221+
CervicalCheck
Patient Support Group

221+ Patient Support Group:

Pre-Budget Submission for Budget 2026

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- An overarching ask fundamental to all improvements: *Ringfenced funding for women’s health*

Our interpretation of the new Programme for Government:

While the intentions are good and many of the major areas in women's health are mentioned, there are no timebound actions (other than for the full term of the government) and crucially, there is no ringfenced funding for women's health or for specific elements within this area.

This is an error that could see these major issues and opportunities for positive change fall by the wayside. We therefore ask the government to work on a more specific, itemised plan to deliver these promises, starting with timeframes and setting aside an appropriate amount of funding for each undertaking.

We are asking for more comprehensive care particularly in gynaecological health, a shift towards prevention and the finances and capacity building to back it.

Continued funding for 221+ now and into the future

221+ continues to provide necessary and impactful support for the women and families affected by the historic failings in the cervical screening programme in Ireland. The safe spaces we provide for members to meet and find shared understanding has been described as a 'lifeline', in a recent report.

Published last year and conducted by researchers at the University of Limerick, the report found that all of our work to provide information and support was seen universally, by members and health care workers alike, as effective. The same report noted that our advocacy work, spearheaded by our incredible patient representatives and based on direct engagement with our membership about their needs and the challenges they face, has improved the quality of information from, and interaction with, the health service providers and improved outcomes for patients generally. The report also credited 221+ with stimulating greater openness in discussing women's health in Ireland.

221+ therefore not only provides an empathetic and highly valued support service to its membership, but we also advocate for essential services which are used by much wider groups of patients as well as more accessible, safe and patient-centered health care for everyone in Ireland.

The value of our work comes from our member-led approach and commitment to continue the legacy of our co-founder and trailblazing woman, Vicky Phelan – who campaigned on behalf of all women too long disrespected and overlooked. Vicky asked not for accolades, but for action.

Commitment to extend the services of 221+ to all women let down by the CervicalCheck screening programme, supported by the necessary funding

221+ is mandated specifically to support the needs of the women whose slides were the subject of unreported auditing, as revealed by the Vicky Phelan case in 2018, and the women who subsequently opted to participate in the RCOG review concluded in 2019.

It has been clear to us for some time that there are other women who find themselves in circumstances like our members, but who we are not allowed to assist. These are women let down by the cervical screening services and dealing with life changing health issues and their consequences. They have been contacting us since 2020 looking for assistance, but we are explicitly precluded from supporting them, a restriction which is actively monitored by the Department of Health.

This is not good enough. We are now asking that the definition of eligibility for the HSE package of supports and 221+ membership & support be changed. No woman who has been let down by screening is in any way less entitled to the supports that we can provide than any other. We should be able to support women on the basis of an agreed social and clinical assessment of need consequent to a verified issue with screening rather than because they presented between two arbitrarily selected dates or via a particular administrative process.

Based on current intelligence of cases pending, this will mean 221+ extending its reach almost immediately for which some incremental Department of Health funding increase will be required.

Commitment to implement the AHR Act and push through the Amendments bill

221+ members and other women are still waiting anxiously for the full implementation of the AHR legislation passed almost one year ago and for the amendments bill to be progressed to ensure full protection and regulation of international surrogacy.

221+ members were harmed by failures of a state institution. Through no fault of their own, they are left with debilitating, lifelong side effects such as the complete loss of fertility. For some, there is no choice other than surrogacy if they wish to have children. To be excluded from the current AHR process because your cancer treatment destroyed all of your eggs, and you are a single intending parent, is discrimination based on personal circumstances beyond the individual's control.

We ask for support in ensuring that international surrogacy is legal and regulated for Irish residents and citizens, with consideration for different circumstances such as a person having no ability to contribute their own genetic material. Setting out parameters for this process through a regulatory bill is the only way to protect the children produced through such procedures, and both the intending parent and the surrogate mother.

Department of Social Protection – exclude 221+ member court payments in means testing for welfare payments

We have been asking for the exclusion of 221+ member court payments from means testing for welfare and other State grant payments since last year. This is an issue that affects the daily lives of many of our members and their families – affecting not only the woman directly affected, but payments such as study grants for their children.

An example of the impact this could have is if the sum received in court by a 221+ member is less than their usual salary, but they are now unable to work due to the long term effects of their cancer and treatment (which is a result of the failures of the screening service). However, this court payment is still counted when assessing them for out of work payments – which can result in the individual having an inadequate income or less than they would receive if they were able to continue working. The payment they then receive will not match what the women would have earned in her working life.

We ask you to remember that the payments received in court are a recognition of the failures of the system and the huge impact that had on their quality of life and family. It makes no sense to then effectively penalise people for having received this payment.

We would also like to note that compensation awarded by courts to those affected by Hepatitis C and HIV contaminated blood products are excluded from means testing for social welfare payments. 221+ members should have the same treatment.

Supporting gynaecological health

There are five gynaecological cancers, affecting the Womb, Ovaries, Cervix, Vagina and Vulva. Women's lived experience is that they do not feel heard when coming to their doctor with concerns about their gynaecological health.

It is vital to prioritise education of both healthcare professionals, particularly GPs, and the public on the signs and symptoms of gynaecological cancers and other gynaecological health conditions that require medical attention.

Equally GPs and consultants should be required to get comprehensive training in women's health beyond maternity care. Gynaecological health affects women's daily lives and should be a major component of medical training.

We are aware anecdotally of women with other gynaecological cancers finding a lack of coordination and consistency in the information given to them by health care teams and that they lack peer support. We know from our members that the ability to access a safe space for shared understanding and experiences can be a 'lifeline'.

Because of the shared symptoms, treatments and challenges, of the five gynaecological cancers identified, we feel strongly that it would be appropriate to offer organised, specialist support to those impacted – all patients with gynaelogical, not just those presenting that have been let down.

Better access to specialists must be facilitated through funding and recruitment, with a focus on equal access both within different groups in the community and regions across the country.

We have six years' experience providing patient support to women and families through the challenges that arise during and after treatment for gynaecological cancer. We are experienced in sourcing and providing specialist assistance on a variety of areas relevant to all gynae cancer patients, and we have solid relationships with other major support organisations (e.g. the Marie Keating Foundation and the Irish Cancer Society). With additional funding, 221+ would be very well placed and willing to take up this added mandate which would provide support and benefit for patients, healthcare professionals and the management of the health system as has already been demonstrated in our existing work.

Implement the Patient Voice Partner Policy and include patient voice in decision-making

It is crucial to recognise the value that the patient voice brings to the table in all areas of healthcare development. The policy must be published and actioned as soon as possible to ensure that patient's contributions are not blocked by financial and practical matters. If patient representatives are reimbursed for travel and subsistence only as is currently policy, they're left in the position of being forced to take unpaid leave from work without reimbursement for those lost hours or using paid holiday time to contribute. We risk losing patient involvement if their time is not respected in the same way that other experts' time and knowledge is valued and reimbursed, to the detriment of us all.

Implementation of the Patient Voice Partner Policy would also advance the need for routine engagement of patient representatives to ensure their experience and knowledge is listened to at all levels when planning health care services.

Better access to treatment for lymphoedema – implement the 2018 Lymphoedema/ lipoedema model of care

Funding and planning is required in order to implement the Lymphoedema model of care and ensure timely access to preventative advice and treatments for anyone at risk, particularly those undergoing cancer treatment. There are currently estimated to be around 18,700 people living with lymphoedema in Ireland and yet the therapist to patient ratio is only around 1 therapist to 800 patients. This is an alarming figure.

Currently, acute cancer services provide lymphoedema services but they are not all staffed adequately and so are unable to provide comprehensive care or do so via private therapists (as is the case for St.Vincent's hospital which only provides this service for breast cancer patients). For those with non-cancer related lymphoemeda access to care is even more difficult particularly as many counties have no service at all for this group.

221+ members have noted difficulty in obtaining diagnosis and then receiving subsequent treatments due to under resourced services and different experiences of accessibility across different regions. Some have even had to look for treatment abroad for this debilitating condition.

Better access also includes awareness of the risks of developing lymphoedema, the signs and symptoms and a patient-centred approach to support. It should be best practice to inform patients on how they can prevent lymphoedema before cancer treatment begins, but this is not routinely happening according to the experiences of our members. This incurs a significant monetary cost to the health service due to lymphoedema being a lifelong condition once contracted, requiring continued treatment and care. It also has huge costs to people's quality of life with discomfort, pain, altered physical abilities and body image being some of its major lifelong impacts. Considering this is a preventable condition, these costs are just too high. We need action now.

Fortunately, the Lymphoedema /Lipoedema Model of Care (MOC) has now been proven to drastically improve outcomes in the Proof of Concept clinics:

"*In the patients reviewed after the first 6 months of treatment there were 3 episodes of cellulitis compared to 49 in the previous year and 0 hospitalisations compared to 7 in the previous year. In addition, GP visits were reduced by 86% and Public Health Nurse visits were reduced by 70%, resulting in reduced demand on acute and community services*" **Geraldine Crowley, Assistant National Director, Enhanced Community Care Programme & Primary Care Contracts**

Thousands of hospitalisations and their associated costs could therefore be avoided by preventing cellulitis, a medical emergency arising from unmanaged lymphoedema. Furthermore, these pilot projects found a significant reduction in actual incidence of lymphoedema in breast cancer patients, which is where we want to get to with all the affected cancer patients.

By investing an estimated 10.4 million euros full rollout of the lymphoedema model of care could be achieved in a few years, avoiding the high costs to the health service of managing a lifelong condition and most importantly, saving patients from the unquantifiable negative impact lymphoedema has on quality of life.

Continued investment in the Elimination of Cervical Cancer campaign

We ask for continued investment and support for the Elimination of Cervical Cancer campaign, a vital initiative that could make cervical cancer a rare disease in Ireland and save hundreds of women a year from receiving this devastating diagnosis and invasive treatment.

Eliminating cervical cancer must include a huge push towards increasing Ireland’s already good record of attendance at cervical screening and fostering trust in the service through continued accountability, communication and sensitive care. HPV vaccination awareness and education is the other absolutely vital element in this campaign, which is why we ask for the reimplementation of the Laura Brennan catch up programme and a ‘mop up’ vaccination program that allows access to the vaccine for free outside of the school program.

An overarching ask: Ringfenced funding for women’s health

Ringfenced funding is promised under your cancer care section but not for women's health. Cancer is said to now affect 1 in 2 people in Ireland so it understandably, requires focus and action. Women’s health also affects over half the population. In order to ensure progress is made in the areas you identified in the programme for government, funding must be set aside and actions taken in a timely manner.

This includes a budget set aside for the Women’s Health Taskforce’s next Action Plan, for gynaecological health care and support for gynaecological cancer patients, investment for your term in government and beyond.