



CervicalCheck
Patient Support Group

221+ Pre-Budget Submission 2024

Supporting women and their families in their health journey

When Vicky Phelan stood on the Courthouse steps in 2018, she instigated an avalanche of positive change within the Irish health system.

As it became evident that her story was one of many, the 221+ Patient Support Group was formed to support those directly affected by failures in the CervicalCheck Screening programme, and to be a voice for change, accountability, and action. Although it has been difficult at times, much has been achieved since.

This progress is a testament to the 221+ patient representatives who have tirelessly used their lived experience to improve health services for others. We must also acknowledge the collaborative efforts of the Department of Health, the National Screening Service (NSS), the HSE and members of the Oireachtas who, by learning from the failings of the past, have begun to implement the changes necessary to deliver a screening service which Irish people can have confidence in for the future.

The recent enactment of The Patient Safety Bill, in May 2023, and the implementation of the patient-requested review process, which the Bill enabled, is an example of how meaningful change can be achieved when we work together.

So much has been done, and yet, there is so much more to do. As we move forward, the provision of support to our members, whose lives have been irreparably changed by cervical cancer and the CervicalCheck debacle, will as it always has, be the main focus and core work of 221+.

221+ will continue to care and advocate for their needs and in doing so, will challenge the Government to make changes and investments in our healthcare system which will benefit everyone.

There is more detail on the pages following of our key asks from the Department of Health for Budget 2024

Continued prioritization and expanded investment in Women's Health



Fully fund the provision of Lymphoedema treatment and care in Ireland.



Increase investment in and promotion of menopause services.



Continued commitment to invest and promote discourse in all areas of women's gynecological and general health.



Ensure future funding for the implementation of the Health (Assisted Human Reproduction) Bill 2022.

Commitment to amplifying the patient voice in all spaces and valuing their time



Progress the implementation of the 'Patient Voice Partner Policy' to embed patient participation in health policy and service development and recognize, and in some cases remunerate, patient representatives for their time and input.



Continued support and funding for the work of 221+.

Continued prioritization and expanded investment in Women's Health

221+ strongly supports the recent focus by Government on women's [1] health and wholeheartedly welcome the objectives and commitments set out in the Women's Health Action Plan 2022-2023 [2].

For far too long, matters pertaining to female gynecological health have been taboo, under-researched, more easily dismissed and severely lacking in adequate services and supports. While this is an injustice of global scale, Ireland in particular has an undeniable resume of failures in this regard.

The Women's Health Action Plan is a much welcome, albeit overdue, first step in allocating the attention and focused investment that is needed to provide the services and the care experience that the women of Ireland deserve.

Outside of the Women's Health Plan, there has been much progress and advancements in cancer screening including the improvements to the cervical cancer screening program specifically on foot of the CervicalCheck debacle and the recommendations of Dr. Gabriel Scally [3].

221+ welcomes the actions outlined in the Plan and commends the progress that has been reported to date. Just as the Plan has committed to 'Listen, Invest and Deliver', through listening to the lived experience of our members, 221+ calls on the Government to do more.

[1] In this document, when we talk about women we seek to be inclusive rather than to exclude and mean to refer to women and people with cervixes.

[2] Department of Health. (2022) 'Women's Health Action Plan 2022-2023'. Available at: <https://www.gov.ie/en/publication/232af-womens-health-action-plan-2022-2023/>

[3] Scally, G. (2018) 'Scoping Inquiry into the CervicalCheck Screening Programme – Final Report. Available at: <http://scallyreview.ie/> Scally, G. (2019) 'Scoping Inquiry into the CervicalCheck Screening Programme – Supplemental Report'. Available at: <http://scallyreview.ie/> Scally, G. (2022) 'Review of the Implementation of Recommendations of the Scoping Inquiry into the CervicalCheck Screening Programme – Implementation Review Report'. Available at: <http://scallyreview.ie/>



Fully fund the provision of Lymphoedema treatment and care in Ireland.

Lymphoedema is a long-term (chronic) condition that causes swelling in the body's tissues, often in the arms or legs. It is caused by a problem with the lymphatic system, a network of vessels and glands spread throughout the body. While primary lymphoedema is inherited, secondary lymphoedema can occur where the lymphatic system is damaged by cancer and its treatment.

While lymphoedema can affect both men and women, the lack of services and care in Ireland for this incurable condition is a cause of significant and ongoing distress for many 221+ members.

221+ knows first-hand that lymphoedema impacts sufferers physically through pain, repeated infections and difficulty with

movement. The psychological impact this has is exacerbated by the lack of services that are available in Ireland to manage symptoms. As a result, we are aware of many cases where our members have had to spend extended periods of time abroad, away from family support, in countries like Germany and Austria, to obtain the help they need. This is not acceptable.

Approximately, 12,500 [4] in Ireland have lymphoedema, of which many will be cancer survivors. It is not enough to survive cancer. All survivors deserve a quality of life and to be provided with comprehensive care and treatment for lymphoedema here in Ireland – 221+ calls on the government to urgently take action and invest in same.

[4] Irish Cancer Society. (2023). 'Pre-Budget Submission 2024'. Page 37. Available at: <https://www.cancer.ie/about-us/cancer-advocacy/prebudget-submission-2024>



Increase investment in and promotion of menopause services.

Difficulties arising from menopause are often compounded or onset early for cancer survivors as a result of their treatment. The ability to access expert care and treatment for their complex menopause related needs continues to be a major issue for 221+ members.

221+ has first-hand knowledge of the fantastic specialist expertise available through Ireland's first complex menopause clinic which opened at the National Maternity Hospital in Holles Street in 2021.

The recent opening of an additional 4 clinics in Nenagh General Hospital, the Coombe, the Rotunda and University Hospital Galway with a 5th expected in Cork this year, is a welcome development.

Through the experience of our members, 221+ is aware that much more needs to be done to ensure that these services and the pathways to access them are better promoted and publicized. Additional investment is also needed to reduce the significant waiting times to access the existing complex clinics.

221+ call on the government to continue to invest and expand the menopause services within the public system (both primary care and complex clinics) so that they are easily accessible by any woman who requires them regardless of their location or economic status.



Continued commitment to invest and promote discourse in all areas of women's gynecological and general health.

"We need to be able to ask questions, and not to feel any shame, any embarrassment, about those things (sex, gynae symptoms, bleeding, incontinence) because until we get to a stage where we can talk about these things openly, a lot more things will go under the radar and women will not be treated properly."

Vicky Phelan, speaking on RTÉ One Claire Byrne Live [5] in November 2020.

We are only at the start of making the changes that are necessary to give women's health the space and attention it deserves. 221+ asks the Government to sustain prioritisation and ring-fenced investment in women's health until such a time as first class and equitable health services are demonstrable and embedded in the public system.

This includes:

- Progressing and implementing the broad range of commitments made in the current Women's Health Action Plan 22-23.
- Ongoing efforts involving input from advocates and patient representatives to identify gaps in research, expertise and services in women's health and progressing the required action in future women's health plans from 2024 and beyond.
- Continued allocation of investment on an increasing scale to maintain and broaden services and ensure that all women (regardless of location, economic status) have timely access to same within the public system.
- Realigning the provision of services to focus on the patient experience as well as the diagnostic outcome. Even in event of a negative outcome, women deserve the experience of a positive health journey where they are respected as equal partners in their care, given the space to discuss their concerns and ask questions and receive treatment that is provided in an empathetic and holistic manner.
- Undertaking promotion and educational initiatives which aim to break the taboo around reproductive health amongst both sexes.
 - Educating men and promoting public discourse about issues that were traditionally 'women's problems', in particular gynecological health, will benefit everyone. Not only will women feel more confident in speaking up and seeking medical help when something is wrong, men will be more empathetic and empowered as partners, care givers, medical professions and politicians.

[5] Recording available at: <https://www.rte.ie/news/claire-byrne-live/2020/11/25/1180346-vicky-phelan-on-the-treatment-of-women-in-ireland/>



Ensure future funding for the implementation of the Health (Assisted Human Reproduction) Bill 2022.

The fallout from the treatment for cervical cancer can have many life changing effects, infertility being one of them. Many 221+ members lost the ability to have children. For them, and for many other families in Ireland, surrogacy is the only option.

Surrogacy is a reality of life in Ireland. It is vital to have comprehensive legislation that:

- Recognizes, and ensures a clear pathway to the recognition of parentage for those families – including women who are taking their surrogacy journey alone.
- Creates a framework that ensures the protection of all parties within the process.

Legislation is needed to ensure that families formed through surrogacy are guaranteed equality to other Irish families. As it stands, the intended mother to a baby born through surrogacy has no clear pathway to being recognized as the parent, even if the baby is her genetic child. Currently, her only option is to apply for guardianship after a period of 2 years.

This creates numerous difficulties and places both mother and baby in vulnerable positions. If the parent's relationship breaks down, the mother has no legal right to her child. If the father needed to be away for a period of time, the mother would not be able to give permission for emergency medical care. The list goes on. It also

creates a vacuum for those single women who are on their own surrogacy journey – there is no pathway for them to access parental rights.

International studies show that when the rights of the baby, intended parents and surrogate are considered equally, the outcome for all is better.

They conclude also that surrogacy is a legitimate option for those who have lost the ability to conceive due to cancer treatment. To quote one such study [6] (on surrogacy and ethics in women with cancer) *“If surrogacy is carried out within an accepted medical ethical framework, it is a highly acceptable way to assist women with cancer to have a child. This requires the clinical team to fulfil their duty of care to the patient by treating the woman with cancer and the surrogate with equal respect for the wellbeing and autonomy of both, regardless of any intervening commercial consideration”*.

With a proper framework that supports the rights of the child, parent(s) and surrogate, it is possible to ensure that all families in Ireland are treated equally in law.

221+ asks that you support the progression of the AHR bill and the inclusion of provisions for a clear pathway to the recognition of parenthood within a framework that supports all involved.

[6] Carr, S V (2019) 'Surrogacy and ethics in women with cancer'. Best Practice & Research Clinical Obstetrics and Gynaecology 55: 117-127

Committing to amplifying the patient voice in all spaces and valuing their time

From any difficult period of life, the experience of failure or being failed, comes with it a chance for reflection, to realize what went wrong and could have been done differently and then the opportunity to do better in the future.

Among the many reasons why Vicky Phelan was so admired in Ireland and beyond is because people saw how she refused to be silenced, she shared her painful experience, she highlighted what was wrong with the system and gave her precious time to work to improve things for others.

Like Vicky, her fellow 221+ patient representatives such as Lorraine Walsh, Stephen Teap, Lyn Fenton and Rosie Condra have also worked tirelessly with 221+ and with officials in Department of Health, the NSS and the HSE to help reform screening and health services for the better.

The enactment of the Patient Safety (Notifiable Incidents and Open Disclosure) Act 2023 [7] in May 2023, is a recent example of how advocates, patient representatives, experts and policy makers can work collaboratively to develop healthcare policy which is fit for purpose and considerate of the past and future patient experience.

From a 221+ perspective a key achievement was the amendment to section 36 of the Act which ensures that those diagnosed with cervical cancer are informed of their right to request a review, as well as at or before the original screenings for said cancer.

While Vicky began this campaign, this change and many other improvements in our health and cancer services have come to fruition though the invaluable work and commitment of patient representatives. While we can thank them for the hours of time and effort they have sacrificed, this is not enough.

[7] Available at: <https://www.oireachtas.ie/en/bills/bill/2019/100/>



Progress the implementation of the ‘Patient Voice Partner Policy’ to embed patient participation in health policy and service development and recognize, and in some cases remunerate, patient representatives for their time and input.

In November 2022, the injustice regarding the treatment of patient representatives was called out by Dr. Gabriel Scally in his report ‘Review of the Implementation of Recommendations of the Scoping Inquiry into the CervicalCheck Screening Programme’. Dr Scally stated [8]:

“Respecting the role of patient advocates also involves treating them as equal partners in the system. It is simply impossible to achieve mutual respect when the patient advocates are the only people taking part in meetings in their own time, often neglecting work or family commitments, and receiving no remuneration for their attendance. I have pointed out this serious deficiency on

previous occasions, and I am disappointed that there has been no agreed path forward to solving the problem.”

While overdue, 221+ strongly welcomes the issuance, by the Department of Health, of a draft ‘Patient Voice Partner Policy’ for consultation in January 2023.

This policy document makes a commitment to embed patient participation in health policy and service development and sets out a framework to ensure that patient representatives are ‘recognised and valued for their contribution’ [9]. It consults on an approach to either reimburse expenses and/or compensate patient reps depending on the activity or level of participation.

221+ was delighted to respond to this consultation and calls on the Government to progress this framework as soon as possible. 221+ reiterates its position that:

- the patient voice should be included in all elements of health policy and service development, reform and implementation.
 - working groups or initiatives which do not benefit from the patient voice should have a clear and documented rationale for why this is the case. Furthermore, an assessment of what changes are needed to incorporate this must also be done.
 - the patient voice must be incorporated at the outset. Patient representation should be a core element of projects from the beginning. It should not be brought in as a review phase or sounding board once key decisions have already been made.

[8] Scally, G. (2018) ‘Scoping Inquiry into the CervicalCheck Screening Programme – Final Report. Page 5. Available at: <http://scallyreview.ie/>

[9] Department of Health. (2023). ‘Patient Voice Partner Policy – Draft for Public Consultation’. Page 4. Available at: <https://www.gov.ie/en/consultation/29a5e-public-consultation-on-a-draft-policy-for-patient-voice-partner-in-the-irish-health-and-social-care/>

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- patient representation should be diverse and represent a broad spectrum of the population with a particular cognizance on involving those from unrepresented communities,

- patient representatives should be given the appropriate training and supports to enable them to contribute effectively and on an even footing with other stakeholders.
 - 221+ welcomes the approach to induction, training and support outlined in the policy consultation.
 - informed by its experience, 221+ asks that training also be provided to medical and professional committee members to ensure they understand the principle that Patient Voice Partners 'are full and equal members of the committee and/or working group and they should be treated fairly and with respect' [10].

- the time, effort and personal cost of reliving and utilizing their experience to improve outcomes for the current or future health service users is recognized and respected.

[10] Department of Health. (2023). 'Patient Voice Partner Policy – Draft for Public Consultation'. Page 14. Available at: <https://www.gov.ie/en/consultation/29a5e-public-consultation-on-a-draft-policy-for-patient-voice-partner-in-the-irish-health-and-social-care/>

In recent years, there has been a 'sea change' in the attention and investment given to women's health and a long overdue transition away from the paternalistic approach which was so widely inherent in Irish society to the involvement of patients as active participants in their care.

In no doubt, the failing of the CervicalCheck program first highlighted by Vicky in 2018 and brought to light by Dr. Scally as part of his scoping inquiry reports vastly contributed to this wave of change.

Since its formation in October 2018, 221+ has done extensive work to look after the needs of its members. At the same time 221+ has worked collaboratively with the Department, the NSS, the HSE and public representatives to advocate for its members and for improvements in women's health and cancer screening and services in Ireland more broadly.

Informed by the lived experience of its members', 221+ have contributed to the Patient Safety Bill, the Restoration of Trust Process recommended by Dr. Gabriel Scally, The CervicalCheck Steering Group and the CervScreen Project. 221+ has worked closely with the NSS on projects such as Research Report on the Disclosures Process with Quality Matters, the design of the process for personal screening reviews and has proven to be an open and positive collaborator on various matters of policy and process.

At present, the important work of 221+ is only funded until December 31st, 2024. 221+ call on the Government to continue to support and fund 221+ into 2025 and beyond.

As per the Patient Voice Partner policy, patient representatives are 'expected to bring their own experience...and are not expected to represent the view of the wider patient cohort' [11]. To complement the personal perspective, 221+ is well positioned and experienced to advocate for wider patient collective.

Without 221+, broader patient insights in relation to cervical cancer, cancer screening, cancer care, the wide ranging impacts of cancer treatment both emotional and physical, would be lost.

More importantly, a decision by Government to remove the supports provided by 221+ to the women and families impacted by the CervicalCheck debacle would be to fail them once again.

[11] Department of Health. (2023). 'Patient Voice Partner Policy – Draft for Public Consultation'. Page 12. Available at: <https://www.gov.ie/en/consultation/29a5e-public-consultation-on-a-draft-policy-for-patient-voice-partner-in-the-irish-health-and-social-care/>

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