice for the Registrar.

In 1980, Professor Scully wrote an ethnography of the behaviour of two institutions, one a private and one a public provider of obstetric care. Nearly 20 years later Dr Pearl Katz did a similar study of an 800 bed general surgical hospital in Canada, where she looked at the behaviour of a group of general surgeons. Both these studies talked of surgical culture where the prime priority is the mastery of technical skills and the development of a self-assurance in the face of any problem which tended to make it difficult to consult with other colleagues and to back down from decisions made. Both studies found the development of the surgeons’ distance from their patients in an attempt to hold up the myth of the doctor as scientist and objective decision-maker. With the development of this surgical culture arises the theory of organisation deviance where an entire organisation condones, and even nurtures, behaviour that would not be acceptable in general society. Members of this culture then justify the reasons for their decisions, trying to bring their ad hoc decisions in line with the myth of being scientific, evidence-based medicine providers.

There’s a whole range of non-evidence-based medicine possibilities for what might influence doctor decisions. These include:

- Past experience
- Previous training
- Colleague opinions and experience
- ‘Intuition’
- Culture of the particular sub-speciality
- Culture of the hospital in question
- Specific cultural background of the provider.

In some respects the doctor is left floundering. Evidence-based medicine has promised a lot but hasn’t necessarily delivered. Economics perhaps provides a resource for them if they do something surgical but doesn’t necessarily support them if they do something medical.

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5 Roemer’s Law is, a bed made is a bed filled.
goes for hospital institutions. It's very hard for hospitals when they are looking at their throughput to say we are going to do 500 less hysterectomies this year but that means 500 less patients that we get through for DHS payments.

Both the ethnographies that I've talked about are cruel indictments of medical institutions and it's hard to believe that this could be the reality of Australian practice in the 21st Century. It certainly seems a bit too easy to just blame it all on the doctors as the demon in the process. Most of the gynecologists and obstetricians that I know and work with care and worry about their patients a lot. But intelligent people who care about their patients are still not following evidence-based medicine.

I haven’t got the answers, I’m really only left with a final set of questions. What is the significance of cultural factors in clinical decision making? Because they are there and they must be important. They are not to be demonised, they are to be understood and to be worked with. What are the processes within an institution that encourages some form of behaviour over another? Does gender or age of the provider make a difference? Is there a difference now that we have more women training? Is there a difference between the practice of a young gynecologist over an older gynecologist? I could say the same thing about anesthetists, I’m not picking on gynecologists per se. Can we identify key opinion leaders that can be targeted for driving a change in practice? And finally, are there some other routes of influence that we can use? Professor Reid referred to some studies that have been done in Switzerland which looked, for example, at the effect of public education forums which have a significant change in the uptake of hysterectomy and one procedure over another. So perhaps there are other ways that we can look at this too.
There are a variety of funding sources for health care in Australia. There is the State Government, which is the primary funder of public hospitals; the Federal Government through Medicare; private insurance funds; and the patient who pays for out-of-pocket expenses. My presentation concentrates on the public health system, because that's where I'm from, and talks about the funding model, what the drivers are, how we impact upon it as a hospital, and what the overall results are.

These are my ideas on what makes an effective funding model. It has to be fair. The Victorian Department of Human Services would argue that the bottom line needs to be fair so whilst we may treat a variety of patients, overall the cost of treating those patients and the revenue received should be equal, if we are doing efficient practice. An effective funding model must reflect current accepted clinical practices, and it must not create perverse incentives. For example, if a funding model drives down length of stay to such a point where patients are discharged earlier than what's appropriate, that's a perverse incentive. Conversely, if you have a *per diem* funding model, there is no incentive, there is probably less desire to discharge the patient because you get more payment for each day they are in hospital. A funding model should never be the sole determinant of clinical practice. The funding model changes every year and every year it responds to changes in clinical practice. It should be used as an identifier of potential issues in relation to clinical practice that need to be examined.

Public hospitals in Victoria are funded via casemix funding. Briefly, this model is based on diagnostic related groups. These are groups that aim to represent homogeneous patients. It doesn't always work that way but that's what the system aims to do. A casemix funding formula such as we operate under in Victoria pays hospitals for the number and type of patients they treat. More complex patients will get more funding than less complex patients. It's based on the average patient staying an average number of days, costing an average amount of money. We all know that there will be a whole range of patients outside that average but although you will lose on some patients, you will win on others, so overall cost and revenue should be equal. Casemix funding is not designed to fund each hospital at their actual cost, it's designed to fund at an average and that's what it is predicated on.

This year's funding formula for 2001/2002 was recently released. It's actually based on 1999/2000 data. Casemix funding formulas therefore reflect clinical practice and cost structures that may be out of date. The cost weights that are used in the funding formula are developed from costing information from 16 public hospitals with only a small representation of rural hospitals. All of the big hospitals (Melbourne, Monash, Alfred, Austin) are in the cost weight study. The majority of public hospitals funding would come from case mix funding. At the Royal Women's Hospital it's about 73 per cent with additional funding coming from some others.
small grants to cover, for example, new technology, which isn't recognised in the funding formula.

Patients that have a hysterectomy fall into six diagnostic related groups (DRGs). These DRGs are based on the patient's principal diagnosis, associated diagnosis, principal procedures and associated procedures. Each DRG has a different cost weight. The cost weight is a relativity, for example, tonsillectomy, may have a cost weight of point two; a heart transplant would have one that's perhaps 16. The cost weight shows that one procedure has a significantly higher cost than the other.

The State average length of stay is the average length of stay that the government as a funder expects patients to stay. Figure 1 shows for the DRGs that hysterectomy patients fall into, that the state average length of stay has dropped since 1996/1997. I have not included 2000/2001 because the DRGs have changed so they are not necessarily comparable with previous years. You can see for each of the different DRGs the length of stay has dropped. That raises a question, does clinical practice cause a length of stay to drop, or does the funding model cause clinical practice to change to meet the funding model for the next year?

Figure 1: State average length of stay

One of the things we can look at to see if a funding model is fair is the comparison between cost and revenue. The Royal Women's Hospital data for different DRGs, are shown in Figure 2. In the majority of cases, cost and revenue are fairly equal. Figure 3 shows a similar comparison by procedure. In four of the six examples shown, cost is greater than revenue, and in one revenue is significantly higher than cost. A funder would argue that this is what the model should do, the service provider will lose revenue on some and win on others.
Funding models tend to be based on length of stay which means we expect a patient to stay an average amount of time. Patients that stay below that are what would be called financial winners. Patients that stay over that are the converse, financial losers. Figure 4 shows the different length of stays for the different procedures and how they vary.

One of the issues with the funding formula is that it assumes an homogenous population which does not always occur. Because the data are often a year and a bit old the funding formula won’t pick up new clinical practices. Laparoscopic procedures tend to cost the same as other procedures, they have more time in theatre but less length of stay in the hospital as a general rule, but that doesn’t always apply. So whilst we change clinical practice, the funding formula may not always respond to those changes in the most efficient time-wise manner.
Figure 4: Average length of stay by principal procedure
**Discussion**

**Marilyn Beaumont:**

We would now like to get some discussion going around some of the issues that were raised. It is a complex area. It is of concern that we have a real focus on difference in terms of treatment for young women, 30 to 44 years of age, for this particular issue, and on women that are educationally and economically disadvantaged. You've heard what drives some of the practice around that. Some of it might be funding related, some of it might be the inability or not wishing to take up new evidence about new ways of treating and non-invasive treatments. Is there anything that anybody has to say about what it is that needs to change? Does anything need to change?

**Jane Smith:**

I was very interested in the comments about culture. I have just spent today in Sydney because the Commonwealth and the States have funded a clinical support system project which is looking at changing the culture of clinicians with regard to taking up evidence-based medicine. They are halfway through this two-year project. They were having a discussion today about whether the clinicians were taking on board these types of projects, whether they were involved in the projects and the different sorts of methods they used to involve clinicians in using evidence-based medicine and using what consumers say what they want in their practice. So this forum was quite timely. It would be interesting in 12 months' time to see how it eventuates but it is seen as one of the primary issues today, how you get people to change practice and be involved, take ownership of the change. They need to feel the need to do it and also see how it would benefit them and their practice and the people that they are serving.

**Sonia Grover:**

That's relevant to some work I was doing with the National Health and Medical Research Council (NHMRC), which looked at changing behaviours around performing curettes. We did a study where we had a clear algorithm for people to use around who needs curettes and who doesn't need curettes. It was very straightforward, very logical and beautifully evidence based. In South Australia we randomised the gynecologists so that half the gynecologists got exposed to this algorithm and in Victoria we randomised a large group of GPs. We thought there might be different issues driving change and practice for GPs and gynaecologists. GPs would be in a position where they could keep patients and not refer them if they took up the algorithm, whereas gynecologists would not be doing procedures where they might otherwise be doing procedures. We asked people at the end of the study what was it that influenced their uptake of the algorithm. It was interesting that GPs and gynecologists said much the same thing. For GPs, medicolegal issues were a reason why they had difficulties sometimes, whereas for gynecologists that was less of an issue. One of things that drove both the GPs and the gynecologists was that women expected to have a curette done. For me, this reinforces the need to give women more information so that the expected behaviour isn't driven by the fact that mum had a curette, sister had a curette, or mum had a hysterectomy, sister had a hysterectomy. Maybe it's time women had the information to say; well, my mum had that but that was old-fashioned treatment, now there are several new things available and I'm going to find out about those new things. I have shifted my camp after that study where I've tried to influence doctors' behaviours, to thinking that I'm going to go for the women.

**Sue Giffney:**

I agree with you that we need to work with women but in our information service a common request we get is women who have seen their local GP, seen a local regional private gynaecologist and been told to have a hysterectomy. They don't even know what it's about and they come to us for information, but then they tell us they are too scared of what the doctor is
going to say if they go back with questions. Some of them have gone back, questioned the doctor, wanted another opinion, and in fact been treated very, very poorly and so they get very scared and nervous about challenging what they are being told. I know, even as assertive women, when you have been told something, especially if you don't feel well, it's hard to remain assertive. How do we help women to be more assertive without getting that attack back from the doctors?

**Kelsey Hegarty:**

I think that you have to have both angles. One of the things some of the recent research is showing is that information is provided in an unequal power relationship. I think to expect women who are disadvantaged economically and educationally to suddenly be able to absorb information and evidence and to be assertive is ridiculous. I think being a GP I can see why you might target GPs because a lot of GPs see themselves as advocates for women in that unequal power situation. Even though some females might be perpetuating continued use of methods that perhaps aren’t best practice, I think more work should be done with GPs because they spend a lot of time giving women information.

**Alison Lilley:**

There's a study I referred to before and which Beth referred to in her report, that was reported in the *Lancet* in 1988 about giving information to patients. This was a study in Switzerland, where they all speak different languages. This gave them a way to provide information to one population without providing it to another and having an uncontaminated control. They provided a media campaign about hysterectomy, what the complications were, the needs and so on. At the start of the campaign and during the following year the annual rate of operations per 100,000 women of all ages dropped by 25 per cent in the area in which they did the campaign. In the reference area, which I think was German speaking, the rate actually went up one per cent. To me it is interesting how useful it is just having general information available. I think this is true for all information. I'm sure if I went to a lawyer to ask for advice I would be taken aback. What is important is having the information out there and known, rather than knowing just the source where they can go to.

**Marilyn Beaumont:**

One of the experiences from Women's Health Victoria is whenever there is an issue in the public general media you get a higher rate of calls or requests for information about that issue. So it seems there is a combination of public education using popular media in all of the forms, providing education in terms of changing practice and involving women in the decision, and education for women themselves. It seems that younger women are much more forward about asking for information, questioning why do I need that, and maybe taking a step back and taking some time to make decisions.

One of the interesting things that was raised for me listening to the speakers was the issue of informed decision making at the time of hysterectomy. What do complications mean? I think it’s rare that women who had hysterectomies in their 30s and 40s, and who are now in their 50s, really understood what complication might have meant. The issue of sexual enjoyment is not explained or gone through. I have been talking with women in my age group about that for some years and it's very rare that any discussion would have occurred around it. Now that there are new approaches, less invasive therapies, better understanding about women's anatomy, it may be that we require some quite radical new thinking. Any other contributions?
Beth Reid:

I would like to raise the idea of the costing thing and take that a little bit further. For the group that come from areas that are socioeconomically deprived, I think we need to explore a bit more what the relative costs of the alternatives are because taking a drug over a long period of time might, for example, constitute quite a cost for some people. It might depend on their occupation and how long they could put up with the symptoms. I would have thought that some of the things that I would want to know is how quickly the relief from symptoms would occur. I was very impressed with the figures that Sonia gave about how much of the menstrual flow could be reduced by taking some of the medical alternatives. I'm sure these figures could be put in a simple way that are easy to understand for all women no matter what educational background. If symptoms stopped after only a month, that would really impress me but if it took six months and I was someone working in a job where I had to stand on my feet all the time and I had to maybe go and arrange for somebody to cover me when I had toilets breaks, I'd be less impressed. Some sociological research that is insightful about these sorts of questions would help us respond with the sort of information that women need to know as well as to the sort of things that have been raised there.

Ilana McLeod:

I've got a couple of questions. Firstly, is there a difference between a male GP and a female GP in terms of encouraging hysterectomy? It's a question I'm interested in knowing about because I know in the rural areas there are mainly male GPs and that's where hysterectomy is very high. That is just an assumption, however, it would have to be proven. The second thing I would like to raise is in relation to information giving. I don't know what it is like in Melbourne but with the GPs that I go to you're lucky if you get ten minutes. I have spoken to GPs and they are supposed to see six patients an hour, that's 10 minutes for each. I don't know how you could impart a lot of information in 10 minutes so I think that that's a big issue, not enough time spent. Another issue is the use of alternative therapies. I know if you go to a naturopath they give you a whole hour for $50, that's cheap. If you go to the doctor, you only get 10 minutes, if you're lucky, so I think that's a big issue. I have women coming in to see me and to talk about hysterectomy. For some women it's not an issue because child bearing is not a question for them and for others it's a big loss and I get people ringing up asking for support groups. I think that if you are only going to spend 10 minutes with a patient the doctor is not going to know if you are interested in having more children, and a whole heap of other issues.

Marilyn Beaumont:

Any response from anybody to those? I think that point about how a woman might perceive herself in relation to whether or not she has a womb, whether or not she wants to have children, is one that there is quite a bit of literature about. It may not be explored adequately in the sort of sessional times you are talking about, it couldn't possibly be.

Sonia Grover:

I can't answer your question about hysterectomy but we do know that female practitioners generally spend more time with patients. There has been a lot of evidence showing that, and that they deal with more women's health problems.

Marilyn Beaumont:

The evidence that has been referred to shows that women GPs spend more time counselling and use longer session times. I think the freeing up of GP time in a fee-for-service environment has been recognised through some longer session times through the medical benefits schedules. There is some recognition of the need for this but that may not be
translating into practice either. There is not much use of double booking either to have a longer consultation. Another option is getting women to come in every few days because a lot of doctors don't have time to spend 20 minutes with a client but they could have two lots of ten minute sessions in a week or something. There is also the ability for them to refer to an information provision source in order for the women to explore herself, or refer for a second opinion. There are other ways that you can enable women to be more involved in the decision.

Valda Comber:

A couple of issues that have come across. If you go for a non-surgical procedure and you go to medications then you have also got side-effects coming in, so we have the consumer medicines information that can be translated to women. That information is really difficult to even understand and so again need lots of time to explain issues. I also work for National Prescribing Services as a facilitator in exchanging information and bringing medical practitioners up-to-date with changing focuses on prescribing, and for a lot of issues it is those non-evidence-based factors that influence the practitioner making a decision. I think that's a big part of any decision, whether it's doing pharmaceuticals or a procedure. I'd like to provide an example with antibiotics. It's usually the consumer who puts the pressure on the medical practitioner to do something. There has to be an education process which has to work from the medical practitioner back to the consumer to rationalise the decision so it's a two-way, maybe three-way, decision. Education plus information are needed before any rational decision can be made and it doesn't happen with just one session or one consultation. All these issues need to be addressed all at once rather than from just a consumer point of view or from just a medical practitioner point of view.

Janet Joss:

We talked a little bit about the culture of the provider. There is a quite a lot of literature around about the influence that culture has on decisions we make around our health, whether childbirth or whether to have a PAP smear or hysterectomy. I think that is literature that hasn't been explored much. Anecdotally I know that we do more hysterectomies on some cultural groups than we do on others and it would be very interesting to explore the drivers there. There are some women from cultural groups who don't like hysterectomy, even though they are poor and disadvantaged and often don't speak English. They have been able to resist that sort of medical intervention so I don't think we should ever underestimate women. I think we need a multifaceted approach, we need to keep these issues on the public agenda. We need to say that we support practitioners who are willing to drive changes because I think some things have been driven from practitioners. If we think of all the babies we held down to do circumcisions 25 years ago, that practice has changed and that was driven by practitioners as well as consumers so I think we can work together on this. If you look at childbirth and the changes in choices around childbirth, that's taken 25 years to change because of a lot of very proactive women and a lot of very proactive practitioners and providers working together to change practice. I think it's something that takes a concerted effort, so we need more discussions like this, I think.
Sex and hysteria: do women and doctors agree on hysterectomy?

Rosie Ilett

Introduction

Hysterectomy is one of, if not, the most controversial women-specific operation, and embodies many of the complexities around medical involvement in women’s reproduction. In Australia 30,000 women every year undergo the operation. In the United States half a million procedures are performed annually and by age 60 one in three North American women will have had a hysterectomy. This paper will consider how hysterectomy is viewed by women and by the medical profession in relation to sexual functioning post-hysterectomy (particularly the experience of orgasm). It will look at writings by women’s health activists, at self-help books, at women’s testimonies and recent clinical research. It is important to declare personal experience of having had a hysterectomy 18 months ago for large and symptomatic fibroids. This does not mean unquestioning support for the procedure, and my personal and professional commitment is for open discussion and accessible information so women can make their own decisions and feel able to question and challenge medical orthodoxies. This paper does not have the space to discuss types of, or options to hysterectomy, recognising that a whole debate can be had concerning these issues.

Feminist views of hysterectomy

Women’s health movement activists in the 1960s and 1970s highlighted medical mistreatment of women and the impact of socially constructed views on medical practice. They demonstrated clearly that hysterectomy was traditionally used to curb women’s uncontrollable sexual desires and emotions. Links between the womb and emotions began in ancient Greece when Hippocrates taught that a ‘wandering uterus’ related to hysteria, and like many other female reproductive conditions, marriage was recommended as a cure. This linkage and meaning remain in the word hysterectomy, and gendered stereotypes – unquestioned motherhood, hetero / sexuality, male control of women and uncontrollable emotions – still appear to underlie medical discourse.

The now defunct British feminist magazine Spare Rib reflected the women’s movement interest in women’s health and challenged the medical profession.

“What is abundantly clear is that doctors, in keeping with their general disregard for women’s health, particularly when treating gynaecological problems, consistently fail to take a woman’s needs and feelings seriously, fail to listen to what she has to say, and fail to consider in conjunction with her, the best form of treatment. When doctors suggest we should have a hysterectomy we should be ready to challenge them. We have to ask why they want to do a hysterectomy and why they aren’t trying alternative forms of treatment for whatever problems we have”.

Health information for women

To be able to question and challenge doctors women need access to accurate and accessible health information. Since the women’s health movement this has become more widespread, and the range of self-help books, coverage in magazines and mass media, and the growing use of the Internet has exploded information possibilities for women. Most of these materials

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are not from an acknowledged feminist position, but will often encourage women to assertively advocate their own health needs. This to some degree fills the gap that many women feel in relation to information from the medical care system, as many women perceive little opportunity to access adequate information from, or to question, doctors about hysterectomy. One British study found that ‘the information available to women about hysterectomy, its alternatives and the consequences is not given in any great detail’. Most women in this study got their information via the mass media. Another British study of information for women undergoing hysterectomy found it a relatively low priority for the medical profession. It is not surprising then that women use mainstream sources and also access information from friends and relatives, continuing the female tradition of sharing personal stories and insights. The Internet is now making electronic ‘gossiping’ even easier, and for women, pre or post-hysterectomy, websites and e-groups like Hyster City, Hyster Sisters and Sans Uteri provide major sources of support and information.

Sex after hysterectomy – how do women know about it?

One area that women want more information about, or sometimes realise post-op that such information would have been useful, is around sexual activity post-hysterectomy. Having a hysterectomy undoubtedly changes women’s experience of sex. Depending on the type performed, parts of women’s complex reproductive and sexual system are removed with inevitable changes occurring. This goes alongside the emotional impact of surgery, which can be positive or negative, and the initial discomfort and pain that occur during the recovery period. Undergoing a hysterectomy can raise many deep-seated feelings of loss and regret, as well as positive responses to the removal of debilitating symptoms experienced by some women prior to the operation. All of these factors can also affect sexual enjoyment or desire. Yet many women do not have access to the correct information, or even know that such issues need to be considered.

Sexual functioning is sometimes covered in self-help books but often omitted, dismissed, or framed in male terms. Overall, the information given is highly contradictory and sometimes completely inaccurate. For example, Hysterectomy and Vaginal Repair, suggests that women and their partners should talk through sexual aspects with a health professional beforehand but then goes on to discuss post-op activity mainly in terms of the ‘husband or sexual partner’. The short section on sexual activity concludes that ‘most women find it reassuring to know that their own sexual response should be very little changed by the operation, since their external reproductive organs are unaltered. If a climax is normally experienced, this will still be possible’. However, the BMA Family Doctor Guide to Hysterectomy and the Alternatives suggests that although most women encounter no difficulties sexually after the operation ‘a minority feel that their orgasms are less intense following the removal of the cervix’.

Some books are more honest and informative, although sometimes with differing views. Hysterectomy and the Alternatives by Jan Clark devotes nearly ten pages to sex, considers physiological impact of the operation and even raises the possibility that nerve damage in the pelvic region during hysterectomy may have an effect. Another popular book, Hysterectomy – The Women’s View by Nikki Henriques and Anne Dickson states that ‘with your clitoris and

11 ibid.
your vagina intact, your sexual response will remain the same. Your capacity to enjoy orgasm need not be affected at all because your clitoris is untouched and even though the uterus is gone, as you probably don’t feel the contractions before, it isn’t going to make much difference’. 14 Suzie Hayman’s Hysterectomy: What it is and how you can cope with it successfully, covers emotional aspects, but also describes the physical impact of the operation ‘during orgasm we know that not only the vagina but also the uterus and the ligaments that hold it in place, contract and spasm. If the womb and its supports are taken away, some of the muscular ripples that excite the clitoris to its explosion of pleasure are removed as well’. 15

Spare Rib (in 1981) covered this in great detail, ‘During orgasm, the uterus contracts and studies suggest that more intense orgasms are sometimes associated with stronger contractions. So for some women after a hysterectomy orgasm may not reach the same physiological intensity as before. If the ovaries are also removed there may be a reduction in vaginal lubrication resulting in painful intercourse and / or delayed sexual response. Some women find these changes distressing and feel there is a marked decrease in their level of sexual pleasure. For other women though, these changes are totally insignificant as compared to the relief the hysterectomy brings. If a woman has a severe pelvic infection or a heavy, tender uterus, orgasms will be painful and the removal of the womb will increase the possibility for sexual pleasure’. 15

The role of the doctor

This brief survey demonstrates that Spare Rib’s 1981 account is still highly contested and does not reflect the general content of health information for women. Post-hysterectomy, women often cite this gap. One American study of over one hundred post-hysterectomy patients found that one-fourth received insufficient information about possible changes in sexual feelings and functioning, and experienced difficulties in obtaining such information from health professionals. In this study many women turned to friends and relatives or the mass media. 17 A similar study of New Zealand women post-pelvic floor surgery, found that half the sample identified the lack of information about the potential effects on sexual functioning as a major deficit. 18 It is important that women share experiences and that public information is more readily available, yet there are obvious issues in the types and content of the messages being given.

It would make sense if women were given the opportunity to discuss sexual issues whilst making an informed decision about their hysterectomy or possible alternatives - yet knowledge is rarely given to women in this context. The difficulty in imagining a male gynaecologist openly asking and advising women about their experience of orgasm emphasises the loaded cultural, social and gendered complexities that surround hysterectomy – and the power / gender relationships within the doctor / patient relationship. (Interestingly, procedures relating to male sexuality, such as testicular cancer and prostate cancer, are viewed in different terms as sex post-operation is on the agenda for discussion. Useful comparisons could be made between medical attitudes to information-giving in these male cases to see where gendered stereotypes and sexual expectations meet).

16 Cape, op cit.
What happens after the operation?

The obvious lack of information leaves many women post-hysterectomy in a state of surprise, shock, grief and dismay as women from the Hyster City e-group show.

I just can’t have an orgasm. It kind of stinks, but I also have no sex drive. Hubby doesn’t like it at all. Oh well I guess he’ll get over it.

Lucy

Well, I kinda believe “something” changes. I have noticed a great change in orgasms. Used to get that deep, almost pulsating feeling. Now, after my hysterectomy. I know it happened but that pulsating feeling is no longer there. It is so different that I almost feel like I “didn’t quite get there” or something. Kinda frustrating. Has anyone else had a similar side effect?

Christy

I haven’t had a normal orgasm in almost two years. I’m very emotional. I cry all the time. I have a wonderful hubby. He says there is hope for me. =o) . . . . I’ve had an orgasm before and I want it back! . . . . I’m not sure how long it might take for my orgasms to come back. If this doesn’t work, I’ll try something else. I’m not giving up!!

Ducky

I feel cheated and lied to by those who told me “Sex is no different”. Well, it is different, very different. I am hoping that with time and more healing things will get better.

Lisa

I also have no sex drive whatsoever. . . . I guess it’s good that I’m not in a relationship since there is no hubby to argue with. If I were, I’m sure this would be a good source of contention. On the other hand I have no motivation at all to go out and get into a relationship.

Lynx

Regular readings of the Hyster City site indicate that women are reporting overall that post-hysterectomy their sex life, especially the level and quality of orgasm, is affected. Occasionally some women disagree or feel that this is not so important as other factors:

Sex is WONDERFUL! No more pain! No back pain or painful intercourse, in fact I can move around more and resume positions that were abandoned years ago because of pelvic and back pain . . . I was worried about some horror stories I heard that sex would not be good or I wouldn’t achieve orgasm again but it has been great and my mind was put at ease when I reached 2 orgasms the first time we had sex.

Liz

For me, the desire to be sexually active returned RIGHT AWAY and I do mean right away. There are some differences since the surgery – but that have not been insurmountable.

Bonnie

Some women are happy to give other women the facts and suggest ways to deal with them:

During orgasm the uterus contracts and for some women this gives a pleasurable feeling. Of course you don’t have that after a hysterectomy. A hysterectomy should not change a clitoral orgasm. . . . My doctor told me to practice a lot and things would improve. I’ve found this to be true. I suggest anything that will stimulate the clitoris. Use your imagination, but don’t limit yourself to just that!!

Artic

19 All these quotes are taken from postings to the Hyster City e-group during April and May 2001.
These few examples indicate women’s need to understand the effect that a hysterectomy will have on all aspects of their life experience. This is reinforced by my own experience of working with individual women who are struggling to come to terms with what has happened.

Doctors and discourse

At the Centre for Women’s Health in Glasgow, Scotland I have had many discussions with women, pre- and post-hysterectomy, who either feel unable to ask their consultants about sexuality and likely sexual functioning, or who are unhappy with the result of the operation and feel that information was denied them. Discussion that takes place, if it does, is usually confined to the role of the cervix that usually assumes heterosexual penetration. This excludes women who do not engage in penetration or in direct clitoral stimulation of any kind, and also may overstate the role of the cervix (although there is evidence that the cervix has a role in vaginal lubrication). However, this does not mean that removal of the cervix, if not necessary, should be undertaken and there are national preferences for carrying out supracervical hysterectomies.

Contemporary medical discourse is that women’s sexual functioning is not reduced by hysterectomy and recent medical studies that confirm this have gained wide publicity. Although Masters and Johnson in the 1960s showed that for some women the uterus plays a key role in sexual pleasure, this has been argued about ever since. Studies which agree that hysterectomy can reduce women’s sex drive and affect sexual experience often appear in non-gynaecological journals, and may not reach the majority of surgeons and consultants responsible for hysterectomies.

Other examples can reach wider prominence. One study, reported in a gynaecological journal, surveyed 110 women in 1999 to understand the role of the uterus in female sexual response and found that even though the number of orgasms did not necessarily change, the richness of the experience was lessened. Some, usually North American, gynaecologists are speaking out on the Net about women’s changed experience. For example Dr Paul D Indman asks ‘How would a male gynaecologist begin to know anything about a woman’s orgasm? In my pre-operative counselling for hysterectomy I discuss sexuality, orgasm and hysterectomy. And I tell my patient that a year later I’m going to ask her about it’. Dr Bill Lloyd says that a hysterectomy can greatly affect the ability to orgasm in some women. He adds that he hesitates to say this ‘mostly out of fear of infuriating my gynaecological colleagues’ as he knows they will disagree.

A number of high-profile recent studies however indicate that experience of sex improves after hysterectomy. One - by Rhodes, Kjerulf, Lanenberg and Guzinski of the University of Maryland, Baltimore - set out to examine changes in sexual functioning via a two year prospective study of over 1000 women who had had a hysterectomy during 1992 and 1993. This included measures of sexual functioning prior to the operation, and at various stages

22 Indman PD. The basics of gynaecology: what every woman should know. Hysterectomy will ruin my sex life: orgasm will never be the same. http://www.obgyn.net/women/articles/indman/indman_archives.htm/ 2001
after. This study – the Maryland Women’s Health Study – has become a new benchmark and although its findings are interesting, there are a number of issues around data collection and assumptions made. I will make a few comments on this study as it has gained much currency in this debate.

The researchers acknowledge that other research has found that women experience a deterioration in sexual functioning post-hysterectomy, as well as that which finds the opposite. They say, in an aside, that ‘it seems plausible that removal of the uterus could have adverse effects on sexual function through one or more of the numerous mechanisms that have been suggested’. Study participants were asked the same questions throughout the research process, pre and post hysterectomy, covering the amount of sexual relations and whether women had experienced pain, orgasm, vaginal dryness and / or desired sex. These responses were supplemented with riders such as, in relation to orgasm ‘in the last month how strong has orgasm been for you?’ with potential answers being very strong, strong, mild or very mild. Responses to this question indicated that orgasm frequency increased after hysterectomy. Overall almost 63% of participants experienced orgasms before hysterectomy, rising to approximately 72% at 12 and 24 months after the operation, although ‘not experiencing orgasms before hysterectomy was the factor most highly associated with not experiencing orgasms 12 months after hysterectomy’. The study also found that women’s libido increased post hysterectomy.

The findings appear quite clear, yet the authors themselves report the inconsistencies in such research findings. They accept that it is ‘plausible’ that the removal of organs impacts on women’s sexual experience but what appears to be missing in this, and other studies is an awareness of the built-in flaws in some of the questions which appear to go on to prove the exact opposite. There are many reasons why some women post-hysterectomy will be happier about their sexual experience. As the researchers say, and some women from Hyster City confirm, prior to hysterectomy many women are in pain or discomfort, so sex after is an improvement. Feeling desired, having better self-esteem, feeling free from the need to use contraception, and free from possibly painful and exhausting periods are other factors which may improve women’s sexual enjoyment. The way that women articulate, describe and discuss their own orgasms – and libido - is a complex subject and for many women being asked such research questions may not necessarily ensure the most accurate answers. This complexity is commented upon in a recent literature review by Canadian researchers which, although it found some evidence that published studies have found that most women experience few sexual problems after a hysterectomy, highlighted difficulties in research design and methodology.

Conclusion – the doctors won’t like it

It appears astonishing that in the 21st century many long-held views about women appear to underpin the way hysterectomy is socially and culturally understood. For women facing a traumatic and irreversible decision and life experience, there is exclusion from decision-making, from the construction of medical opinion about women’s bodies and from potentially receiving a good and positive health outcome. There are strong lobbies pro and against hysterectomy and shades of morality and Hippocrates frequently arise. Having fully orgasmic women enjoying sex into their later years, with all the self-confidence and self-esteem that that may bring (and with no ability to procreate) may be quite a threat ! Recently reported findings that Viagra can affect women similarly to men links into this, and it may be of interest to see if this becomes part of the hysterectomy discourse.

25 ibid.
26 ibid.
It could be argued that giving women the correct information could reduce the number of hysterectomies taking place, which will undermine the knowledge and power base of some medical specialisms and will also affect the income of many gynaecologists in countries with private medical care. As the anti-hysterectomy book, *The Case Against Hysterectomy*, says ‘women are clearly faced with a dilemma if they are presented with true information about the consequences of hysterectomy: they alone must decide whether to have this most serious operation, or not. If a woman’s pain, or continuous debilitating condition, is so severe that a hysterectomy is the only reasonable solution after other lesser therapies have been tried, it may well be that she will feel so much better from the relief of pain that she is prepared to live with a subsequently less satisfactory sex life. What is certain for all hysterectomised women is that sex will not be improved by having a hysterectomy as is often stated in books and magazine articles written by gynaecologists.’ From the evidence this has to be true. Women are being (sometimes deliberately) prevented from accessing information which will allow them to make better informed choices about their own health and quality of life. Whether they make the same decision or not, the process of absorbing and mulling through knowledge and possible outcomes is vital and empowering.

Most societies are not comfortable with women’s sexuality being self-determined, and the role and power of the medical profession in this arena cannot be denied. I have recently been working with gynaecological nurses on an information booklet for hysterectomy patients in local hospitals. Discussing the material to include has been an interesting process and never more so than in relation to sex. The nurses are committed to women, their right to knowledge, to health and to good sex but are wary of what (male) consultant doctors will think and how they (as female nurses) will be viewed as trouble-makers by giving women too much information. Evidence-based medicine is the contemporary medical credo, and this has to expand to include recipients of health care, in this case women, who are traditionally underserved in information provision. No-one should have a hysterectomy and feel like Lucy or Lisa or Ducky. Ignorance is very definitely – in this case - not bliss.

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Evaluation

The forum was held on the evening of Monday, 2nd July 2001, at the Hotel Grand Chancellor, Melbourne. Invitations were targeted at regional women’s health services, gynaecologists, general practitioners and the Department of Human Services. Sixty-nine people advised WHV that they would attend the forum, with 58 attending on the night, including speakers and some WHV staff. Most attendees heard about the forum from professional networks (44%) or from a personal invitation (31%), a reflection of our advertising of the forum via the College of Obstetricians and Gynaecologists and a large mail out to individuals.

Evaluation forms were completed by 32 participants, just over half of all attendees. Respondents were asked to rate various aspects of the forum and the responses show that overall, participants were pleased with the forum, as shown in the figures below.

The topic was obviously a popular one with most people rating it as 6 (out of a possible 7). The average rating for the speakers and the content of the forum was also 6. The discussion and ability to participate at the forum rated slightly lower, with an average of 5 being given by respondents. As shown in the figures below, however, these aspects of the forum received some ratings at and below the average.

The time, venue and refreshments available at the forum were generally rated above the average at 5 or 6, with most dissatisfaction being shown for the refreshments. These results have already been conveyed to the caterers.
Content of the forum

Discussion at the forum

Ability to participate at the forum

The time of the forum
In addition to the forum ratings, we received the following comments from participants:

- Raised very pertinent issues.
- Need food before start – hypoglycaemic!
- Fantastic speakers – great information for practitioners.
- More time should have been allocated to the speakers – just a little rushed. [Comment from another attendee:] I agree.
- A topic that needs to be discussed – great to see we are finally focusing on it. This forum is the beginning of the way forward.
- Important topic – not a ‘fashionable’ topic – need to ensure it stays in the public [eye].
- Great – diversity of speakers and audience.
• Much-needed topic for discussion! Would be good to have consumer perspective.
• Extremely interesting, thought-provoking. Working in a private hospital, these issues apply to us as well as public sector. Short discussions were too rushed. Questions could have been asked at the end or during the speaker’s talk – would have been ideal.
• Speakers appeared rushed. Questions for individual speakers might have been more appropriate.
• Some terminology used was not useful to me.
• Stimulating and relevant to work. Very pleased to be at a clean function with no drug companies’ sponsorship. Thanks.
• Great venue in terms of situation in city. Very difficult to see overheads. Made it difficult to get utmost out of speakers.
• Difficult to see overheads at back of room.
• Would have liked to hear more from both the rural perspective and also from women’s experiences of hysterectomy and the options (or lack of) offered.
• Very informative.

These evaluation results show that hysterectomy and its alternatives is an extremely important topic for discussion and that further forums of this nature are one way of engaging in open debate on the issue. This is something that Women’s Health Victoria as well as other organisations can be involved in organising. For Women’s Health Victoria, these results also highlight how important it is to let invited speakers have adequate time to speak. They also indicate the need to explore ways of engendering better attendee participation.
List of Participants

Damon Adamson  Dorothy Martin
Rita Bachowski  Jackie Mellett
Charles Barbaro  Sue Murray
Marilyn Beaumont  Aviva Nathan
Gabrielle Bennett  Marcela Pasieczny
Pam Bull  Jenny Radnell
Sue Burke  Beth Reid
Josephine Chan  Mary Russell
Joo Chua  Naomi Schwarz
Marian Collis  Rosemary Sexton
Valda Comber  Sekai Shand
Rosemary Coulter  Sarwat Shenouda
Kay Currie  Janet Spink
Barbara Dight  Lesley Thornton
Mary Draper  Victoria Wheeler
Anna Drylie  Jane Widdison
Leonie Feery  Laurie Williams
Chris Ferlazzo  Jillian Woinarski
Dianne Fletcher  Christine Woon
Sue Giffney
Sonia Grover
Kerry Hampton
Kelsey Hegarty
Miew Hoi
Sharyn Jencke
Charmaine Johnston
Kim Johnstone
Janet Joss
Michelle Kealy
Raphael Kuhn
Kaixin Lee
Yoke Beng Lee
Alison Lilley
Lee Lim
Sue Low
Carolyn Lunt
Eileen Lynch
Jane McEniery
Ilana McLeod