The 1987 National Women’s Hospital (NWH) ‘Unfortunate Experiment’. Accusations of unethical experiments and undertreatment, resulting in excess deaths from cervical cancer. Facts and fables

Was there an ‘Unfortunate Experiment’?—From the early 1960s NWH clinicians became increasingly aware that eradication of grade 3 cervical dysplasia CIN3, (abnormal cells but not cancer) was unpredictable and often had little relationship to the initial management or the completeness of excision of the lesion—thus the standard management of immediate, major, sterilizing surgery of hysterectomy on young women began to be questioned.

In 1966 Professor Green and other senior NWH clinicians endorsed policy changes in dysplasia management. Younger women were to be continuously monitored, by repeat smears, colposcopy, lesser biopsies and appropriate more major surgery if evidence of early cancer. This policy was later described in Metro 1987 as the Unfortunate Experiment. In this era, diagnosis of CIN3 rapidly escalated worldwide. Opinions in grading of cytology, histology and microinvasion were contentious and often acrimonious.

The McIndoe Review—In 1984, three NWH staff, a pathologist, and a colposcytologist (both now deceased), and an obstetrics and gynaecology (O+G) clinician Dr Ron W Jones, published a retrospective review (known as the McIndoe Paper) of the management of 948 women presenting at NWH 1955–76 with CIN3.1 (Available at http://www.nzma.org.nz/journal/123-1319/4244/McIndoe.pdf with handwritten comments by G Overton)

The objective of the review was to clarify whether post-treatment continuing CIN3, was related to the type of initial treatment or the completeness of excision of the lesion. Treatment had been by three separate clinical teams at NWH.

The McIndoe authors in 1984 divided the 948 women reviewed, into two groups, based on cervical cytology two years after initial treatment,1 (p452, para 7) Group 1: 817 women with post treatment normal smears. Group 2: 131 women with post-treatment continuing abnormal smears. The statistician of the McIndoe Paper confirms that the division of the 948 women, into two groups in 1984 was based on post-treatment cytology and not on treatments received.2

The principal initial treatment of the 948 women reviewed was hysterectomy in 250, cone excision of cervix 667, amputation of cervix 6, punch or wedge biopsy 25—total 948.1 (p452, Table 1)

In the 817 group 1 women with post-treatment normal smears, the initial treatment had been hysterectomy in 217 (26%), cone excision 579 (70%), amputation of cervix 6, punch or wedge biopsy 15.1 (p456, Table 4)

In the 131 group 2 women with ‘post-treatment’ continuing abnormal smears (CIN3), the initial treatment had been hysterectomy in 33 (25%), cone excision in 88 (67%) and punch or wedge biopsies in 10 (p454 para 4). Note the percentage of initial major
treatments is similar in groups 1 + 2. Because of post initial treatment continuing CIN3, the 131 group 2 women received a subsequent 107 additional major treatments of hysterectomy in 29 and further cone excisions in 78.1 (p455 para 2) The total major treatments in these 131 group 2 women, were now a total of 228.

The genesis of the NWH 1987 Inquiry was a 1983 liaison between two groups disaffected with the two senior NWH Professors. The first group was the authors of the 1984 McIndoe Paper who believed that conservative management of CIN3 was an increased risk of invasive cancer—but could not convince the Professors or most of the senior NWH clinical staff. The second group comprised of members of a women’s reform group (Fertility Action) who had antipathy to male-dominated issues of women’s health and one of the Professor’s negative attitude towards ‘abortion on demand’, rather than for medical reasons.

Unexpectedly, the 1984 McIndoe Paper statistics listed below showed no relationship between the type of initial treatment or the completeness of excision of the lesion—to persisting CIN3.

- ‘Thus whether or not the lesion is completely excised does not appear to influence the possibility of invasion occurring subsequently’. 1 (p457 para 4) 
- ‘The 817 patients in group 1 remained clinically and cytologically normal for the first 4 years after the initial biopsy irrespective as to whether or not there was evidence of complete excision of CIS’.1 (p453 para 6) 
- ‘The 131 patients in group 2 continued to produce abnormal cytology—irrespective of the initial management or completeness of excision of the lesion’.1 (p 454 para 4) This failed to confirm the McIndoe authors’ belief of dangers in conservative management. What to do now? The solution—create a major scandal.

**Genesis of a major medical scandal**—The division of the 948 women reviewed 1955–76 into groups 1 and 2 was by the McIndoe Paper in 1984, and was based on positive or negative smears 2 years after initial treatment. However the McIndoe Paper text paradoxically implies groups 1 and 2 were two separate groups treated differently in an unethical prospective study (1955–76). Page 458 para 3 states ‘the conservative management of group 2 patients in whom complete excision was not considered a necessity’.1 There were no groups 1 and 2 in the 1955–76 era reviewed.

The McIndoe authors further enhanced the above damaging inferences by stating1 (p458 para 7)—that continuing abnormal cytology after initial treatment had a high risk of developing cervical cancer—again inferring inadequate initial treatment. They failed to inform that after their 121 initial major treatments, the 131 group 2 women received a subsequent 107 major treatments of hysterectomy in 29 and cone excision in 78. A total of 228 major treatments in 131 group 2 women.

The McIndoe authors ‘concealed’ the subsequent 107 major treatments in the 131 group 2 women, uncured by their initial 121 major treatments. They stated they were further biopsies. ‘Final diagnosis in this group was established by further biopsy’—‘by cone biopsy in 78 and hysterectomy in 29’.1 (p455 para 2) Stating these 107 additional, major treatments were ‘further biopsies’, later gave validity to the 1987 Fertility
Action, *Metro* accusations of ‘limited or no treatment’ of the 131 women of McIndoe group 2.

**Perfidious manipulation**—In *Metro* 1987, members of Fertility Action compounded the McIndoe Paper’s damaging inferences of two separate groups treated differently. They stated that the 1984 ‘McIndoe group 2’ of 131 ‘uncured’ women, was a group 2 of 131 ‘limited or no treatment’ women. Ref. *Metro* June 1987 p60 para 5, ‘12 of the total number had died of invasive cancer, 4 or 0.5% of group 1 women, and 8 or 6% of the group 2 women who had limited or no treatment’. This fiction was accepted. The Unfortunate Experiment was now a proven reality and remains so.

**The McIndoe text is duplicitous**—Are the 1984 McIndoe cancer deaths’ statistics correct? They showed 41 cancers and 12 cancer deaths (1.25%) in 948 women treated for CIN3 at NWH 1955–76. In 1988 a larger review, 1955–86, was completed by two senior NWH cancer unit clinicians. It included the 948 women from the 1955–76 reviewed in the McIndoe Paper. This later review showed 32 cancers and 8 cancer deaths (0.25%) in 3037 women treated for CIN3 in the 30 years 1955–86. These discrepancies require clarification.

In a book *The Unfortunate Experiment* (Penguin 1988, p17) a 1987 *Metro* author confirms that in 1985 (2 years before their 1987 *Metro* article) they knew that groups 1 and 2 were not treatment-based but were cytology-based and designated as such in 1984. They were thus aware that the McIndoe 131 group 2 women had received 228 major treatments. This *Metro* unchallenged accusation of a mythical ‘limited or no treatment’ group 2, precipitated a major medical scandal—The Unfortunate Experiment.3

In the above book, *The Unfortunate Experiment*, page 6 refers to the final submission of the Ministry of Women’s Affairs to the 1987 Inquiry, ‘Ultimately the issues are about who controls medicine’ and ‘the central issue above all others is power’. This suggests that the Ministry’s agenda was wider than an investigation into alleged patient mismanagement. There was rapid endorsement of the 1987 *Metro* revelations, by the Ministry of Health, the Ministry of Women’s Affairs, Fertility Action and sensation-seeking media.

A Judicial Inquiry, and its terms of reference, was announced by the Minister of Health, just 6 days after the *Metro* accusations. This announcement was prior to any dialogue with the accused NWH clinicians or their employers, the Auckland Hospital Board. Was the Inquiry waiting in the wings for the *Metro* exposé?4

**The 1987 Judicial Inquiry**—Pivotal was the McIndoe authors (including Dr Jones’) continued silence throughout the Inquiry in regard to the correct statistics of 228 major treatments in 131 women they designated as group 2 in 1984. This allowed the Fertility Action accusations of ‘limited or no treatment’ in the 131 group 2 women to remain unchallenged.

This incorrect information presented to the Inquiry by two disaffected groups, was accepted.

Inquiry Report p95: ‘The *Metro* article and its emphasis are correct’. Inquiry Report p150: ‘The McIndoe Paper distinguishes between two groups and 22% of those whose abnormalities were ‘untreated’ developed invasive cancer.’ Following the acceptance
of these extreme accusations, the acceptance of others, involving ‘patient’s rights and informed consent’, were little more than a formality. For over two decades this fallacy of an undertreated group 2, has been promoted and zealously guarded by a coterie of agenda driven groups—some not medically qualified, and others ‘non’ clinicians. They have powerful political connections, essentially unlimited resources, favoured media access and show degrees of demeaning paranoia to opposing opinions.

Following the ‘scandal’ of the ‘Unfortunate Experiment’ there were demands for major changes in control and direction of New Zealand Health Services. These were very successful. The Medical Profession was essentially disenfranchised and mainly excluded from the Medical Council. Expensive, escalating bureaucracy, sympathetic to specific agendas, became the new order.

The Post Graduate School of O+G was closed. The respected NWH and the Greenlane Cardiac Unit were downgraded. St Helen’s Obstetric Hospital was closed and midwives replaced doctors as lead caregivers in maternity services. General practitioners were strictly controlled. Availability of state-funded first class medical services has rapidly declined. Many New Zealand doctors have moved overseas to better salaries, less control by bureaucrats and greater respect for their contributions.

The learning curve—Optimal management of CIN3, in the 1960s–70s was controversial and sometimes acrimonious. Contrary opinions were rife and exploited by Fertility Action in their 1987 fictitious Metro accusations. The astute observations of clinicians, such as Professor Green and others worldwide, were well ahead of the ‘later clarification’ of the role of the human papilloma virus. Countless young women were thus spared unnecessary, major sterilizing surgery. Who did what, how, where and when, in this 40–50 years dysplasia treatment debate shows an excess of variable subjective opinions. The only non-contestable denominator is ‘patient’ deaths. To repeat—8 cancer deaths in 3037 women presenting at NWH with CIN3, over 30 years, 1955–86, confirms excellent management. NWH deserves praise and gratitude. Vindication of the wrongly accused and disgraced NWH clinicians is of paramount importance.

Postscript—The value and strengths of a democratic process are that credible and verifiable opposing opinions should be able to be expressed without prejudice—and be open to public debate. However in revisiting the Unfortunate Experiment this is not possible. Contrary opinions are not welcome, are seldom printed and invoke demeaning criticism rather than discussion. In New Zealand, revisiting the Unfortunate Experiment is a minefield inviting self-destruction. This is a dangerous precedent and merits urgent discussion involving the public, politicians and unbiased media.

Graeme H Overton
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Reference and endnotes

2. A memo from Statistician of 1984 McIndoe Paper to the lawyer Mr Kevin Ryan, 15-6-90, “The implication that the abnormalities were untreated is, on the information presented in our 1984 paper, quite false: the group was defined as “continuing to produce abnormal cytology”, not as having been untreated. Again the 1984 Paper was in terms of a second group of patients who “continued to produce abnormal cytology”, not a group that was “conservatively treated”.

3. Confirmation that the 1987 Metro authors were aware group 2 was not untreated. Book “The Unfortunate Experiment”, Penguin 1988, page 17—Quote Metro author “The first mistake concerned how the authors had divided the women into two groups. “We thought this had been done on the basis of the treatment they had received, whether conservative or otherwise. But the key fact in establishing the two groups, had actually been whether the women had positive or negative cytology” (post treatment).

4. Confirmation by Superintendent in Chief of Auckland Hospital Board (AHB) of announcement of Judicial Inquiry prior to discussion of Metro accusations with NWH clinicians or AHB. On 5-6-87, AHB received a letter from Minister of Health requesting a report on the Metro article, re cancer treatment at NWH. “On or about 8-6-87 I prepared a preliminary report to the Board and on the 10-6-87 a letter was forwarded to the Minister of Health”, i.e. on the same day the Minister announced the establishment of a committee of Inquiry and its terms of reference, i.e. just 6 days after the Metro Magazine accusations.