

# 221+ PATIENT REPRESENTATIVE AND ORGANISATIONAL IMPACT

A report prepared for  
221+ Cervical Check  
Patient Support Group  
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## Table of Contents

Acknowledgements .....	4
Foreword .....	5
Executive Summary of Present Research.....	6
Introduction.....	10
Context and Purpose of the Research .....	10
The Present Research: 221+ Patient Representative and Organisational Impact .....	13
Aims.....	13
Objectives .....	13
Research Methodology and Design .....	13
The Research Process.....	14
Research Participants .....	14
Phase 1: Stakeholder Evaluation.....	15
Phase 2: Patient Pathway Evaluation.....	16
Recruitment and Data Collection: Phase 1 and 2 .....	18
The Research Team.....	18
Limitations of Present Research.....	19
221+ Patient Representative and Organisational Impact: Research Findings ....	20
Phase 1: Stakeholder Evaluation.....	20
1. Stakeholder Perspectives on Key Contributions of 221+ .....	20
1.1. Legacy of Patient Support .....	21
1.2. Patient Voice in Advocacy .....	22
1.3. An Improved Healthcare System .....	24
2. 221+ Stakeholder Perspectives on Key Areas of Strength .....	26
2.1. Communication with Stakeholders .....	27
2.2. Sustained Persistency in Advocacy .....	28
3. 221+ Stakeholder Perspectives on Future Developments.....	30
3.1 Extension of Advocacy .....	31
3.2 Education and Training.....	33
3.3 Key Role in Restoration of Trust.....	34

3.4 The 221+ Identity .....	35
Phase 2: Patient Pathway Evaluation.....	37
221+ Contributions: Views from Medical and Health Professionals .....	37
221+ Areas of Strength: Views from Medical and Health Professionals .....	38
221+ Areas of Development and Future Directions: Views from Medical and Health Professionals .....	40
Recommendations.....	43
Expansion of Advocacy .....	43
Strengthen Patient Advocacy: .....	44
Promotion of Cervical Screening and Vaccination uptake.....	45
Education and Training.....	46
Embed sustainability of 221+ to develop a robust Restoration of Trust.....	46
221+ Identity .....	47
Conclusion .....	48
References .....	50
Appendix 1: Survey schedule .....	53
Appendix 2: Interview schedule .....	54
Appendix 3: Links to Relevant Reports .....	55

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We are grateful to all who commissioned and contributed to this research including the 221+ Patient Support Group and patient representatives, and the 221+ management team and steering group members.

## Foreword

*Since CervicalCheck failures were first brought to light by Vicky Phelan in 2018, many individuals who were affected have worked tirelessly as patient representatives to ensure that that the same mistakes are never made again. The work that has been done by the members of 221+ has changed the landscape of the Irish healthcare system; some changes are easily measured, for example, the implementation of the Scally report recommendations; others are less tangible.*

*The work that has been done on restoring the Public's trust in the screening service, or amplifying the patient voice is harder to measure but no less important. The 221+ patient representatives have committed a huge amount of time and energy to advocacy, alongside coping with illness, treatment, bereavement and other difficult circumstances, ensuring the women of Ireland have access to a better screening service, and a healthcare system that listens to women, in future years. This research evolved from a need to measure the value of that work.*

- Ceara Martyn, 221+ CervicalCheck Cancer Support Group  
Manager (March 2024)

## **Executive Summary of Present Research**

### **Aims and Objectives**

The overall aims of this research were to 1) assess the work and impact of the 221+ patient representative group (“221+”) and patient representatives since 2018, and 2) to explore how 221+ might further develop its operations into the future, including how the organisation and associated patient representatives may influence progressive change in the provision of healthcare for women in Ireland in the future.

The main objectives were:

- To document and evidence the work of 221+ and patient representatives since 2018, drawing perspectives from 221+ members, patient representatives, employees, key stakeholders, and health and medical professionals;
- To explore, from the viewpoints of multiple stakeholders, potential developments for 221+ as an organisation in the future;
- To make research-informed recommendations about how 221+ might operate into the future.

### **Methodology and Design**

The research utilised a qualitative approach involving survey and interview methods. The team conducted semi-structured interviews with fifteen key stakeholders (Phase 1) and a survey (Phase 2) sent to a purposeful sample of medical and health professionals ( $N = 86$ ) to capture the breadth and depth of perspectives relevant to the research aims and objectives. The survey, including demographic information and open-ended questions, was distributed via an online platform to a purposive sample of medical and health professionals, and received 86 fully completed responses.

Data gathered from the qualitative interviews and online qualitative survey was analysed using reflexive thematic analysis. The data from the interviews and survey responses were analysed separately, and key themes for both Phase 1 and Phase 2 were interpreted by the researchers. Specific recommendations, based on a synthesis of Phase 1 and Phase 2 findings were then formulated.

## Overview of Key Findings

There were similarities in how Phase 1 and Phase 2 participants perceived the past work and future directions of 221+, which adds validity to the overall research findings and recommendations.

### Phase 1

Key findings identified from data collected during the stakeholder interviews:

- Stakeholders' views about the key contributions of 221+ patient representative group included their **support of 221+ members** and **effective advocacy by patient representatives** contributed significantly to an improved healthcare system in Ireland
- **Communication** with key stakeholders and **persistence in advocacy** were highlighted as areas in which 221+ demonstrated strength
- Stakeholders proposed a number of **potential paths forward** including an expansion of advocacy and support to include all women with cervical cancer and, perhaps even, other forms gynaecological cancer albeit with greater national visibility required. Given their experiences, 221+, were identified as a group that could continue to promote the importance of the patient voice in medical

and health domains. 221+ was identified as a key player in the **Restoration of Trust** process.

## **Phase 2**

Key findings from data collected in a survey of medical and health professionals:

- 221+ were viewed as creating an **effective support group** for their members and engaging in **advocacy** efforts for members across the Irish healthcare sector and through liaison with media and governmental groups
- 221+ were perceived as **providing trusted and honest information**, and were credited with **working towards improvements in healthcare provision for women**
- 221+ was described as **developing effective networks** and securing key stakeholder support, and as having guided key stakeholders towards improvements in healthcare provision
- Survey respondents emphasised the ongoing importance of 221+ in the **Restorations of Trust** process
- 221+ were encouraged to build on existing collaborations with key stakeholders to continue to **promote greater trust in healthcare** through advocacy for cervical checks, promotion of vaccination uptake and greater involvement of medical and healthcare professionals.
- 221+ were encouraged to **expand its remit** to include all women with a cervical cancer diagnosis and to further **raise awareness** through targeting young people regarding the importance of vaccinations
- 41.86% ( $n = 36$ ) of survey respondents were unaware or unsure of the organisation, 221+, or their work which suggests the



organisation may need to consider **amplifying their visibility** in the future

## Synthesis of Phase 1 and 2: Conclusions and Recommendations

- Explore the development of an awareness campaign about the importance of both cervical screening and vaccinations – **actively dispelling misinformation and reducing stigma** associated with cervical cancer
- Consider opportunities to expand services to **represent all women impacted by cervical cancer**, with caution urged that the organisation maintains a clear focus and clear scope of work
- Explore opportunities for improvements in ongoing **support and protection of patient representatives**
- Identify scope for participation in aspects of **education, training and development** programmes for medical and health professionals, particularly to highlight the importance of the ‘patient voice’ in healthcare service delivery through use of story narratives about patient’s lived experiences
- Explore ways to **embed 221+** in sustainable ways and to ensure continued engagement in the Restoration of Trust process
- Continue to prioritise **collaboration** as a means to further enhance relationships with key stakeholders and achieve desired outcomes.
- Once future scope is clear, explore strategies to generate greater brand **recognition** in Ireland and beyond

## Introduction

This report details a research evaluation of 221+ patient representative group, an Irish organisation established in 2018 that supports women and families directly affected by past issues in the CervicalCheck Screening Programme. The research was conducted by an external team of researchers from the University of Limerick and consisted of a survey targeting medical and health professionals to ascertain their views about the work of the 221+ patient representative group, and interviews with fifteen key stakeholders. The findings of the evaluation provide research-informed insights and may help to document past contributions and shape the strategic development of 221+.

## Context and Purpose of the Present Research

In Ireland, the National Cervical Screening Programme, CervicalCheck, was established in 2008 with more than three million cytology tests carried out in a ten-year period (2008 – 2018) in 1.2 million women aged between 25 years and 60 years <sup>1</sup>.

An audit of cytology in cases where women had developed cervical cancer was undertaken, and in 221 cases a discordance with a previous cervical screening test was noted<sup>1</sup>. In 2018, the audit generated media publicity resulting in the Minister for Health commissioning a scoping inquiry into the Cervical Screening Programme, conducted by Dr Gabriel Scally which was published in 2018 <sup>2</sup>. Further investigation into the CervicalCheck program revealed issues with how it was managed, including problems with communication, disclosure of information to patients, and quality assurance processes. The majority of recommendations arising from the

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<sup>1</sup> [221+ Consultation Research Report \(hse.ie\)](#)

<sup>2</sup> Scoping Inquiry into CervicalCheck Screening Programme (Final Report, September 2018): [Scoping-Inquiry-into-CervicalCheck-Final-Report.pdf \(scallyreview.ie\)](#)

scoping inquiry have been implemented<sup>3</sup>, resulting in many reforms within the CervicalCheck programme and changes in relation to how cervical screening services are delivered and managed in the country.

The 221+ patient representative group was established in 2018 to provide information and support to the women and families impacted by failures in the National Cervical Screening Programme. This research aims to provide an independent review of 221+, the only patient representative service for women impacted by cervical cancer. The research findings will inform 221+ future directions and their relationship with funders and provide an evidence-base for any future development of support and advocacy programmes for women, and their families, impacted by cervical cancer.

To date, the outcomes produced by 221+ have not yet been formally assessed so it is unknown whether the service is delivering support and advocacy in a way that is responsive to the needs of its target group, or whether it is achieving its desired outcomes and what views key stakeholders, including medical and health professionals hold about its work. In the context of 221+ being the only patient representative group in Ireland for those directly impacted by past issues in CervicalCheck, there is little information currently available regarding the needs of this cohort for services. The present research aimed to address this gap, and specifically to assess the outcomes being delivered by the service and offer an understanding of the support and advocacy needs of women impacted. The present research utilised both interview and survey methods of data collection and analysis.

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<sup>3</sup> Implementation of Dr Scally Reports: A review by the National Screening Service (January 2023): [Implementation of Dr Scally Reports - A Review by the National Screening Service \(hse.ie\)](#)

According to the 221+ Strategic Plan 2021 – 2023, the organisation has focused on two main aims<sup>4</sup>:

1. To support their members in accessing necessary services and aim to enable supportive, listening and caring engagement with these services. Furthermore, information and promotion of cervical screening and the HPV vaccine can be found on the 221+ website and the social media site, X (formerly Twitter).
2. To increase members' voices, both current and from the past so that 'working to remember the past and drive change in the healthcare system to hold decision-makers to account, ensuring to the best of our ability that the women of Ireland have access to a world class screening service and health care'<sup>4</sup>.

221+ overall vision is that 'all women in Ireland have access to the best cervical cancer screening, treatment and support, which builds on learning, experience and actions of the women and families of 221+ members'<sup>4</sup>.

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<sup>4</sup> Summary of 221+ Strategic Plan 2021 – 2023 [Final-221-Plus-Strategy-Summary-2021-23.docx \(live.com\)](#)

## **The Present Research: 221+ Patient Representative and Organisational Impact**

### **Aims**

1. To assess the work and impact of the 221+ patient representative group and patient associated representatives since 2018; considering services to members and external impacts.
2. To explore how 221+ may operate in the future, and how the organisation and associated patient representatives may influence progressive changes for the provision of healthcare for women in Ireland and beyond in the future.

### **Objectives**

1. To document and evidence the work of 221+ and patient representatives since 2018, drawing perspectives from of 221+ members, patient representatives, employees, stakeholders, and health and medical professionals.
2. To explore potential futures of 221+ as an organisation from the viewpoints of multiple stakeholders.
3. To make research-informed recommendations for how 221+ may operate in the future and influence progressive changes to the healthcare landscape for women in Ireland and for women internationally.

### **Research Methodology and Design**

The research team employed participatory methods in the research process and worked closely with 221+ throughout to ensure that the evaluation was in line with their organisational principles. A participatory action research methodology (Cornish et al., 2023) enabled a collaborative

process in the development of the evaluation project. The evaluation design centred on an impact evaluation approach (Gertler et al., 2010). This approach involved the consideration of the broader impact and outcomes of the activities of the 221+ organisation including their effects, intended or unintended.

The evaluation design and implementation were collaborative, characterised by ongoing communication between researchers and 221+, to generate greater engagement with the evaluation and implementation of recommendations (Fetterman et al., 2018). Consultation with the manager of 221+ informed the development of the research design. Drafts of the survey and semi-structured interview schedule were provided to the manager of 221+ with further contact to discuss their feedback. This approach ensured that the survey and interview schedule questions were appropriate for the targeted participants of both the survey and interviews before the commencement of data collection. Confidentiality, anonymity, respect and dignity were core values and principles upon which all aspects of the research process were developed.

### **The Research Process**

The team adopted a qualitative approach, using interview (Phase 1) and survey (Phase 2) methods, to capture the breadth and depth of perspectives relevant to the research aims and objectives. This approach allowed for the breadth of the survey data to be combined with the depth and contextual relevance of interview data (Gibson, 2017).

### **Research Participants**

To be eligible to take part in the study, participants were required to be over 18 years old, and participation was voluntary with no reward offered for participation. All participants were asked to read through the participant information sheet and sign an informed consent sheet if they wished to

take part in the research. Full ethical review of the research project and associated materials was conducted by the University of Limerick Research Ethics Committee prior to ethical approval being granted.

### **Phase 1: Stakeholder Evaluation**

The first phase of the research involved a stakeholder analysis to understand the perspectives from a range of individuals, groups and organisations that have worked with or interacted with 221+ since 2018. Stakeholders were identified through engagement with the 221+ management group. By interviewing stakeholders, the aim was to gain insights into their perspectives, interests, concerns, and priorities relating to 221+, considering past actions and future opportunities. The research team examined themes and commonalities across all interviews as means to identify key areas of focus (thematic analysis; Braun & Clarke, 2021). It must be noted that not all identified stakeholders were available for interview during this phase of the research project, therefore, there may be some stakeholder views which are *not* captured in the present analysis.

Semi-structured interviews with key stakeholders within the 221+ organisation and key individuals across the health system, in both statutory and voluntary sectors, provided a deeper understanding about the effectiveness and value that 221+ has generated within the Irish health system. The interview schedule was tailored to capture areas in which 221+ has been most effective and included information about opportunities in which 221+ might capitalise further in terms of their ongoing service delivery (see **Appendix 2**).

Fifteen individuals volunteered to speak with the research team. Participants were recruited with the assistance of the manager of 221+ and were associated with the 221+ organisation, the National Screening Service (NSS), voluntary sector organisations that deal with

healthcare in Ireland, HSE personnel and medical professionals. The majority of interviews were conducted both online, via Microsoft Teams platform and four interviews were conducted in-person at the Irish Cancer Society offices. All interviews were conducted between October 17<sup>th</sup> and November 27<sup>th</sup> 2023.

Interviews were digitally recorded and transcribed by the research team. A thematic analysis was conducted using NVivo software when interview transcripts were coded to identify and develop themes. In addition, the use of thematic analysis recognised the researcher's role in the interpretation of data (Braun & Clarke, 2021).

## **Phase 2: Patient Pathway Evaluation**

The second phase of the research aimed to engage the anonymous views of a limited sample of health and medical workers in Ireland about the work of 221+ and patient representatives. An open-ended qualitative survey was distributed to a purposive sample of clinicians along the 'patient pathway' — those medical and health professionals that women encounter as part of the cervical smear process. It was hoped that the information obtained from the survey would serve to further an understanding of clinicians' views about 221+ organisation and patients associated with 221+ (see Scally, 2022). The anonymous survey data obtained from healthcare professionals would potentially generate opportunities to build stronger communication bridges between medical and health professionals along the 'patient pathway' and patient advocates in the 221+ organisation. The survey consisted of five key qualitative questions along with basic demographic information including gender, occupation, and age range (see **Appendix 1**).

The survey received 86 completed responses which were included for analysis. Key demographic characteristics are summarised in **Table 1**.



**Table 1:** Summary of Phase 2 Survey Participant Demographics

<b>Participant Characteristics</b>	<b>Summary</b>
Gender	Female: 75 Male: 7 Prefer not to say: 4
Age Ranges	35-45 years: 21 45+ years: 60 Prefer not to say: 5
Employment	Healthcare Professionals: 82 Care Worker: 2 Prefer not to say: 2

In addition, responses to a question about whether the 221+ organisation has had a positive impact on healthcare in Ireland, 44 respondents indicated their agreement (51% of the sample), 11 respondents actively disagreed, and a further 31 respondents declined to respond to the question.

Survey responses were collected via Qualtrics survey software and then imported into the NVivo software package for analysis. Demographic data were analysed within NVivo, and frequencies of attributes were generated within the software package. Given the small sample size, the use of NVivo software was beneficial in facilitating the synthesis of qualitative responses to survey questions with demographic information and this approach was appropriate to provide a broad understanding of the sample group (Andrew et al., 2008). A thematic analysis of qualitative data generated in the open text boxes was conducted.

## **Recruitment and Data Collection: Phase 1 and 2**

A recruitment strategy was agreed upon as part of the consultation process between the research team and 221+.

The 221+ manager provided the research team with the names and contact details of key stakeholders who were then contacted by researchers with a request to participate in an interview about their experiences with 221+. Interviews began on the 17<sup>th</sup> of October 2023 with the final interview occurring on 27<sup>th</sup> of November 2023. In total, fifteen semi-structured interviews were completed with those identified as key stakeholders across the healthcare system in Ireland, who were associated with the work of the 221+ organisation (Phase 1).

221+ facilitated the survey circulation through partner health service agencies. The survey was active from 20<sup>th</sup> November 2023 until 23<sup>rd</sup> December 2023 during which time 221+ remained engaged with various health services requesting assistance in relation to survey distribution. Throughout the data collection period, regular updates were provided to 221+ regarding engagement levels in both interview and survey processes. In total, 86 respondents who identified as healthcare professionals completed the survey.

## **The Research Team**

The external research team consisted of three female, highly qualified and experienced researchers, all with postgraduate qualifications in psychology. The project lead was Dr Elaine Kinsella, who is an associate professor in psychology and chartered organisational psychologist at the University of Limerick. The postdoctoral research fellow, Dr Elaine Kavanagh, is a qualified social worker and holds a PhD in psychology. The research assistant, Julie Ann Baxter, holds an accredited master's degree in psychology. All three researchers identify as Irish women who had

some limited previous knowledge of the work of patient representatives in cervical cancer in Ireland but who were not overly familiar with the work or contributions of the organisation, 221+, prior to tendering for this research project.

As researchers, while we are experts in the field of psychology and experienced researchers, and yet, human biases and assumptions may have influenced the research process and analysis. The team, aware of our position as women who are screening service users, strived to maintain a balanced approach through the research process. Steps were taken to reduce unconscious bias through the process by engaging in reflexivity (reflecting on own biases, position, assumptions), adopting structured interview and survey formats using open-ended questions, employing multiple, highly qualified interviewers with diverse employment experiences, using multiple data collection methods, ensuring anonymity and confidentiality for all research participants, clearly documenting steps in the research process, and engaging in weekly peer debriefing and review. In analysing the data, the team acknowledge that participants' views and perspectives are constructed through shared social understandings rather than objective realities, and that these views are influenced by power structures within Ireland and the healthcare system within Ireland.

### **Limitations of Present Research**

As with all research approaches and methods, there are limitations of the present research project which must be acknowledged explicitly. Both Phase 1 and Phase 2 of the research have been conducted with a *limited* sample, which may not represent the views of all stakeholders (Phase 1) or all medical and health professionals (Phase 2). The findings reported in this report reflect a thematic analysis of the views of the included stakeholders (Phase 1) and survey respondents (Phase 2) only. The

research findings are based on participants' understanding, interpretation and recollection of events and interactions, and those opinions and views may differ between individuals. We have attempted to give equal consideration and voice to each interviewee, due to existing social and power dynamics which may have influenced what interviewees felt they could share or elaborate on. It is within the context of these constraints that the present research findings should be scrutinised and used to inform future decisions.

## **221+ Patient Representative and Organisational Impact: Research Findings**

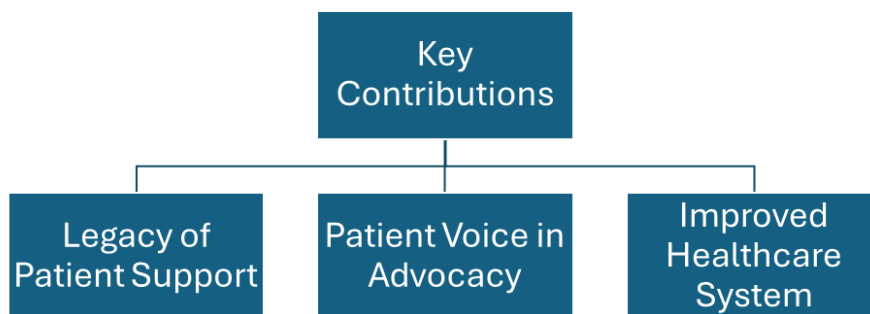
### **Phase 1: Stakeholder Evaluation**

The following section presents the thematic analysis of fifteen interviews which explored the views of stakeholders about 221+. Findings are summarised, with evidence provided through the inclusion of confidential extracts from interviews. To maintain the anonymity of participants, names of participants are not used and instead were assigned a number and are reported as Participant 1 (P1) and Participant 2 (P2). In some cases, information within a particular quote has been omitted to protect the identity of the individual, and in those cases the omitted lines have been indicated through the use of three dot ellipses [...]. All quotes included in this report have received explicit permission to be included for present purposes, over and above, their explicit and informed consent to take part in the research.

### **1. Stakeholder Perspectives on Key Contributions of 221+**

The following section describes the key contributions of 221+ to women's healthcare, as recounted by stakeholders. The support of women and families impacted by operational systems failures and strength of the patient voice in advocacy were described as key features of 221+, and

overall, the work of 221+ was generally viewed as having contributed to improvements in healthcare provision in Ireland.



### **1.1. Legacy of Patient Support**

As an organisation, 221+ has aimed to provide support (emotional, social, instrumental) to those women (and wider family units) impacted by failures in the National Cervical Screening Programme since 2018. Through the interviews, stakeholders described the value of 221+ becoming an effective support group for the women and their families. 221+ was viewed as offering valuable peer support and a safe space for shared understanding. Through the use of the phrase “lifeline” we see how dependent a patient was on the support offered by the 221+ group:

*The 221+ group have been a lifeline. It has been a lifeline I didn't know I needed. When I was told that I was part of the CervicalCheck failure in Ireland and trying to get my head around initially...I didn't know who to turn to, I didn't know anything about anything... So then, to be able to get in touch with the 221+ group was such a lifeline because you were able to meet like-minded people. People who just get you. People who actually understand.*  
(P6)

The crucial part of the support offered was connecting people based on their shared identity — individuals who shared psychological experiences as a result of their life experiences. The members were able to relate to one another (“*there are people there that will just **get me***”), to offer mutual understanding, and importantly, not require lengthy explanations of the extremely challenging negative physical effects of cervical cancer and treatment. These shared situations were acknowledged as an important support for those impacted, as P6 outlines:

*I know no matter what I went through...that there are people there that will just get me. You don't have to explain why you have to get up and go to the toilet every five minutes because you have bladder damage from treatment. (P6)*

The findings from the research are consistent with existing research on how peer support buffers negative emotional experiences. The available literature has highlighted how the benefits of in-group support can diminish stress experiences and enhance wellbeing allowing those impacted to interpret a significant life challenge as more manageable (Haslam et al., 2008; Haslam et al., 2004; Sani et al., 2012). For some, the 221+ group also offered a space to work as a collective to challenge perceived injustices in the healthcare system.

## **1.2. Patient Voice in Advocacy**

Patient advocacy is concerned with advocacy for patients, survivors, and caregivers in healthcare settings. 221+, as an organisation, has engaged with patient representatives and patient advocacy as a key means of striving to exert change in healthcare. During interviews, stakeholders expressed views about the importance of 221+ patient advocacy particularly in the area of women's health. The role of patient

representatives was considered, by stakeholders, central to the advocacy work of 221+. Patient representatives were described as valuable assets in advocating for the development of healthcare services. Importantly, the ongoing presence of the patient voice in decision-making processes was noted as effective and beneficial. The work of 221+, and associated patient representatives, was viewed as valued since 2018, but with more still left to do with regard to women's healthcare. One stakeholder articulates this sentiment clearly:

*The voice of 221+ is needed. It really adds a lot in the area of women's healthcare around patient voice and patient involvement and it would be my hope that it continues to work in those areas to make sure that women are empowered when engaging with the health system and that that will ensure that all of us are the owners of our health and that it's not someone else who makes decisions for us. (P7)*

These findings are consistent with existing literature on the positive impacts of patient representatives in healthcare advocacy and reform. Public patient involvement (PPI) is recognised internationally as best practice in research and practice settings (Armstrong et al., 2018). Moving forward, it will be important that the input of 221+ patient representatives is welcomed by all stakeholders, and not as a tokenistic symbol of true PPI, which has been raised as a concern in existing international literature (see Hahn et al., 2017; Ocloo & Matthews, 2016).

In interviews, it was acknowledged by stakeholders that patient representatives can become overburdened due to the demands of the position. This important caveat is consistent with the international research that has pointed to difficulties in the recruitment of patient representatives as workload demands and financial burdens can make the position

unattractive (Austvoll-Dahlgren et al., 2017; Hult, et al., 2020; Ocloo & Matthews, 2016).

In the context of the value attributed to patient advocacy by key stakeholders in the present research, 221+ may be well placed to facilitate effective future recruitment of patient representatives and required supports, while also advocating their central role in the development of improved healthcare delivery over time.

### ***1.3. An Improved Healthcare System***

In addition to the facilitation of important peer support scaffolds for women impacted and patient advocacy via the voices of patient representatives at key decision-making forums, stakeholders specified how these collective aspects of the work of 221+ improved healthcare service delivery for women in Ireland. One stakeholder explains:

*The biggest impact...has been the work that the patient representatives did on the personal cervical screening review or the patient request review leaflets...and I think those leaflets put in language that was truthful, factual, honest, open, transparent but in the best possible way, not traumatizing. (P8)*

Some stakeholders have viewed the advocacy efforts of 221+ as initiating an ongoing process of improvements in healthcare provision for women in Ireland, as P7 outlines:

*We've seen a significant investment by government in women's healthcare really since the establishment of 221+. And it goes much wider than cancer, but we now have, the National Women's and Infants Programme that has been financed quite significantly, the gynae cancers have also received funding, the fact that there is*



*a screening laboratory that has been built. I think that these are all results of the advocacy of 221+ and a collective voice from women's organisations and women themselves that has really driven a lot of change in the area and I don't think that it is finished yet. (P7)*

In the present research, selected stakeholders expressed views about how the actions and advocacy work of 221+ led to the organisation and patient representatives being blamed for highlighting systems faults, which were seen to undermine trust in the CervicalCheck screening services. These complex viewpoints are explained by P10:

*I think some people would blame 221+ and the families involved for, I suppose, engendering a lack of trust in the screening services through what happened, and you know, some people just stick to the narrative, 'oh, you know, screening is never 100% effective and people should have known that'.*

Stakeholders reinforced the view that 221+ remain strong advocates of both cervical screening and vaccinations with a clearly expressed understanding that the cervical screening services would not capture 100% of the population.

An aspect noted in a number of interviews was related to a stigma associated with becoming diagnosed with cervical cancer which led to some women withholding their diagnosis from family, friends and the community. It is known that a majority of cervical cancers are a result of the HPV virus which is transmitted via sexual intercourse. Women's concern about sharing a cervical cancer diagnosis was related to perceived judgements and potential accusations of sexual promiscuity, as P14 explained:

*It wasn't known that they'd cervical cancer. And largely that was because of the stigma of cervical cancer and their feeling that they would be judged morally because of their cancer. (P14)*

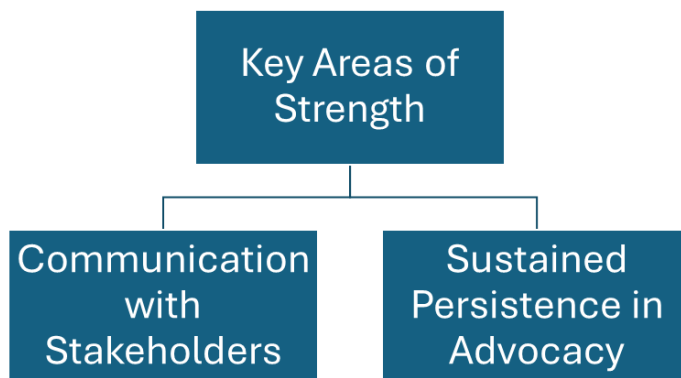
221+ have stimulated greater openness in relation to women's health in Ireland, particularly in relation to cervical cancer, which was viewed as alleviating the associated stigma which is experienced by women only:

*I think the openness to talking about women's health, the openness about talking about cervical cancer, and 221+ are open and are good at talking about cervical cancer. I think that helps remove the stigma (P8)*

Further representation for those who chose to remain 'hidden' due to fears about being judged may be an area which would benefit from further advocacy and continued openness to dispel the wider stigma relating to women's health and particularly, cervical cancer.

## **2. 221+ Stakeholder Perspectives on Key Areas of Strength**

221+ has demonstrated strength of conviction in their interactions and effective communications with key stakeholders, across statutory, voluntary and political sectors. Their persistent advocacy for improved healthcare provision and specifically, an improved cervical screening programme for women was acknowledged by many stakeholders.



### ***2.1. Communication with Stakeholders***

Participants viewed 221+ as an effective communicator across the statutory, voluntary, non-statutory and governmental sectors. This identified strength of 221+ and its patient representatives was used effectively to achieve its goals and objectives. From its beginnings, the 221+ group was a focus of significant media attention. In some ways, 221+ was described as capitalising on the media publicity surrounding the scoping enquiry and reports (Scally, 2018) to ensure recommendations were implemented in full:

*They [221+] realized early on that it wasn't just about a report being published. It was about holding the state agencies to account to ensure that they were fully implemented (P7)*

221+ successfully communicated with all key stakeholders and garnered extensive support — engaging with health services, voluntary services such as the Marie Keating Foundation and with political stakeholders to advocate for positive changes for its members and ensure a better healthcare system for women, as P15 explains:

*I think they (221+), it was one of those few processes that got all-party support across the Dail, across the Oireachtas, and you know,*

*I think the influence that they had was that it didn't get politicised if you like, you know, everybody wanted to see this fixed and the harm that was done acknowledged. (P15)*

221+ yielded considerable influence particularly in relation to the Patient Safety Act (2023) and associated communications which was recounted by P11:

*The Patient Safety Bill was signed into law in April of this year [2023], and, back in February you'll find quotations from the Minister of Health, Stephen Donnelly, who wouldn't bring it to the Dail unless it was approved or agreed upon with 221+ support group. (P11)*

221+ were viewed as instrumental in ensuring that systems failures were not forgotten and that progress in consistently working toward improvements in women's healthcare were prioritised:

*Without 221+, you would never know, it would be forgotten, it would be a past headline and people would move on (P10)*

## **2.2. Sustained Persistency in Advocacy**

Sustained advocacy is difficult to maintain due to the costs (physical, social, emotional, financial, time) associated with maintaining efforts. Nonetheless, 221+ and their patient representatives remained persistent in their advocacy. P14 explains:

*It's taken a lot out of some of the 221 leaders, in particular participating with the Department of Health and so on. I mean, all of these things come with enormous cost to them.... Have come with an enormous cost to them, and enormous benefit to them as well, I'm sure, in terms of the respect that they've quite rightly gained and*

*that they're feeling they're doing the right thing. But, you know, there's a downside to it for them as well. (P14)*

Stakeholders noted how the enduring advocacy efforts have brought about positive changes in healthcare provision. The 221+ **persistence** for systematic changes has had an impact, but also, through advocacy work, 221+ have facilitated members' to find a space where they feel 'listened to', as P6 recounts:

*Doing different things and telling your story and you know, it's actually, it's lovely to be listened to, to be in a room, especially with the HSE and NSS [National Screening Service] now, and it's only now that it's coming about, that we feel listened to, and heard and that something is done about it. (P6)*

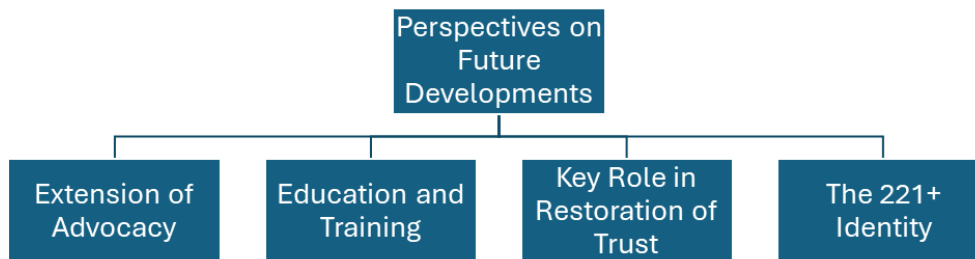
In addition, 221+ advocacy efforts were cited to have influenced recent changes to the guidance provided to doctors in Ireland by the Irish Medical Council, as P14 explains:

*The Irish Medical Council has only recently changed its guidance to doctors...it did say that doctors 'should' practice open disclosure...they have now changed the wording to '**must**' practice open disclosure. This took 5 years, which is ridiculous, ridiculous, one word, they just needed to change it. The point was to change it so that there's a presumption that doctors will tell the truth to their patients, and if they don't tell the truth to the patients, well, then it's up to them to argue back, you know, in a disciplinary forum or whatever, why they were right not to tell the truth to the patients rather than the previous situation where it was an optional thing. (P14)*

Some stakeholders communicated a need for ongoing and persistent advocacy by 221+. As P4 recounts, there are “*no patient representative on the women’s health taskforce*” which was set up by the Department of Health on foot of recommendations from the Scally report (2018), with the omission being interpreted by some stakeholders as an “*indicator of the fact that some areas have gotten how important the patient voice is and others have not*” (P4). This sentiment suggests that there is further work to do in educating all areas of health and healthcare provision on the value of patient representation.

### **3. 221+ Stakeholder Perspectives on Future Developments**

Stakeholder views about future directions for 221+ included extending their advocacy efforts to capture *all* women impacted by cervical cancer (not just those who were affected by CervicalCheck failures highlighted since 2018), and advocating for increased and improved gynaecological services. Stakeholders noted the value of the ‘lived experience’ in educational and training forums, and importantly, viewed 221+ as a key player in the Restoration of Trust processes. Some stakeholders felt that the 221+ identity might benefit from greater visibility as many were not familiar with the name “221+” or the day-to-day work of the organisation and patient representatives.



### **3.1 Extension of Advocacy**

Stakeholders expressed views that 221+ has contributed positively toward greater awareness about women’s health needs in Ireland (*“I think women’s health, in particular, has had a light shone on it in Ireland”* P2).

Stakeholders, when asked about the future, suggested that 221+ consider expanding its remit to capture all women impacted by a cervical cancer diagnosis:

*I guess that is my hope for 221+ is that they could move into a space where they support women with cervical cancer and could support all women with cervical cancer (P8)*

Gynaecological issues were also suggested as an area on which 221+ might focus in the future with participants reflecting on the difficulties women have had in the past with securing an appointment with a gynaecologist and identifying a need for advocacy in this area of healthcare for women.

Stakeholder views about the importance that the advocacy efforts of 221+ continue to ensure that women's health is a priority area for governments and health systems are exemplified by P15:

*I think, very firmly, I think they should continue to concentrate on building that confidence in the health system, in women's health issues, being strong advocates for women's health, getting priority within the health system, within the political system, being strong advocates for people coming forward for screening, so I think just generally women's health, continue to advocate for it to be a priority for government, a priority for the health systems, to be invested in, to seek guaranteed commitments on funding. (P15)*

Notably, some stakeholders expressed cautionary views that 221+ needed to ensure it retains its unique position in advocacy, as P15 explains:

*I think one thing they [221+] have to be is careful, it can't be a voice for **everybody on everything**. I think they have to be careful... what business are they in, what advocacy area are they in, because, you know, you can diminish it if it just gets too broad, and I think 221 had a very clear focus throughout. Yeah, I'd just urge a bit of caution that if it becomes too general it becomes meaningless, the voice that they have gets weakened. (P15)*

The message from this stakeholder is to have a clear remit and ensure the focus is specific and strong. Yet, almost all stakeholders prompted 221+ to consider expanding their advocacy efforts to encapsulate all women with a cervical cancer diagnosis, particularly as the agency is the only service in Ireland that represents those impacted by cervical cancer.



### **3.2 Education and Training**

Training and education was another important theme which cropped up across multiple interviews with stakeholders. In particular, 221+ were urged by some stakeholders to consider using vignettes derived from 221+ members' lived experiences to educate future medical and health professionals about the value of the patient perspective in healthcare provision:

*I think there's a tremendous amount of work to be done in educating, in the current medical student world or nursing student world, of helping people understand the patient perspective (P14)*

*They have good vignettes, good real-life stories, experiences of what people had, to make it real, you know, for people, it's powerful (P15)*

GPs and gynaecologists were explicitly named as professionals that might benefit from training in the importance of open disclosure and issues related to women's gynaecological issues:

*I think one of the pieces would be how to get some of these things into the training of GP's and gynaecologists when they're actually being trained in Med school (P9)*

Harnessing the accumulated knowledge and skills, some stakeholders urged 221+ and its patient representatives to consider how to appropriately share this knowledge to continue to make positive changes within healthcare:

*I think that 221+ could be expert speakers and teachers in in a number of these spaces for healthcare workers (P9)*

Stakeholders saw value in incorporating the lived experiences of 221+ members in training programmes and awareness campaigns to highlight the importance of screening and vaccination services, for young people and adults.

### **3.3 Key Role in Restoration of Trust**

Stakeholders consistently identified 221+ as key players in the Restoration of Trust process. Indeed, stakeholders reflected that trust restoration was important for medical and health professionals, as well as for women and families impacted. Restoration of Trust was viewed as an important factor in building stronger future partnerships between healthcare providers and service users into the future.

Restoration of trust processes were cited as a key pathway toward stronger partnerships. P14 commented on how 221+ were a group that wanted to ensure systems failures encountered by their members would never re-occur, and outlined how trust could be rebuilt:

*When something goes wrong for a patient, they want three things; they want to be told the truth above everything else, they would like someone to say sorry and someone who has skin in the game, not an assistant administrator but someone, preferably sitting across the table with them and telling them what went wrong, why it went wrong and apologise, and really being sorry. Not just saying sorry, but being sorry. And the third thing is, patients, and 221 are a very good example, they are entirely altruistic. I mean they are riven through with altruism. They want this not to happen to anyone*

*else... in this case getting the same sort of rubbish deal on cervical screening from the State as they've had. (P14)*

221+ and its members were identified as important players in rebuilding trust:

*They (221+) also played a very key role...of building that process of trust or re-building the process of trust (P15).*

Stakeholders also shared views about how the Restoration of Trust process was extremely important for healthcare and medical professionals as well as 221+ members because staff were deeply affected by the events, and often felt a sense of letting patients down. Feelings of blame and experiences of trauma were described as commonplace among healthcare workers working in cervical cancer screening and treatment.

The available literature supports the promotion of patient empowerment as an important aspect of genuine engagement and establishment of trust due to the significant power differentials existing between patients and medical and healthcare professionals in decisions around healthcare service delivery (Ocloo & Matthews, 2016). Building trust and more collaborative networks with key stakeholders was noted by participants as a potentially challenging road, but an important path going forward.

### **3.4 The 221+ Identity**

Stakeholders were familiar with the organisation, 221+, and its work, yet some stakeholders queried how visible the organisation is on a national level. Indeed, one stakeholder suggested that there may be a widespread lack of knowledge about the existence of 221+ patient representative group. Many noted how the small 221+ team, and limited funding available, limited the visibility and impact of the organisation at a national and international level.

A further complication was that the 221+ identity would seem to be both part of and separate to other charity agencies which advocate for cancer patients, namely, the Marie Keating Foundation and the Irish Cancer Society. P11 outlined how the Irish Cancer Society acts as a conduit for 221+ funding:

*The Department of Health, when they agreed the funding, said 'we'll fund you, but we'll only pay the money to the Irish Cancer Society, it's up to the Irish Cancer Society to distribute it outward', so, that's why there's SLA's (Service Level Agreements) in place in the background. (P11)*

While it remains possible that the 221+ identity is complicated by associations with other charity agencies, P11 explains the importance that 221+ received both backing and supports from these organisations:

*The Irish Cancer Society was probably, I think as well, what was great about that...I think it gave the 221+ support group an elevated position of respect because it meant that we had the backing of the Marie Keating Foundation and also the Irish Cancer Society. I think that, from like a marketing perspective, when you're trying to bring your brand out there, like the 221+ brand...we're in bed with these two fine established foundations you know. (P11)*

It was questioned whether 221+ might consider becoming an agency independent of other charities: "*is there benefit...to set up as a charity, a regulated charity going forward*" (P11). However, a confounding factor was that the 221+ identity may not be well known beyond 221+ members and those working in cervical cancer screening or treatment areas:

*I didn't know about 221+...So I'm not sure that people do know about it and maybe it's something that could be included on a, you know, on some of the leaflets of the CervicalCheck screening because I don't think it's known other than by the members. (P9)*

Raising awareness about 221+, the organisation, brand, advocacy and services, was offered as a key recommendation by several stakeholders.

## **Phase 2: Patient Pathway Evaluation**

The following section presents a thematic analysis of qualitative survey responses from a sample of 86 medical and health professionals who work along the patient pathway of those being screened or treated for cervical cancer. Key findings are summarised below, with evidence provided through the inclusion of selected extracts from the survey responses.

### **221+ Contributions: Views from Medical and Health Professionals**

221+ was described as making a number of important contributions since 2018. The contributions can be grouped thematically in three key areas.

First, 221+ were acknowledged to be effective by creating an **effective support network for their members**, women affected by cervical cancer, and their family members, and support for women/their families who have brought legal action to the HSE. The support offered was considered as playing a crucial role in supporting these individuals and families through their most difficult life challenges. 221+ has offered ongoing emotional, social (peer-based) and practical support to patients and their families. One health or medical professional described a sense of relief that there was an organisation working on behalf of women and their families:

*[It is] wonderful knowing that they are actively working behind the scenes to ensure the support for patients and their families, and all future women that will be using the CervicalCheck screening programme.*

Second, 221+ were described as **offering a strong voice and trusted information** to others. By setting up a Steering Group, producing reports, launching a website, lobbying the government, and supporting research, 221+ were seen to offer patients and members of the public accurate and timely information. 221+ were described as working diligently to ensure that recommendations from the Scally report were implemented, challenging paternalistic models of healthcare, seeking to have the Patient Safety Bill (now Act) amended to include open disclosure, and contributing to the open disclosure policy.

Third, as an organisation, 221+ were credited with **working to improve the healthcare system** in Ireland. For instance, they have advocated for vaccinations against HPV, service-user engagement, patient representation, and providing advice and support. One health or medical professional noted how the work of 221+ has prompted them to seek out service-user feedback within their own area of work:

*It has made me more conscious of the need to include the service-user in the conversation about services, the need to seek service-user feedback.*

### **221+ Areas of Strength: Views from Medical and Health Professionals**

There were two key areas of strength associated with 221+. First, the organisation was viewed as having **developed effective networks and**

**consistently seeking stakeholder support.** 221+ was viewed as meeting relevant stakeholders and communicating with the Health Service Executive (HSE), Department of Health, government and political representatives; and working with these networks to lobby for improvements in healthcare and advocate for women's health. 221+ were viewed as keeping the HSE & Department of Health accountable for the implementation of key recommendations.

Second, the organisation was viewed as playing a **persuasive role in guiding healthcare provision** in Ireland. 221+ were described as increasing awareness of need for openness and transparency in cancer screening for women in Ireland, seeking ongoing assurance to prevent deficits in future care, requiring accountability at all levels of decision-making, using service-user experiences to inform policy, seeking to influence policy, highlighting the lack of disclosure around cervical smears in Ireland, and changing how the screening service operates for the better. One nurse felt that the work of 221+ had a positive impact on screening awareness and uptake:

*I think it raised awareness of cervical screening on the whole and encouraged uptake.*

221+ were described as encouraging women to be proactive in their own health, as well as engaging in screening:

*[The work of 221+] reinforced to me as a nurse that the test is only as good as the person carrying it out, and the person interpreting the results and the need to advise clients to always follow their gut instinct i.e. if they feel that things are not right even though they have been reassured by professionals to seek further advice.*

## 221+ Areas of Development and Future Directions: Views from Medical and Health Professionals

There were four key areas of development and future directions associated with 221+.

First, medical and health professionals urged 221+ to **mitigate against collateral harms** in the future by working collaboratively with healthcare professionals, promoting cancer screening, and restoring and promoting trust in healthcare. Some health and medical professionals were concerned that 221+ had (unintentionally) played a role in reducing trust between the national cervical cancer screening service and service users, and that while there was support for becoming informed about healthcare, some survey respondents felt that this should be handled in a balanced and collaborative way. It was noted that by raising awareness about cervical cancer, the number of women engaging in “unnecessary extra” screening increased.

Some respondents cautioned against being known as a litigious agency and the potential that a screening service may become unviable because of the large costs associated with legal cases. In seeking to restore trust in healthcare, respondents urged that 221+ advocate for honest, fair and balanced reporting in the media and to the general public. Some concerns were raised about the need for clear communication to quell misinformation and misrepresentations, unhelpful narratives in the media and in legal contexts, conspiracy theories regarding vaccination and screening programmes, and aggression directed towards medical and health professionals. One health or medical professional described how perceived loss of trust in healthcare and ongoing litigation negatively affected patients and their families in both psychological and social ways:



*I have cared for members of the group in their palliative stages. This has invariably been challenging due to the loss of trust in the healthcare system and the professions within and by where litigation is ongoing this comes with very significant impacts on the patient and family's journey psychosocially, often with increased anguish and a heightened anxiety around the legacy left behind if these issues are left open and/or unresolved*

Other health or medical professionals described the negative impact of the controversy regarding the National Screening Service on healthcare workers and relationships between patients and healthcare workers:

*When the controversy commenced regarding NCSS and failure to manage the communication about the 'look back', staff felt demonised and very let down by the public discourse around the messaging, and the sense that they were somehow involved in 'hiding' cancer diagnoses from women*

The media narratives surrounding the controversy (while not directly attributable to 221+ communications or advocacy) were perceived as promoting misinformation which resulted in negative impacts on healthcare professionals, and their relations with patients:

*It has added to the aggression and misinformation directed at all healthcare professionals.*

*Dealing with unfair and inaccurate accusations surrounding cervical screening.*

*Very difficult in dealing with aggressions, nearly to a point of leaving the health care service.*

*It did impact on our ability to attract staff into cervical screening.*

Healthcare and medical professionals were generally of the view that 221+ could play a stronger role in the future in promoting trust in healthcare and dispelling misinformation as it arises.

Second, medical and health professionals noted a need for 221+ to **build on existing collaborative work** to promote trust in healthcare. Respondents urged 221+ to go into healthcare settings and meet with staff directly, to include other groups, to guide healthcare policy, and to advocate for HPV vaccination, continue advocacy and patient education and information services but involve healthcare professional stakeholders, such as a representative from CervicalCheck to foster a collaborative approach going forward. To continue to ensure that women's health screening is taken seriously.

Third, medical and health professionals encouraged 221+ to **strive for future impact through targeted education and training** regarding the need for cancer checks and smear testing. Respondents suggested that 221+ advocates for childhood vaccinations against HPV, engage in working with young people, schools, colleges educating and advising on the benefits of proactively engaging in cancer screening, and contribute to higher education programmes to influence students in areas relating to politics, sociology, medicine and health programmes. Respondents urged 221+ to increase the impact of the messaging that screening should continue, develop into a powerful organisation to support *all* cervical cancer sufferers (akin to Jo's Trust in the UK), work with the HSE to reduce the impact of this preventable disease, and to clarify and educate about screening (and the limits of screening).

Fourth, given that a number of health and medical professionals were either unsure or unaware of 221+ or their work, there is a need to **identify the scope of 221+ in the future and consider how they might increase their visibility** as an organisation. Many respondents were not familiar with 221+ and knew little about their work. Some healthcare and medical professionals felt that to be effective in the future, the organisation would need to consider growing its online presence and seek out effective marketing and advertising.

### Recommendations

The following recommendations aim to inform 221+ about areas for consideration in its future development and are based on a synthesis of the findings from Phases 1 and 2 of the present research.

While 221+ was found to be an effective communicator and valuable in its support of members and advocacy functions, the evaluation identified key areas that 221+ might take into consideration in the future. Recognising that the implementation of these recommendations is **contingent on resources**, the below list represents potential future directions for 221+ to explore and consider in future funding requests.

### Expansion of Advocacy

Recommendation	Rationale
Explore opportunities to expand services to represent all women impacted by cervical cancer	<ul style="list-style-type: none"> <li>221+ is currently the only service in Ireland that offers support specifically to women and families impacted by CervicalCheck systems failures.</li> </ul>

	<ul style="list-style-type: none"> <li>• 221+ might consider expanding their advocacy and supports to capture <i>all</i> women diagnosed with cervical cancer, comparable to services provided by Jo's Trust Service in the United Kingdom, particularly as no such specialist service exists in an Irish jurisdiction</li> <li>• Caution was expressed that 221+ should not dilute its voice or become unfocused in scope of work</li> </ul>
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### Strengthen Patient Advocacy

Recommendation	Rationale
Explore opportunities for improvements in the recruitment and support of patient representatives	<ul style="list-style-type: none"> <li>• Patient representatives were recognised as an important presence in decision making processes.</li> <li>• There have been acknowledged difficulties in the recruitment of patient representatives.</li> <li>• Barriers to such work included its time-consuming and voluntary nature, including a lack of financial reimbursement which negatively impacted individuals with financial and childcare responsibilities.</li> </ul>

	<ul style="list-style-type: none"> <li>• 221+ could explore an advocacy function to include greater acknowledgement for patient representatives for their crucial role and ‘voice’ in healthcare provision and seek relevant supports to be made available to ensure that patient representatives do not become overburdened with expectations and time commitments</li> </ul>
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### Promotion of Cervical Screening and Vaccination uptake

Recommendation	Rationale
<p>Development of an awareness campaign about the importance of both cervical screening and vaccinations</p>	<ul style="list-style-type: none"> <li>• Some negative perceptions about 221+ exist. Specifically, that 221+ actions were responsible for a loss of trust in the Irish Cervical Screening Programme.</li> <li>• To counter such narratives, 221+ might consider applying a greater public voice to its endorsement of cervical screening and uptake of HPV vaccinations.</li> <li>• An awareness campaign about cervical cancer screening and the importance of vaccinations could dispel perceived stigma associated with cervical cancer</li> </ul>

## Education and Training

Recommendation	Rationale
<p>Explore scope for participation in aspects of education/training and development programmes for medical and health professionals, specifically to highlight the importance of the 'patient voice' in healthcare service delivery</p>	<ul style="list-style-type: none"> <li>• 221+ was well-placed to highlight the importance of the 'patient voice' in healthcare provision</li> <li>• 221+ and its members might engage as, for example, guest speakers, as part of professional training programmes for medical and health professionals to advocate the importance of the patient perspective in service delivery through the use of story narratives about their lived experiences</li> <li>• While 221+ can play a role in training and development, it is important that the scope of input aligns with expertise and qualifications, and that 221+ input complements existing professional medical/health training and development</li> </ul>

## Embed sustainability of 221+ to develop a robust Restoration of Trust

Recommendation	Rationale
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<p>Explore ways to both maintain and sustain organisational priorities while also expanding services and contributing to a durable restoration of trust with and between key stakeholders</p>	<ul style="list-style-type: none"> <li>• The importance of 221+ in Restoration of Trust processes was acknowledged through engagement with stakeholders including HSE, NSS (National Screening Service) and the Department of Health as a means to build trust and more collaborative networks with key stakeholders</li> <li>• The path toward a durable trust with and between all stakeholders was identified as potentially challenging, but crucial to restore a lasting trust in cervical screening services</li> <li>• In order to sustain 221+ through these processes, there could be the development of a strategic plan that ensures the growth of 221+ in a way that adheres to their core values of support and advocacy to members while building a structure that is future-focused (for example, expansion to all those impacted by cervical cancer and advocating for recruitment of patient representatives)</li> </ul>
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## 221+ Identity

Recommendation	Rationale
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<p>Development of greater name recognition and branding</p>	<ul style="list-style-type: none"> <li>• The 221+ patient representative group might not be well-known outside of the cervical cancer domains</li> <li>• Exploration of strategies to generate greater brand recognition, which in tandem with awareness campaigns could serve to develop greater awareness about both cervical cancer and the 221+ identity; but first, the future scope of work and available funding must be clarified</li> </ul>
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## Conclusion

The overall aims of this research were to assess the work and impact of the 221+ patient representative group (referred to as 221+) and patient representatives since 2018, and to explore how 221+ might further develop its operations into the future, including how the organisation and associated patient representatives may influence progressive change in the provision of healthcare for women in Ireland in the future. The present work, through analysis of interview and survey data, has outlined several key areas where 221+ have made significant contributions, and areas where they have shown considerable strength and influence. In understanding feedback from stakeholders and patient-pathway professionals, there are some key areas which 221+ may wish to consider as they reflect on past work, and consider future needs and opportunities. To maximise the impact of this report, key research-informed recommendations are offered regarding how 221+, the organisation, and the 221+ patient representatives might operate sustainably and effectively



in the future with the overarching aim of positively impacting healthcare provision for women, in Ireland and beyond.

***Closing statement from An Roinn Sláinte / Department of Health,  
Government of Ireland***

The 221+ Patient Support Group was established in July 2018 to provide information, advice, and support to the women and families directly affected by events of 2018 in services provided by the CervicalCheck Screening Programme. While 221+ is completely independent of the Department of Health, we have worked together through challenging circumstances to develop a shared vision that allows a diverse range of stakeholders to come together with a shared goal of delivering the best Cervical Screening Programme for the Women of Ireland.

The current research report is insightful and a testament to the persistent efforts of the 221+ Patient Support and Advocacy Group. As a member-led organisation, hearing the voices of members was key in this research. Additionally, the experiences of other stakeholders, including healthcare professionals, politicians and communication experts was essential in gathering perspectives. This report, which employs participatory research and reflexive thematic analysis, stands as a testament to the power of patient voices in shaping our healthcare landscape.

By centering the experiences and insights of 221+ members, and other stakeholders, including healthcare professionals, this research not only highlights the unique challenges and needs of those affected but also contributes to a deeper understanding of how our healthcare systems can be more responsive and compassionate. It is a valuable addition to the rich tapestry of patient voice work currently taking place across Ireland, reinforcing our commitment to ensuring that every patient's voice is heard and respected.

I commend the 221+ Patient Support and Advocacy Group for their dedication and meticulous approach. This report is an important resource for policymakers, healthcare providers, and advocates alike, providing insights that will drive better health outcomes and support for all. Together, we can build a healthcare system that is truly reflective of and responsive to the needs of those it serves. This is reflected in our ongoing collaborations to deliver Ireland's ambition for Cervical Cancer Elimination by 2040. Through vaccination, screening and early treatment, future generations of Irish women will live in a world where Cervical Cancer is a rare condition.

**- Joanne Uí Chruailaich, 5<sup>th</sup> June 2024**

**Principal Officer, Population Health Screening and Cardiovascular Policy**

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## Appendix 1: Survey schedule

**The purpose of this short survey is to establish a range of views of the organisation of 221+ and patient representatives from the perspectives of medical and health professionals in Ireland.**

*The 221+ Patient Support Group was established in July 2018 to provide information, advice, and support to the women and families directly affected by failures in the CervicalCheck Screening Programme that came to light following Vicky Phelan's court case in April 2018. It is a completely independent organisation and is not operated by the HSE or Department of Health.*

1. What do you know about the work of 221+ Patient Support Group in Ireland?
2. In your view, what have been the key activities and/or contributions made by 221+ Patient Support Group?
3. What, in your view, have been the missed opportunities of 221+ Patient Support Group as an organisation?
4. How has the work of 221+ Patient Support Group impacted your work life and/or personal life?
5. In what ways do you think 221+ Patient Support Group could contribute to Irish society in the future?

**Before completing the survey, please answer the following demographic questions:**

**6. Please tick the box that best represents your age:**

- 18 – 30 years old
- 30 – 45 years old
- 45+
- Prefer not to answer

**7. Please tick the box that best represents your gender identity:**

- Woman
- Man
- Transgender
- Non-binary/non-conforming
- Prefer not to respond.

**8. Please tick the box that best represents your occupation:**

- Health professional
- Health associate professionals
- Personal care workers in health services
- Health management and support personnel
- Other health service providers

**9. State your occupation here (optional):**

## Appendix 2: Interview schedule

### **221+ Interview schedule**

The purpose of the interview is to establish the key activities and associated impact of the organisation of 221+ from the perspectives of different stakeholders.

1. What is your connection to the 221+ Patient Support Group?
2. How familiar are you with the work of 221+ Patient Support Group as an organisation?
3. What activities have 221+ facilitated or contributed to, in your view, that have been important?
4. How has 221+, as an organisation, impacted i) those with cervical cancer that was not identified through screening and their families, ii) the healthcare system in Ireland iii) Irish or international politics, and iv) and Irish society and culture [including financial/economic, institutional]? *Follow up:* What, in your view, have been the most significant contributions of 221+ as an organisation? Are there any other impacts that you haven't covered yet?
5. How can 221+ build on previous work to improve women's healthcare in Ireland?
6. What, in your view, have been the missed opportunities (if any) for 221+ as an organisation?
7. In what other ways can 221+ contribute to Irish society in the future, particularly in relation to women's healthcare and patient voice?
8. We are coming close to the end of the interview now. Is there anything else that you would like to add?

## Appendix 3: Links to Relevant Reports

### Scoping Inquiry Reports

#### **First reports in 2018:**

The first interim report published in June 2018 provided 4 recommendations. The report paved the way forward for further developments on recommendations: (<https://www.hse.ie/eng/services/news/media/scally-interim-report-implementation-plan/scally-interim-report-implementation-plan-04-july-2018.pdf>).

The first interim report was followed by a status update: (<https://www.hse.ie/eng/services/news/media/scally-interim-report-implementation-plan/scally-interim-report-implementation-plan-status-02-august-2018.pdf>).

An additional Progress Report published in June 2018 was released as a status update in October 2018: (<https://www.hse.ie/eng/services/news/media/scally-interim-report-implementation-plan/scally-interim-report-implementation-plan-status-update-15th-october-2018.pdf>).

#### **Second reports 2018:**

The second interim report was published in September 2018 as a final report and included information about outsourcing of screens to laboratories located outside of Ireland, as well as findings related to governance issues associated with CervicalCheck: (<https://www.gov.ie/pdf/?file=https://assets.gov.ie/9785/9134120f5b2c441c81eed06808351c7.pdf#page=null>).

#### **Supplementary Report 2019:**

The Scoping Inquiry into the CervicalCheck Screening Programme Supplementary Report June 2019. This supplementary report was requested by the Minister for Health and provided two further recommendations on issues relating to procurement and assurance processes: (<https://www.gov.ie/pdf/?file=https://assets.gov.ie/10738/ba4f9a6299bb4ab6aa8d239b951eb71a.pdf#page=null>).

#### **HSE Progress Report 2019:**

The HSE released a Progress Report in September 2019 on the Implementation of Recommendations with status updates: (<https://www.hse.ie/eng/services/news/media/scally-interim-report-implementation-plan/scoping-inquiry-into-the-cervicalcheck-screening-programme-progress-report-september-2019.pdf>).

#### **Review of the Implementation of Recommendations 2022:**

The final review report was published in November 2022 and outlines progress on the implementation of recommendations to the end of October 2022: ([\\*Review-of-the-Implementation-of-Recommendations-of-the-Scoping-Inquiry-into-the-CervicalCheck-Screening-Programme.pdf](https://www.scallereview.ie/Implementation-of-Recommendations-of-the-Scoping-Inquiry-into-the-CervicalCheck-Screening-Programme.pdf) (scallyreview.ie)).