

2024 GENERAL
ELECTION

221+ PATIENT SUPPORT GROUP

MANIFESTO

<https://221plus.ie/>

@221plus (on X)





Introduction: What we are asking for

Continued funding for 221+ so that the group can continue to support women and families directly affected by the failings of CervicalCheck as well as use its experience to further good use in extending support to women who have a gynecological cancer and do not have suitable, cancer-specific support at present.

We ask that essential women's health services of specific benefit to those living with cervical cancer such as lymphoedema treatments, gynecological physiotherapy, menopause services and colposcopy examinations are put in place in a timely manner and are accessible.

221 members are also currently affected by the inclusion of courts payments in means testing for social welfare – we ask for this to be rectified.

We ask that patient advocates are supported and that the incredible value that the patient perspective brings to decision making on health service provision is respected and facilitated to ensure a better health system for us all.

Finally, specific funding for women's health must be ringfenced and large enough to protect and expand services and care for future generations. This requires oversight, which is why we also ask for a new governmental position specifically for Women's Health. Government commitment to women's health as a priority is a vital requirement to ensure that women can enjoy their right to health in years to come.

Summary of Actions:

- Continued funding of the 221+ Patient Support Group
- Finish and implement the Patient Partner Voice Policy
- Include patient representatives on the Women's Health Taskforce
- Protect and prioritise women's health, ensuring that the taskforce or any health programs have ringfenced funding
- Commit to engaging with patient representatives at all levels in the delivery of the Women's Health Action Plan
- Fully fund the lymphoedema and lipoedema model of care and ensure equitable access across regions
- Further funding and commitment to ensure availability and accessibility of menopause services. 1) Clear referral pathways 2) Increased staffing or more hubs
- Fund gynecological physiotherapy in every CHO
- Permanent oversight of the continued implementation of Scally report recommendations and culture of transparency
- Commitment to and oversight over women's affairs via a suitable senior governmental post
- Stop including payments made to 221+ members in court proceedings as 'means' when assessing applications for means-tested welfare payments

Ask 1: Continued and expanded funding for 221+

Many of our members live with lifelong side effects from cancer, its treatments and from the fallout of the CervicalCheck debacle. It is essential that we are able to plan ahead and support members for as long as they need. To do so, we must have assurance of longer-term funding.

We have successfully supported members since our founding, providing a 'lifeline' for the women and families affected by failures in the CervicalCheck screening programme, as research conducted by Limerick University ¹ found. You can find more information about the kind of support we provide in the [Context: About 221+](#) section of this document.

With a relatively small increase in budget, we could use our expertise to expand support to a large group of women who currently have no support specific to their cancer and its post-treatment effects – gynecological cancer patients.

By increasing our budget, which amounts to a fraction of the overall health budget (calculated as 0.02%), we would be able to support at minimum 500 more members (the approximate number of cervical cancer patients) plus our existing members, and account for inflation which has increased costs by 15% in the past few years (our annual budget has not changed since our founding in 2019).

¹ [221+ Patient Representative and Organisational Impact](#), March 2024, Dr Elaine Kinsella, Dr Elaine Kavanagh, Julie Ann Baxter, Limerick University



Ask 2: Provide a framework for supporting patient advocacy

We ask that the Patient Voice Partner Policy is finalised and implemented.

Patient Advocates are extremely valuable in the evolution of effective healthcare delivery in Ireland. Their achievements can be seen throughout much of the progress made in health care in recent years.

This extends far beyond the work of 221+ to patient advocacy in general that has influenced many legislative changes and policies that have improved the outcomes and quality of care for patients.

Within 221+ alone, Vicky Phelan's trailblazing work to secure access to Pembrolizumab for cervical cancer patients, her steadfast insistence on patient safety legislation and the huge commitment of other 221+ Patient Representatives such as Stephen Teap and, Lorraine Walsh to getting the Patient Safety Act passed in a way that considers the patient's right to open disclosure as paramount shows the immeasurable value of a voice for patient experience.

Despite the incredible dedication Patient Advocates show to their work, they are not financially or systemically supported. This 'only voluntary' standing means that despite their experiences, their voices are not engaged as often as they should be.

Case study: 221+ patient representative Lyn Fenton spends on average, around 15 hours per week in her role advocating for 221+ members and women's health, including travel time. Yet we are only able to reimburse her for subsistence costs. It is not fair that the time spent by advocates like Lyn is not valued, when so much of their time and emotional resources is spent improving health systems for others.

It also means that we risk losing the opportunity that patient advocacy presents, to build on the experiences and needs of patients to create more patient-centered systems, because many simply can't afford to put in the required hours without reimbursement.

Finalising the Patient Voice Partner Policy would ensure that they are supported within their roles, in the same way that any other external expert is compensated for their time and knowledge.

Actions:

- Finish and implement the Patient Voice Partner Voice Policy
- Include patient representatives on the Women's Health Taskforce
- Put in place plans to engage with patient representatives at all levels in the delivery of the new Women's Health Action Plan for 2024-25 (and in all subsequent plans) as part of its 'Listening & Learning' Pillar. The patient voice needs to be part of decision-making processes, not only at review. Having a patient voice forum is an important step, but a framework for involving patients in all aspects of development and decision making must be implemented. National surveys and research are important ways to involve the whole



population and different women's voices, and we believe that having the patient voice front and center will complement this approach.

This would be in line with the WHO resolution for social participation in primary health care², which Ireland was a proposer for, which urges members states to *“implement, strengthen and sustain regular and meaningful social participation in health-related decisions across the system”* (pg 4, Resolution³) and which encourages patient advocate involvement in *“implementation, co-designing the mechanisms for embedding and institutionalising such partnerships, as well as for unlocking the funding mechanisms to make it happen”* (IPPOSI⁴).

² [Seventy-seventh World Health Assembly – Daily update: 29 May 2024](#), WHO Media Team

³ [Social participation for universal health coverage, health and well-being](#) - SEVENTY-SEVENTH WORLD HEALTH ASSEMBLY A77/A/CONF./3, Agenda item 11.1, 28 May 2024, WHO

⁴ [Patient & Public Involvement in Health decision-making endorsed by World Health Organisation](#), IPPOSI

Ask 3: Ringfenced Funding for Women's Health

Ringfenced funding for women's health is vital to ensure that initiatives to improve access to, quality and scope of care are available to women throughout the country. It is high time to act and show up for women's health – a commitment to provide funding alongside the oversight in Ask 4 would be an important step forward.

There is precedent set for reserving funds for women's health, in particular with the National Women and Infants Programme and the Women's Health Taskforce.

The new Women's Health Action Plan (WHAP) 2024-2-25 has been published and we are pleased to see that 11 million euro is to be invested in its delivery this year with a commitment to future investment via the Budget 2025 process. However, not every aspect of women's health is covered by the plan and without prioritization, women's health will fall behind.

- This is why we would ask for commitment to the next iteration of WHAP for 5 years, with ringfenced funding for this timeframe, to ensure longevity and the promised advancements are fully resourced.



Ask 4: Improved services and fast access

“Globally, gynecological health is one of the least prioritised areas of health, despite an enormous burden of morbidity and mortality” and due to the toll it takes- “The reality of this is that many women and girls are unable to enjoy their right to health” (RCOG⁵)

We have seen this statement played out in the lives of 221+ members. We have had to help members find treatments for post-recovery, lifelong side effects due to their lack of accessibility or availability in Ireland.

It is particularly shocking that gynecological cancer survivors and others who need it cannot access appropriate specialist lymphedema treatment in Ireland, having to turn abroad to alleviate what can be a debilitating condition. If the support they need is there, services are often under resourced leading to long delays in appointment times or waiting lists. Currently, funding is inconsistent across lymphoedema treatment sites and members have reported to us difficulty in accessing diagnosis and subsequent treatment.

As noted by a 2018 Lymphoedema/ lipodema model of care Working Group report⁶, *“Delayed treatment will require increased utilisation of specialist lymphoedema services and MDT support with potential poor outcomes for the patients, increased hospitalisations due to related complications and increased costs for the health service”* (Page 34). For example, the management of cellulitis related to lymphoedema or chronic oedema via hospital stays costing the HSE 13.6 million euros. The working group calculated that up to 87% of this could’ve been saved by comprehensive assessment and lymphoedema treatment services (Page 36).

Specific actions:

- Fully fund the lymphoedema and Lipoedema Model of Care, ensuring equitable access in all regions of the country
- Long waiting lists must be addressed across the board – assess where the roadblocks are to faster access and remove them. Our specific ask is to reduce colposcopy waiting times. Being seen in a timely manner improves the likelihood of early detection of cell changes and / or cancer.
- Complex menopause hubs – in the Action Plan for 2024-25 an action to increase opening hours to menopause hubs is noted as a solution to meeting the higher demand. We believe further action is needed to combat long waiting times, mainly 1) Clearer referral pathways 2) Increased staffing or more hubs.
- Improve access to gynaecological physiotherapy in every CHO
- Permanent oversight of the continued implementation of all Scally report⁷ recommendations and culture of transparency

⁵ Global Cancer Statistics 2020: GLOBOCAN Estimates of Incidence and Mortality Worldwide for 36 Cancers in 185 Countries, 4 February 2021, Hyuna Sung PhD, Jacques Ferlay MSc, ME, Rebecca L. Siegel MPH, Mathieu Laversanne MSc, Isabelle Soerjomataram MD, MSc, PhD, Ahmedin Jemal DMV, PhD, Freddie Bray BSc, MSc, PhD – referenced in [Gynaecological health](#), RCOG - webpage

⁶ [Lymphoedema and Lipoedema Treatment in Ireland, A Model of Care for Ireland](#) – A Working Group Report, 2018, HSE

⁷ Scally Reviews by Dr Gabriel Scally and team - all reports available [here](#)

Ask 5: Women's Affairs Minister

Currently, there is an absence of oversight and consideration of the woman's experience and perspective across all legislative programmes and government work. There are many areas where gender inequality is stark.

A dedicated ministerial capacity to coordinate and monitor the implementation of a perspective in policymaking across all departments that would help shift legislative planning to more inclusive thinking that incorporates women's needs as a primary consideration and would be of huge benefit.

The brief for this role in the lifetime of the next Government would be to undertake and publish a review of measures to introduce gender mainstreaming⁸ and to set out in response how the Ministerial role can be used to best advantage.

Examples from the legislative programme for summer 2024 where such a role would have had special interest:

Maternity Leave for Members of the Oireachtas Bill

Health (Adult Safeguarding) Bill

Civil Reform Bill

Social Welfare and Civil Registration (Miscellaneous Provisions) Act

Health (Assisted Human Reproduction) Act 2022

Automatic Enrolment Retirement Savings System Bill 2024 [Dáil] Order for Second Stage

Health (Miscellaneous Provisions) Bill 2024 [Dáil] Order for Report

Criminal Law (Sexual Offences and Human Trafficking) Bill 2023 [Dáil] Order for Report

Health (Termination of Pregnancy Services) (Safe Access Zones) Bill 2023 [Dáil] Committee Stage (resumed)

Criminal Justice (Incitement to Hatred or Violence and Hate Crime) Bill 2022 [Dáil] Order for Committee

Family Courts Bill 2022 [Seanad] Order for Committee

By appointing a Minister for Women's Affairs, women's perspectives will always be central to debate despite the unequal makeup of the current Dáil and Seanad Éireann.

⁸ [What is Gender Mainstreaming?.](#) Council of Europe, webpage



Ask 6: Exclude payments awarded to 221+ members in court proceedings related to the failures of CervicalCheck from means testing for welfare payments

Currently, the payments members receive from court proceedings are included as income or 'means' in the means testing for welfare payments. This affects many, if not most of our membership and has a negative effect on their quality of life. As an example, the sum received by a member may be less than their usual salary. If they are unable to work due to the long term effects of their cancer and treatment, however, this payment is counted when assessing them for out of work payments and can result in them having an inadequate income, or less than they would receive if working. The payment they then receive will not match what the women would have earned in her working life.

This is unfair. These payments are awarded on the basis of the failures of the screening system which have had a huge impact on their quality of life and their family. These payments should not then negatively impact a person's welfare payments or extend beyond themselves for example affecting their child's right to study grants.

Compensation awarded by courts to those affected by Hepatitis C and HIV contaminated blood products are excluded from means testing for social welfare payments.⁹

By excluding courts payments to 221+ members as means for welfare payment assessments, you would positively impact many members.

⁹ [gov.ie](http://www.gov.ie) - Operational Guidelines: Means Assessment (www.gov.ie) Operational Guidelines: Means Assessment, DSP, gov.ie



Context: About 221+

221+ continues to support around **360 women and next of kin / families** directly affected by the failures in the CervicalCheck screening programme, providing much needed peer support, facilitating workshops and advocating for their needs. As time passes many of our members have progressed from active treatment to coping with lifelong side-effects. We engage with members as regularly as possible to ensure that our supports match their evolving needs.

We support members through online meetings and workshops, training for patient representatives, provide individual support via email and phone and facilitate member involvement in campaigns and engagement with stakeholders. This patient advocacy work is vital to improving cervical cancer services and the health service for us all.

In the past five years we have held up to four regional member conferences every year, providing an opportunity for affected women and next-of-kin to attend sessions on specific topics important to the members with a wide range of experts, engage with an ongoing artistic project and to meet their peers.

This peer support is incredibly important, as 221+ Member and Patient Representative Lyn Fenton said - *“As a member firstly I can vouch for the immeasurable value of having a place where what I have experienced and am feeling is felt equally by others, where I don’t have to explain myself and where people just ‘get it’”* (221+ Press Release¹⁰).

In this time **our patient representatives and organizational advocacy has left a hugely positive impact on the healthcare landscape**, from pushing for legislative changes such as open disclosure in the Patient Safety Act, to implementing a key recommendation from Dr.Scally by developing the restoration of trust process over 2 years in partnership with stakeholder organisations, to working on accessibility of literature around the personal cervical screening review process.

The numbers:

In the past 5 years we have run

19 member conferences with full itineraries featuring a diverse range of workshops / talks / classes / presentations

6 courses

2 video series

1 survive and thrive programme with the Marie Keating Foundation

¹⁰ [“Patient advocacy improves healthcare” University of Limerick study confirms](#), 18 June 2024, Lily Fox, Pdraig McKeon, 221+ Patient Support Group



19 online talks/workshops

4 training sessions specifically for Patient Representatives

Regular virtual coffee mornings

In addition to many external engagements such as the launch of our [new report](#) in June 2024 or [The Forest That Won't Forget](#) launch at IMMA, and regular internal governance and planning meetings. We also engage daily with our members, offering support.

We have developed a members-only website (which was relaunched with new user-friendly design in 2023), which acts as a private social media space where members can find recordings of supports, 221+ news updates, trustworthy information and connect with peers via a forum, messages or topic-based groups.

If you would like any further information about the work of 221+ or would like to connect on the issues described in this manifesto, please contact us at info@221plus.ie