

## Joint Health Committee – Meeting of 17<sup>th</sup> December 2019

### **Opening Statement by Ms. Lorraine Walsh, advocate for CervicalCheck patients**

The last 18 months have been the most psychologically challenging in my life. No citizen of this country would seek this trauma out. When myself and the other women in the 221+ Group were told of a potential missed opportunity to detect our cancers at an earlier stage compounded with the fact that this information was withheld from us it threw us into a black hole and we all needed and wanted the truth and as patient advocates that is what this journey for Vicky, Stephen and I has been about.

Why do we do what we do as patient advocates? To restore the trust for ourselves which in turn will help restore trust for others in the system. We bore the pressure of that for the benefit of everyone. We did not want what happened to us to happen to anyone else. The needless pain, loss and suffering. Advocacy has been a chance for us to rebuild hope and trust, but it comes at a price, it has been cathartic, heartbreaking, emotionally draining and has had a huge impact on our everyday lives and work, relationships and mental health.

Gabriel Scally's investigations and subsequent reports brought many answers but not every answer. Dr Scally stated it was "a system doomed to fail" and "The Scoping Inquiry concluded, on the basis of visits to laboratories and examination of their records, that there was no reason why those laboratories **currently** providing screening for CervicalCheck could not continue to do so. It was not feasible to reach conclusions on how satisfactory, or otherwise, was the operation of the laboratories which provided services to CervicalCheck in the early years of the screening programme. Some of these laboratories no longer exist, some no longer conduct screening and, in any event, making such retrospective judgments was not feasible. The Final Report of the Scoping Inquiry recommended that 'Audits should continue to be an important component of cervical screening'. It is important that clear priority is given to clinical audit of contemporary screening services so that improvements can benefit women in the short term". Dr. Scally reported on huge deficiencies in oversight, procurement, quality assurance and auditing of the system and his findings gave insights into what went so wrong for so many of us. The real success of his report and recommendations can only be appreciated when it is fully implemented, this is paramount for the future success of screening in Ireland.

RCOG were commissioned to compile a report into individual cases to see if there were missed opportunities and if so their implications for women. RCOG found an array of missed opportunities in relation to screening together with some colposcopy management concerns. The HSE worked on the communication and disclosure of this information and put in much effort into working with Clinicians to ensure that the women and families were treated with sensitivity, respect and compassion and given the appropriate support they needed to process what was for many heart scalding information. I want to thank each and every one involved in this process as by and large the feedback from women and families was very positive in relation to disclosure.

My own experience has not been positive or reassuring in seeking the truth in relation to RCOG

- I had worked closely with the HSE over the last year in relation to the planning of RCOG and giving the patient's voice in this. The reports finally started to filter through in late August, early September, from an early stage it was clear there were various issues in relation to

accuracy of the information in reports which were continuously returned to RCOG, examples of these included incorrect smear dates, incorrect diagnosis dates and incorrect staging of their cancer. On one call to discuss the issues it was suggested that there were “cutting and pasting” issues arising that may be contributing to the inaccuracy of the reports.

- On 2<sup>nd</sup> October I was contacted by HSE and informed that following the return of the slides from RCOG to the labs that the lab had identified a mislabelling issue with 3 women’s slides, the labels had been removed and replaced on the incorrect slides. Two of the three women involved with this mislabelling were Vicky Phelan and I.
- On 3<sup>rd</sup> of October I attended a Cervical Check Steering committee in Dept of Health where I voiced my concerns in relation to verification of reports and their quality assurance process involved in the checking of reports before releasing. I was appointed to this committee in June 2018 by the Minister for Health to give a voice to the women involved in the Cervical Check Debacle. Meanwhile, women were feeding back to me that the reports they were receiving still contained inaccurate information. I was placated and informed there was no need for any concern and also informed they did not like my tone, I knew what that meant, so I retreated to a position of silence.
- Finding the reply at the Cervical Check Steering committee unsatisfactory, I raised the matter with the 221+ Board group, we wrote to Dept of Health on 9/10/19 reiterating our concerns, they replied on 11/10/19
- People often forget what is said, but you don’t forget how you are treated, eventually I had enough of being treated like I was not worthy and did not matter so I removed myself, my resilience could no longer sustain the pressure. A culmination of feeling irrelevant, the inaccuracies in the RCOG reports I was aware of from HSE, women contacting me directly regarding inaccuracies and the amount of time I felt I was wasting not being listened to, forced me to resign, an act I did not take lightly but had to for my conscience. I wrote to Minister for Health on 31/10/2019 advising him of my resignation, I did not include my concerns in my resignation letter as I did not have any proof at that stage, but I did tell him exactly the reasons why I was resigning when he called me that day.
- 15<sup>th</sup> November – I receive RCOG Report No 1 – outlining my one and only slide prior to diagnosis from June 2011 was unavailable, by their classification of this report was in the concordant group.
- 15<sup>th</sup> November – My solicitor receives 3 page letter from HSE outlining the movements of my slide from June 2011 that was deemed “unavailable” by RCOG (ironically the first and last paragraph refers to the fact that the errors would have no impact on my RCOG review)
- 15<sup>th</sup> November approx. 6pm – HSE call to say that RCOG had produced Report No 2 and that they would hand deliver it to Galway
- 16<sup>th</sup> November – two very kind compassionate ladies from HSE that I had worked with closely through my advocacy hand delivered my report no 2 to my home, my husband was so angry that he couldn’t even stay in the house he had to leave, he was angry but I think more hurt that I was so upset. For the record I have the utmost respect for the employees that have worked with us from the HSE, they always treated us with absolute respect

- RCOG Report No 2 – the missing slide was found and my report was now classified as a discordant result
- I became the victim of my own concerns, I voiced my concerns to the most senior people in our Health System but it would seem that women are still not being listened to

It is important from our experience to caveat the RCOG aggregate report findings with the following:

- A little over half participated, of approximately 1850 women invited to participate that had screening prior to diagnosis through the Cervical Check Programme, 1038 participated which is 56% participation rate, so we are not looking at the full picture
- Whilst not questioning the clinical assessment of each case, the accuracy of the administration of those reports and how they processed the information has not been accurate in some cases from our experience
- A Statement signed by RCOG and three other organisations working in the UK's Cervical Screening programme on 18<sup>th</sup> April 2019 stated there "was an urgent need to address the outdated IT systems that support screening, the programmes IT infrastructure was deemed not fit for purpose in 2011, since then, little progress has been made". This raises concerns of the integrity of the statistical reporting capabilities.
- RCOG success based on percentages of discordant versus concordant but the percentage of concordant would seem skewed and non intuitive. Cases involving missing slides were classified in some cases as concordant when they should intuitively have been classified as inconclusive
- Further concerns around the integrity of the processing of the information were raised by the mislabelling incident (the circumstances surrounding the removal of labels and incorrectly replaced on a different woman's slide were not adequately explained)
- Where a system produces incorrect reports subsequently spotted by the women concerned the reliability and the accuracy of all reports cannot be trusted

I can't face another year of negativity and anguish leaving myself and other women feeling distraught, hopeless, powerless and with burn out. It is not good enough that we are still going around in circles seeking the unpalatable answers to allow us to try and regain our peace of mind and the ability to sleep at night.

Last week I met my consultant for the first time since this broke in April 2018 feeling apprehensive, hurt and broken. I had trusted this doctor with my life who has always treated me with the utmost respect. We had an honest and frank discussion airing our views, concerns, criticisms but both coming to and desiring the same outcome being a screening system that women can have faith in. I am asked all the time by Irishwomen can they trust the results of their smears. We need to encourage the uptake of HPV vaccinations for girls and boys in order to reduce incidences of cervical cancer, but this takes time and faith on behalf of parents to vaccinate their children. In the meantime, women are

being diagnosed with cervical cancer every day, battling the disease through treatment. We have a huge survivorship that desperately needs care in dealing with and living with the after effects of this cruel disease. No Government should condone substandard care for their citizens and all these patients suffering as a result of cervical cancer should have access to adequate post treatment care and support. I myself had to go to the UK to get a definitive diagnosis of lymphedema last year, another horrible after effect of cervical cancer that I must live with.

We need to focus on the following supports:

- Psycho Oncology service
- Onco Social Worker
- Onco Fertility run in the public system, currently the government fund this through a private clinic, so the pathway to this not direct
- Psycho Sexual support
- Dieticians to help with gastroenterology and post radiation bowel toxicity
- Pre-Clinical Lymphedema Assessment & Early Diagnosis and management
- Physiotherapy for Pelvic Floor and lymphedema

We must recognise and acknowledge that Clinicians feel unsupported, isolated and undervalued. All involved have felt the strain but in different ways. As patients we must value the concerns of the Clinicians on whom we rely on. The health care professionals such as colposcopists, nurses and smear takers are essential to the provision and promotion of good care and healing and deserve respect.

Screening is so important and helps save lives

It is hoped that any impasse can be lifted by constructive dialogue such as that from Dr Noirin Russell and Prof Donal Brennan. We all have a vested interest in preserving life and health and good relationships.

We are saying this today in a place of neutrality in the house of our Oireachtas and invite doctors to work with us and come together for mutual benefit, we need you, we must heal any divisions and emerge united and strong.

Perhaps we have established as much of the truth as is possible and the time has come to come out of the trenches and focus on better futures and outcomes for women and their families. For Vicky, Stephen and I there is no going back or undoing the past. We all must live with the consequences of these failures and in doing so we should not forget but should also strive for a stronger voice for the patient and to build better communication channels and synergies with all working in our health system.

Advocacy has been a heavy burden by times so I want to thank the health committee for the invitation to come here today and give us a voice instead of the usual talking about us, the references often made to us sound like we are an army of people but it was generally just Stephen and myself, we were far from perfect but we were always honest and did our absolute best.