



Submission to the Oireachtas Joint Committee on Gender Equality

Responding to the Recommendations of the Citizens Assembly on Gender Equality

Executive summary

221+ Patient Support Group (221+ PSG) was formed to assist the women and families directly affected by the failures of CervicalCheck which came to light following the Vicky Phelan's case in 2018. Advocacy on behalf of members is a key function of the 221+ which includes working with the relevant institutions of State to achieve system changes within healthcare to guarantee those failings are not repeated.

That advocacy is informed by our lived experience supported by the expert analyses of independent expert reports completed Dr. Gabriel Scally and Prof. Brian MacCraith. Those governing and planning for healthcare provision and management must recognise that women have discrete and unique healthcare needs.

Healthcare for women and girls was not addressed specifically by any of the Citizens' Assembly's recommendations.

That notwithstanding, we believe that the committee on its deliberations would consider that a specific Government Department be given responsibility for the improvement of the healthcare outcomes of women and girls throughout Ireland and be named specifically for that purpose.

There are three specific recommendations that are relevant to our experience and on which we would urge the Oireachtas also to act.

- Recommendation 42 proposes a *statutory body reporting to a single Cabinet Minister to coordinate gender equality issues across government. We strongly support this recommendation*

Additionally, and with respect to the healthcare system specifically, we would like to have the inclusion of patient representatives ringfenced into the oversight process, with adequate supports and protections to maintain the integrity of that function.

- Recommendation 43 recommends *data gathering on key gender equality issues (including care), regular publications of such data and remedial action when necessary.*



We fully support the value of data collection to support the healthcare outcomes of women and girls in Ireland is named specifically in your final recommendations.

- Recommendation 44 proposes *gender impact assessment of all proposed legislation and legislate for equality budgeting across all Government bodies including local authorities.*

We note and support the view of the assembly that gender impact assessment and gender budgeting, which was recommended for global adaptation by the OECD in 2018, should become a matter of routine in the Irish legislative process,

1. Introduction and context

221+ Patient Support Group (221+ PSG) is a member-based organisation established in July 2018 as a support group to assist the women and families identified by the Health Service Executive (HSE) as being directly affected by a series of system failures on the part of the National Screening Service (NSS) – CervicalCheck – that came to light following Vicky Phelan’s court case in April 2018.

These failures led to the botched disclosure of CervicalCheck audit results to over 200 women and their families. Many of those women had developed cancer which, due to that incorrect reading of their smear tests, went unattended with devastating consequences - life changing for all, life ending for some.

221+ PSG aims to be a ‘meaningful caring presence’ that provides information, advice and support to the women and families affected by these failures through connection and peer engagement.

Advocacy on behalf of members is key to the purpose of the organisation to enable its members’ experiences, views and needs to be understood and responded to by the State and State agencies.

The group is governed by a steering committee, which includes representation from the Irish Cancer Society, the Marie Keating Foundation, the Irish Patients Association, and several patient members.

We are a completely independent organisation and are not operated by the HSE or Department of Health.

2. The rationale for looking at things differently

Women experience many generic healthcare challenges differently to men - cardiovascular disease, cancer, urology, neurology for example. We also have discrete and unique healthcare needs. In the same way that there are distinct streams for the care of children and the elderly because there are



healthcare issues that are specific to growing or aging, so also should there be a specific provision in the allocation of resource and planning to the healthcare needs of women.

221+ PSG 's goal of advocacy includes working alongside the relevant institutions of State with responsibility for the healthcare sector to ensure there is learning from the failings identified from the CervicalCheck experience and a commitment to wider system changes within healthcare to guarantee those failings are not repeated.

Ours is a lived experience that has been borne out by separate expert investigative reports completed in 2018 and 2019 by Dr. Gabriel Scally and Prof. Brian MacCraith. We are now working to ensure that the recommendations of these reports are implemented in full to improve the support services and healthcare outcomes for girls and women throughout Ireland.

3. Response to the recommendations of the Citizens Assembly on Gender Equality

3.1 Giving priority to healthcare

221+ PSG would first like to highlight that the healthcare of women and girls was not addressed specifically by any of the commission's recommendations.

In that context we will make an overarching recommendation that we believe is critical to addressing the issues we have experienced and observed.

In his 2018 Scoping report Dr Scally specifically recommended (recommendation 2) that Government *“should give consideration to how women’s health issues can be given more consistent, expert and committed attention within the health system and the Department of Health¹.”*

He did this having looked at the history and capacity of the Irish Healthcare system to give womens’ health the necessary specialist care and attention that it merits.

Noting the ‘disappearance’ of a previous initiative – the Women’s Health Council² – he said *“more and different attention needs to be paid to women’s health issues”*

¹ Scally (2018) ‘Scoping Inquiry into the CervicalCheck Screening Programme’ pp. 20-22

² The Women's Health Council (Establishment Order) 1997. S.I. No. 278/1997.

Independent of those comments, Prof MacCraith concluded that in his assessment he found no emphasis on putting ‘women first’ and he recommended that “human resource needs to be dedicated solely to this ‘Women First’ approach”.³

Like Dr Scally we are struck by how almost all of the major controversies about maltreatment of patients or denial of rights in the Irish healthcare system have involved issues of women’s health.

Reflecting these findings that give testament to our lived experience, 221+ PSG recommends that a specific Government Department be given responsibility for the improvement of the healthcare outcomes of women and girls throughout Ireland and be named specifically for that purpose.

3.2 Recommendations of the Citizens’ Assembly

In respect of the recommendations of the Citizens’ Assembly’s work specifically, 221+ PSG would make the following observations and recommendations

Recommendation 42.

Empower and adequately resource a statutory body for gender equality under the responsibility for a Cabinet Minister charged with cross government coordination of gender equality issues.

In our experience, for this to happen there is a need for specific and continued oversight with the input of service users – in our case patients – to ensure the maintenance and continued improvement in outcomes for women and girls throughout Ireland.

As referred, the Scally Report specifically recommends that the Minister for Health give consideration to how women’s health issues can be given more consistent, expert and committed attention within the health system and Department of Health. It repeatedly states the need for patient representatives to be included in oversight and decision making in that regard.

221+ PSG has worked alongside the HSE, Department of Health and the National Screening Service for the past two and a half years to ensure that the recommendations of the Scally report are implemented in a meaningful way.

That work and specifically the input personally of the 221+ Patient Representatives on the CervicalCheck steering committee illustrates the importance of patient participation in oversight to ensure improved healthcare outcomes for women and girls.

³ MacCraith (2019) ‘Independent Rapid Review of Specific Issues in the CervicalCheck Screening Programme’ p.41



Accordingly, 221+ PSG strongly supports the recommendation that a specific Cabinet Minister be charged with cross government coordination of gender equality issues and that improved healthcare outcomes for women and girls throughout Ireland to be a specific named priority.

Additionally, and with respect to the healthcare system specifically, we would like to have the inclusion of patient representatives ringfenced into the oversight process, with adequate supports and protections to maintain the integrity of that function.

Recommendation 43.

Ensure data gathering on key gender equality issues (including care), regular publications of such data and remedial action when necessary.

The failings of CervicalCheck clearly illustrate the negative impact an absence of transparency and accountability can have on health outcomes for women.

221+ PSG, through our work on the implementation of the Scally report understands how the collection, management and publication of accurate data is essential to ensure that work is actioned, and the outcomes are measurable. It creates a level of transparency and accountability that ensures the outcomes of steps taken are measurable, facilitates continuous improvement, and allows the targeting of healthcare outcomes that have the welfare of patients as its priority – all of which are essential to building public trust in that system.

The CervicalCheck failings, outlined in detail in the Scally report, illustrate the damage done when there is a lack of accurate data collection and the difficulties it creates in identifying issues as they arise. This impacts the ability of our healthcare system to respond to problems.

In that context, 221+ PSG would like to strongly agree with the recommendation to ensure data gathering on key gender equality issues (including care), regular publications of such data and remedial action when necessary.

We recommend that the need for data collection in relation to the healthcare outcomes of women and girls in Ireland is named specifically in your final recommendations.



Recommendation 44.

Reflecting international best practice, require gender impact assessment of all proposed legislation and legislate for equality budgeting across all Government bodies including local authorities.

We note and support the view of the assembly that gender impact assessment and gender budgeting, which was recommended for global adaptation by the OECD in 2018, should become a matter of routine in the Irish legislative process,

The need for the collection of aggregated data in relation to the specific healthcare outcomes for women and girls is vitally important. There is a very real need to understand the specific barriers that negatively affect their healthcare outcomes.

221+ agrees with the Gender Equality Commissions recommendation to require gender impact assessment of all proposed legislation and legislate for equality budgeting across all Government bodies including local authorities.

We would like to recommend the specific requirement for gendered data healthcare outcomes for women and girls, to ensure that all actions undertaken have a measured positive affect.