Quality Matters
supporting improvement in social services

221+ CervicalCheck Patient Support Group

Consultation with 221+ Members

Research Report February 2022

Contents

1 Acknowledgements

This report has been researched and compiled by Quality Matters in close collaboration with the members of the Engagement Group (See appendix 8.1). We would like to thank all the women of 221+ for their time and for sharing so generously their experiences, opinions and thoughts about what changes are needed to improve future processes of cervical cancer audit and disclosure for women.

2 Executive Summary

2.1 Background

During July – December 2021, the National Screening Service (NSS) and the 221+ Patient Support Group have jointly developed a consultation to capture the views of 221+ members on the development of screening audit and disclosure processes for women diagnosed with cervical cancers. The intention is to understand and document the experiences of 221+ members and use these insights to improve future processes of audit and disclosure. An Engagement Group was established, consisting of members of 221+ and NSS representatives, and an external facilitator engaged to lead a number of meetings in which the affected women were given a space to discuss various personal topics related to their patient experiences. The purpose of these meetings was to give the women voice and to build trust and dialogue between the members of the group. NSS and 221+, appointed Quality Matters, an independent social research charity, to undertake the research element of the consultation process. The main goal of the research was to encapsulate the essence of the women's experience and translate these learnings into future recommendations in a way that can lead to meaningful change for all women affected by cervical cancer. The Engagement Group and Quality Matters worked together to design the research process, pilot and edit the questionnaire and make decisions about the scope of the research.

2.2 Aim and Objectives

The overall aim of the consultation is to improve the audit and disclosure processes for women diagnosed with cervical cancer.

The main objectives are:

- Capture and document the lived experience of members of 221+ who have been directly affected by the failures in the audit and disclosure processes, i.e. cases where the cytology review indicated discordance with a previous cervical screening test.
- Formulate patient-centred recommendations for the HSE that prioritise womens' wellbeing and aim to improve the future experience for women diagnosed with cervical cancer with a particular focus on auditing and review processes.
- Present the findings and suggestions for improvements to HSE in order to encourage the implementation of initiatives

2.3 Methodology and design

The research utilised a mixed-methods approach. This included qualitative in-depth interviews with 221+ members as well as an online questionnaire sent to all members of 221+. The recruitment posed some challenges, that were addressed through adaptation of the initial methodology. However, the process and difficulties of recruitment provided valuable knowledge in terms of the overall objectives of the consultation process as, according to those interviewed and the 221+ women in the Engagement Group, the reluctance of some 221+ members to participate might be linked to distrust in NSS and/or HSE. Data collected from the quantitative survey informs the main analysis while the qualitative interviews are used to elaborate on and validate the data.

Qualitative interviews

A total of five members of 221+ participated in an interview, including bereaved members. Of these, one was a double interview conducted online and three other were single interviews; two conducted online and one face-to-face. Apart from providing qualitative insights, the information from these interviews was also used as input for the quantitative questionnaire.

Quantitative survey

A quantitative survey was drafted and tested by the Engagement Group, revised and distributed to all members. The quantitative survey consisted of 20 questions of which seven were open-ended, hereby encouraging participants to write down narratives of their experiences within the healthcare system. The number of open-ended questions was upscaled in order to get as much in-depth information as possible.

Analysis of data

Data gathered from the qualitative interviews and online survey was analysed thematically and the overall process was mapped as a patient journey. While the objectives of the research were focusing on audit and disclosure it turned out to be relevant to broaden the focus to also include the processes of screening and post-disclosure as these are strongly linked to the participants' experience of audit and disclosure. Thus, the patient journey was broken down into the following four steps:

1. Screening
2. Audit
3. Disclosure
4. Post-disclosure

Each step was analysed through an identification of patterns and shared experiences related to the past as well as to participants' wishes for an improvement of future processes. The findings were then synthesised and divided into distinct themes identified in the overall patient journey experience and specific recommendations and rationale for these were formulated.

2.4 Main Findings

Despite of the fact that every history is unique, there are clear similarities in how participants experienced their overall patient journey. Apart from a few exceptions, such as a 'kind nurse', or a 'supportive liaison officer', the dominant experience among participants describes a flawed and unempathetic healthcare system that has let down its patients during a very vulnerable time. Overall, those involved identified a clear and urgent need for future improvement in every step of the patient journey. The most dominant perceptions of the patient experiences are:

The overall process:

- Confusing, unclear, disorganised, seemed random, dishonest
- Lengthy, emotionally draining
- Traumatising, stomach-punching, shocking, insensitive
- Prioritising orders and law over human needs and wellbeing

Communication:

- Lacking, unclear, incoherent
- Clinical/difficult to understand
-

Healthcare professionals

- Lacking empathy, unapologetic, impersonal, indifferent, unsupportive
- Not treating patients as individuals, not listening, not encouraging patients to ask questions

Emotional impact on participants

- Causing painful suffering, anxiety, anger, frustration,
- Leaving people feeling loneliness, isolation, feeling abandoned, let down, frightened
- Belittling, betrayed, being lied to, denied access to information about own body/health

2.5 Main conclusion and recommendations

The research documents an immense need for changes within processes of audit and disclosure for women in Ireland diagnosed with cervical cancer. In a broad perspective, the following principles were identified as core to the patient experience, hence it is recommended to make their associated values play an essential part of future initiatives for improvement of the patient journey:

Empowerment and respect through transparency and choice

- The system needs to be transparent. The culture needs to change so that it encourages staff to share information. Failure to do so 'belittles' women and creates an unequal distribution of power which is painful for the patient and detrimental for building trust and confidence in treatment and system.
- The system to provide thorough information on audit and patient requested-review upon diagnosis, and provide a variety of choices in terms of context/setting for disclosure of results.

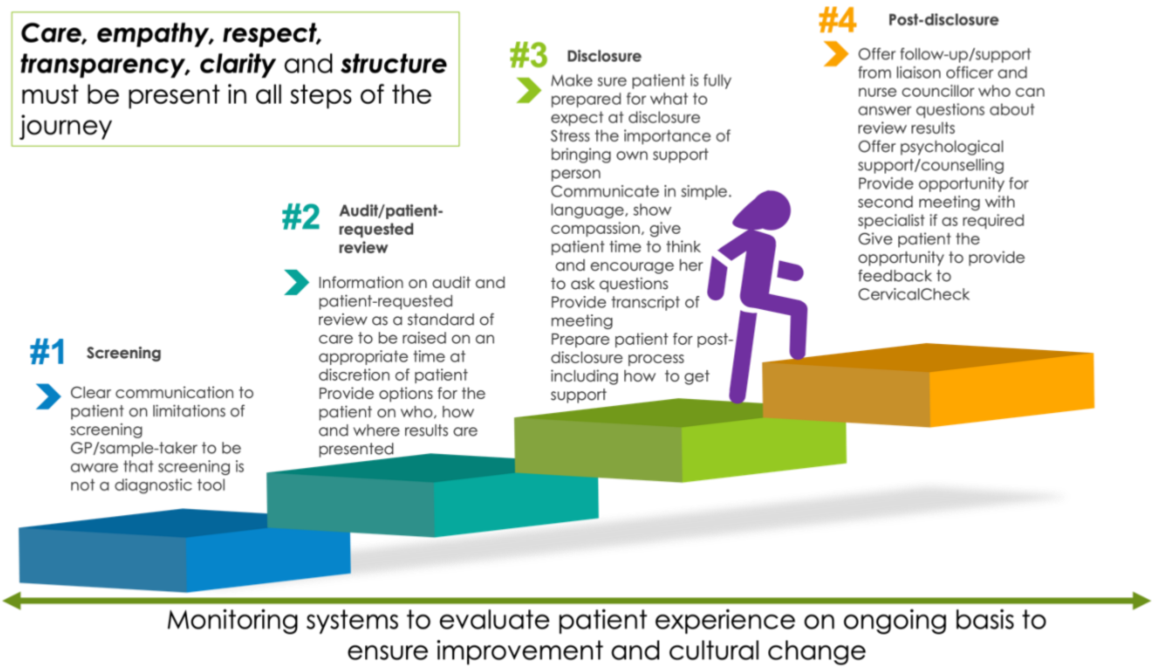
Empathy, personal contact and care

- There is an acknowledgment that the level of empathy, personal contact and care directly impacts patient wellbeing, stamina and resilience during the patient journey. It is crucial that the process is centred around people and not rules and regulations. Everything that is being said and communicated in the process must, per default, be considered as having intrinsic impact on the patient's life.

Structure, organisation and clarity

- All the steps are aligned across the involved professionals so that patients feel confident that they are in 'good hands'.
- All information and communication must be clear, concise and in a language that is easy to understand and serves to include the patient.
- There should be genuine opportunities for patients to ask questions. This means professionals should focus on establishing a calm space where there is enough time for the patient to think, reflect and get clarifications though questions.

Each step of the journey has been discussed and analysed in order to understand the unique characteristics and gain input for recommendations for improving the future processes as shown in the following illustration:



Care, empathy, respect, transparency, clarity and ***structure*** must be present in all steps of the journey

#1 Screening

Clear communication to patient on limitations of screening
GP/sample-taker to be aware that screening is not a diagnostic tool

#2 Audit/patient-requested review

Information on audit and patient-requested review as a standard of care to be raised on an appropriate time at discretion of patient
Provide options for the patient on who, how and where results are presented

#3 Disclosure

Make sure patient is fully prepared for what to expect at disclosure
Stress the importance of bringing own support person
Communicate in simple. language, show compassion, give patient time to think and encourage her to ask questions
Provide transcript of meeting
Prepare patient for post-disclosure process including how to get support

#4 Post-disclosure

Offer follow-up/support from liaison officer and nurse councillor who can answer questions about review results
Offer psychological support/counselling
Provide opportunity for second meeting with specialist if as required
Give patient the opportunity to provide feedback to CervicalCheck

Monitoring systems to evaluate patient experience on ongoing basis to ensure improvement and cultural change

3 Introduction

3.1 Background

CervicalCheck, The National Cervical Screening Programme, was established in Ireland in 2008. Between 2008 and 2018, more than 3 million cytology tests were carried out across 1.2 million women aged 25–60 years.

In Ireland, an audit of cytology in all women known to be diagnosed with invasive cervical cancers in the first 8 years of the CervicalCheck programme was undertaken. In total, 1,482 cases were reviewed, of which 1,296 had participated in CervicalCheck. In 221 cases (15%), the cytology review indicated discordance with a previous cervical screening test. In 2018, publicity surrounding this audit resulted in the Minister for Health commissioning a Scoping Inquiry into the CervicalCheck Screening Programme, which was conducted by Dr Gabriel Scally and published in September 2018. The recommendations of Dr Scally's report are now being implemented[1].

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[2]. National Screening Service and 221+ have jointly developed an outline consultation process to capture the views of 221+ members. An Engagement Group consisting of two NSS representatives, four members of 221+, one 221+ coordinator and an independent facilitator to support the process was established in order to build a dialogue between the involved parts and hopefully rebuild trust on the side of the 221+ members. The group worked together to co-design a meaningful and appropriate consultation with 221+ members in order to obtain as much information as possible to feed into the improvements that were going to be made. The Engagement Group decided to recruit QM as an independent research company to assist with the research element of the consultation in order to ensure integrity and independence in the analysis and recommendations. All members of 221+ have been invited to participate in the research by engaging in a 1-1 interview or in an online survey. The research has been a way to engage members of 221+ and translate their experiences into meaningful recommendations that can hopefully be used to improve future processes within CervicalCheck/NSS in a way that benefits all women.

3.2 Aims and Objectives

The aim is to ensure that the views of 221+ members can be incorporated and inform the development of the cervical interval cancer audit programme and disclosure process in a way that leads to meaningful change for other women. The main objectives are:

- Capture and document the lived experience of women who have been directly affected by the failures in the audit and disclosure processes in Ireland.
- Formulate patient-centred recommendations for HSE that prioritises womens' wellbeing and aims to improve the future experience for women diagnosed with cervical with a particular focus on auditing and review processes.

---

[1] HSE, 2020

[2] 221+, n.d.

3.3 Process

The process has been highly iterative and characterised by a close collaboration between the Engagement Group and QM in the sense that the methodological set-up as well as the final report and recommendations have been discussed at several meetings and agreed upon in a co-creative process/consultation where all voices and opinions have been taken into account.

- Engagement group (EG) established. The group worked together to co-design a meaningful consultation with 221+ members
- QM entered the process. QM and EG discussed and agreed on methodological set-up
- QM conducted qualitative interviews
- Questionnaire for survey formulated by QM. evaluated by EG, adjustments made by QM. 2nd round of revision by EG. Questionnaire finalised and distributed
- Initial Analysis of data and recommendations by QM, presented to EG .QM and EG to discuss findings and agree on recommendations to bring forward
- Draft report by QM circulated to EG, feedback provided and QM to adapt report
- Final report sent to NSS

4 Research methodology and design

This research was used a mixed-methods approach, combining interviews and survey. This consisted of:

- Qualitative interviews with five 221+ members including bereaved members
    - 1 duo-interview conducted online
    - 3 individual interviews. 2 conducted online, 1 face-to-face
    - Duration of each interviews approximately 1 hour

- Quantitative survey distributed to all members of 221+
    - 20 questions, of which 7 are were open-ended
    - 24 completed questionnaires returned to QM

A semi-structured interview method was used in interviews to determine patients' personal experiences and views of future solutions. The process aimed to ensure women's personal experiences and personal stories were shared in a space of empathy and trust. Given the sensitive character of the research topic it was anticipated, however, that some women would prefer to participate without a face-to-face interview, and indeed there was a greater interest in participating though the online survey than the qualitative interviews.

There was, however, resistance among some 221+ members to participate in the project which was explained by the fact that it was associated with NSS and HSE. Though emails and internal 221+ conversations, a couple of 221+ members explained that their resistance was related to distrust towards these institutions and fears that the research would be tokenistic and ineffective, undertaken primarily to 'tick a box'. The reluctance to participate and prevalent scepticism about the purpose of the initiative was also mentioned by 221+ members of the Engagement Group during planning meetings and by those who participated in a qualitative interview who had discussed the issue with other 221+ members at a recent meeting. This perception was, above all, due to members personal history but the relatively low uptake for the interviews could also relate to the fact that many of the members are currently involved in litigation with HSE, which was pointed out by a couple of the interviewees. To address this challenge members were actively encouraged to engage with in the research. The survey included seven open-ended questions that aimed to give those who preferred *writing* about their experiences an opportunity to participate in the research.

It should be noted that efforts to engage people in the survey were successful and this report is considered an acceptable representation of the thoughts and experience of members which has been confirmed by the 221+ representatives in the Engagement Group who have confirmed that the findings closely mirror their own personal experiences as patients.

4.1 Recruitment and ethics

The recruitment for the interviews and the online survey was done through emails sent to 221+ members as well as advertising via social media and a video made by QM. All participants were guaranteed full anonymity and that names or any information that might render them identifiable, would not be included in any publication. Prior to the interviews the participants were, in a caring way, advised by the interviewer to not feel obliged to provide any information/answer any question if they felt uncomfortable doing so. In the survey, participants were encouraged to skip any question that they were not comfortable answering. All documents were kept in encrypted, password protected files and will be deleted after completion of the research.

4.2 Analysis of data

The analysis of data focused on participant interactions with the healthcare system in order to understand the impact of their experience and how processes can be improved. Data was analysed combining a thematic analysis with a mapping of the patient journey. This approach was chosen to secure that the patient perspective was fully included in any suggestions for changes and improvement. The benefit of using the patient journey as an analytical framework is that it provides a holistic approach to care and a systemic understanding of the patient experience which proved to be a valuable way to approach the overall aim and objectives of the research. Thus, the patient is the only person who experiences the path as a whole process by connecting each step of the journey[3]. In this context, the patient's narrative can be used to help understand the deeper layers of a healthcare system's approach to treatment through identification of patterns and common denominators present in the whole patient pathway[4].

The patient journey is divided into stages. As the different steps are intertwined, it was occasionally challenging to keep a separation in analysis, especially in relation to auditing and disclosure. In these cases, connections and overlapping themes have been identified and outlined in the report.

In the analysis of quantitative data, the following coding system has been applied:

1) Almost all (75% or more)

---

[3] Gualandi et. al, 2019

[4] Ben-Tovim et. al, 2008

2) The Majority 50 – 75%,

3) Significant portion 25% - 50%,

4) Some (5 – 25%)

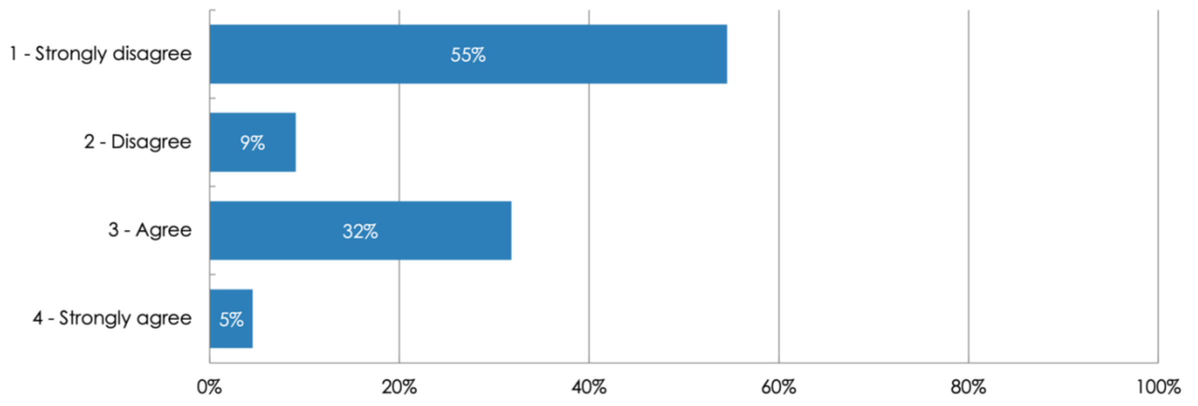
The screening for cervical cancer forms the starting point of the patient journey as almost all participants saw this as their first important interaction with the system related to cervical cancers. The patient journey does not have a defined endpoint as many women still require continued medical assistance and support related to their treatment and recovery.

5 Findings: The Patient Journey

5.1 Patient journey Step#1: Screening

The starting point of the patient journey was considered to be the introduction of screening tests, usually performed by a GP or a nurse. Participants discussed interactions/ communications surrounding the introduction of test results as playing an important role in later stages of the process. Almost all participants experienced their GP ascribing importance to screening results, and therefore waiting for further cancer screening, while exploring other medical explanations for symptoms. This dynamic was viewed as delaying the time of diagnosis. Among these participants, it was a shared perception that GPs to a large extent, counted on the validity of screening and used it as a diagnostic tool, over and above what test results should be used for, when people present with symptoms which could be associated with cervical cancer. Before the cancer diagnosis, it was a common understanding among participants as well that a 'clear' screening result meant no risk of cancer.

FIGURE 1: "When participating in CervicalCheck screening, the limitations of screening were explained to you".



The following quotes highlight the challenges in relation to patients and some GPs' understanding screening results in the light of future symptoms and dialogue:

'I was told that if there was anything there, it would show'

'I never understood that the screening wasn´t a diagnostic test'

'The screening process, including limitations, were never mentioned at any time when engaging with the process'

> *‘I was given to believe that screening was definitive and always accurate’*

> *´When I had symptoms of cervical cancer consultants would not see me any quicker or thoroughly as my smears were "negative". This led to over an extra year of cancer growing inside of me(...) .if they were fully aware of the "limitations" then maybe I would have been diagnosed earlier and would not have to live with the devastating aftermath of treatment´*

Despite the fact that around two-thirds of the participants recalled that the limitations of screening were not explained to them (or given this in written information), some mention that they were expected to have this ‘common sense’ knowledge later in the patient journey, as described in the following quote:

> *‘No, I was not made aware of its limitations and I understand now that it forms part of the screening consent process(…). When you become one of those who has been affected by these limitations it’s almost like it’s “oh yeah sorry that happened to you but that is just part of the limitations of cervical screening!”’*

The lack of knowledge of the limitations of screening had a knock-on effect on the shock that unfolded later in the patient journey in the case that abnormalities were found during the audit. As one woman explained the trust in screening prevented her from being prepared for changes:

> *‘A nurse called me to tell some abnormalities had been picked up and was told I needed a repeat smear. I was told there was absolutely nothing to worry about and it was perfectly normal for this to happen. I trusted in this. If I had known the limitations I would have been concerned and followed up with a call to my GP.’*

Whether due to a slowness in testing from the GP, or because the women waited to consult their GP with symptoms, all participants felt they were delayed in their treatment for cervical cancer due to a falsely ‘clear’ screening test. This caused continuous regret and frustration as an earlier diagnosis could have reduced some of the painful treatment and side effects that the women had to deal with.

5.2 Patient journey Step # 2: Auditing

Overall the process of auditing appeared unclear, confusing, non-coherent and was communicated in a way that the participants experienced as cold, impersonal, indifferent and severely lacking empathy. Almost all participants describe how they received a phone call or a letter ‘out of the blue’ asking them how they wanted to receive their results. Some of those were following the news and suspected it was related to the public cases while others were completely unaware of the purpose and content of the letter or phone call. Nonetheless, no one was prepared for the implications of the auditing and, retrospectively, did not feel they were able to make a well informed choice about how they wanted their results disclosed. This resulted for some in a random decision-making process, followed by a very traumatic experience in the later steps of the journey as the following quotes describes:

> *‘A letter came asking me how I wanted to receive my results. What results?! I had no idea what it was about. A month later arrived envelope number two, with a ton of papers. One of the last pages was about my smear tests with the HSE basically saying that it was not their fault. It was worse than the cancer. I felt like a soldier that had been to war and done a great job but hearing this hit me like a tidal wave.’*

Overall there were common themes that information was not clearly explained and was not introduced in a way that made it clear, understandable or offered appropriate support. This is explained in the following quotes:

'Did I want a SAGE rep? I had no idea what that was'

'The persons who rang me were always in a hurry, did not display empathy, did not clarify or answer my queries'

'This should not have been dropped on me without any warning or even knowledge that an audit takes place when there is a cancer diagnosis'

'While at work I got a phone call from the consultant. The consultant said something about an audit and something about the behaviour of the cancer cells of my particular cancer (nobody had ever discussed such with me in any detail before though I had asked) and I was in shock. I was not really sure how I was involved'

5.3 Patient journey Step#3: Disclosure

'The disclosure, on every level, was thoughtless and cruel'

Following the lack of clarity related to the audit, the experience of disclosure was viewed as a traumatic experience that, in and of itself, has led to anxiety, anger, regret and disbelief among participants. All participants shared the common experience of shock and unpreparedness for what was being presented to them at the disclosure meeting. This frequently resulted in a feeling of powerlessness and/or them feeling de-humanised. A repeated reason for this was that it felt that patients' needs were deprioritised as the system responded to the need to inform patients prompted by the court case of Vicky Phelan. Almost all participants found that the healthcare professionals involved did not show sufficient empathy and were frequently communicating in a complex, clinical language that was difficult to comprehend. The process of disclosure was not perceived as grounded in any consideration or understanding of patients' potential reactions and emotions, which impacted on the healthcare professionals' communication and wording. Overall, the dominant impression among participants was that the right effort was not made to mitigate harm.

For participants, a crucial issue is that is important to have a support person at the meeting and many did not have one as they were not advised to bring someone. The feeling of confusion and not being prepared for the meeting was exacerbated by the fact that participants were also not provided with a satisfactory summary of the meeting although they were promised they would receive a detailed transcript afterwards and therefore did not need to take notes themselves.

'I was asked to attend a meeting in a Hotel. I didn't really know what I was going for other than that they were going to explain my result of the RCOG Report and I wasn't told that I should bring someone with me. The meeting took over an hour. I was quiet distraught as I didn't realise what they were about to tell me. Luckily I had brought my sister with me (…) I was told that there were four misread smears over three years that, if read correctly, could have changed the outcome of my case which ended in me having a radical hysterectomy'

'I was phoned to go into a consultant, but was not told why. I was not told to bring anyone with me. The consultant and nurse met me in the rooms and briefly explained audit and that results of one of my

> *smears had been revised. I was not given any advice or comfort from consultant. (…) I left the hospital in shock, by myself knowing that my cancer could have been prevented. I have never felt so alone. I subsequently discovered that two of my smears had been misread, not just one'*

> *'To my mind the consultant was more interested in making sure I understood that it was difficult to see cancer cells down a microscope etc. no acknowledgement of me being upset. (…) Humanity and respect and dignity is so easily stripped away. Not until my last meeting when I met a new consultant was I acknowledged as being a young woman going through this life-altering experience'*

> *'Both my sister and I left total distraught and puzzled by the whole experience and what they were telling me I should do. When I was given back the minutes of the meeting very little of what was actually said was written down'*

> *'The transcript they sent me afterwards appeared very lacking. It quoted me saying that I was happy to be alive but it did not include all the things I said about being let down by the system'*

Almost all participants described how it had become clear to them afterwards through discussions with other 221+ members that there was no uniformity in the process of disclosure for patients. This made the process appear random and based on coincidences rather than well-considered policies focusing on the wellbeing of the patients.

5.3.1 Timing of disclosure

In most cases disclosure took place a number of years after diagnosis and treatment which had the effect of retraumatising people as the majority describe that they were finally on a slow path to emotional recovery. The process of disclosure abrupted the journey of recovery by bringing up painful memories of diagnosis and treatment while also resulting in new feelings of shock, disbelief, anger and sadness.

> *'I had heard that there was an issue brought to light, but had decided not to call to find out, as I did not cope well with my hysterectomy, and my life had been destroyed (lost job, lost partner) so I did not believe I would cope with more on top. However, I received an insane amount of missed calls and eventually I answered one, and was met with a review of my case file, being reminded about things I had wiped from my mind, and being forced to relive a horrendous experience, and then to be told of the error(...). It was too much to take. It was devastating and should not have been told to me by phone, when there was no one there to help me understand what I had just been told, and even remember'*

As the above quote describes, the timing of disclosure is an important issue, which can have significant consequences for people. Disclosure needs to be voluntary and considered.

5.4 Patient journey Step#4: Post-disclosure

All participants described having had major side effects after treatment. Almost all also experienced being left adrift with little follow-up support offered to them. Consequently they had to seek help themselves which could be difficult and unmanageable due to a lack of energy and/or finances. There is a future need for women in this situation to have access to medical as well as emotional support, ranging from how to manage side effects to how to deal with issues such as anxiety and survivors guilt.

'I was told that I had to manage my symptoms. No help. No advice. Just manage. Manage incontinence. Manage poor sleep. Manage brain fog. Manage poor libido. Manage returning to work'

'They literally kicked me out. No support, no follow up. I paid for psychological counselling afterwards, where I was diagnosed with PTSD'

'I lost confidence in myself. I turned the anger inwards and blamed myself for the cancer (...). I thought it was my fault. I also have survival guilt. Why did I make it when so many of the younger women with small children did not?'

'I felt like the soldier that had survived the blast that all my comrades were killed in or seriously hurt in. Survivor guilt is horrible and should be included in follow-up'

Apart from physical pain and suffering, the side effects of treatment also made it hard for the women to heal emotionally as there were constant reminders of 'system failures' and that the leaders within this same system were continuously refusing to take responsibility for these failures. The experience resulted in a significant level of scepticism and a lack of trust in healthcare professionals which affected women's ability to engage with health systems in the future.

'I just feel betrayal and to a certain point paranoid with present and future medical situations(…) who can I trust when the people I trusted with my life let me down?'

'I feel a great degree of concern and disbelief with how the HSE were so disorganised in collating the slides and patient information for review'

6 Findings: Improving the patient journey

6.1 Overview

In order to improve future processes and experiences within the patient journey, participants agreed that it is crucial to feel 'in good hands', i.e. secure, listened to, supported, prepared for each step of the process and confident of where to seek support. Participants stated it is important to have access to the right professionals throughout each step of the journey to ask the questions that will inevitably come up. In the words of participants, the ideal process should be characterised by: Reliability, accountability, responsibility, structure/ organisation, professionalism, transparency, inclusion, human contact and coherence so that nothing seems random or coincidental but thought through and planned in a way that prioritises the wellbeing of the patient.

> *'It would be comforting to feel like there was a professional organisation with their house in order handling and overseeing such sensitive and important services'*

6.2 Screening

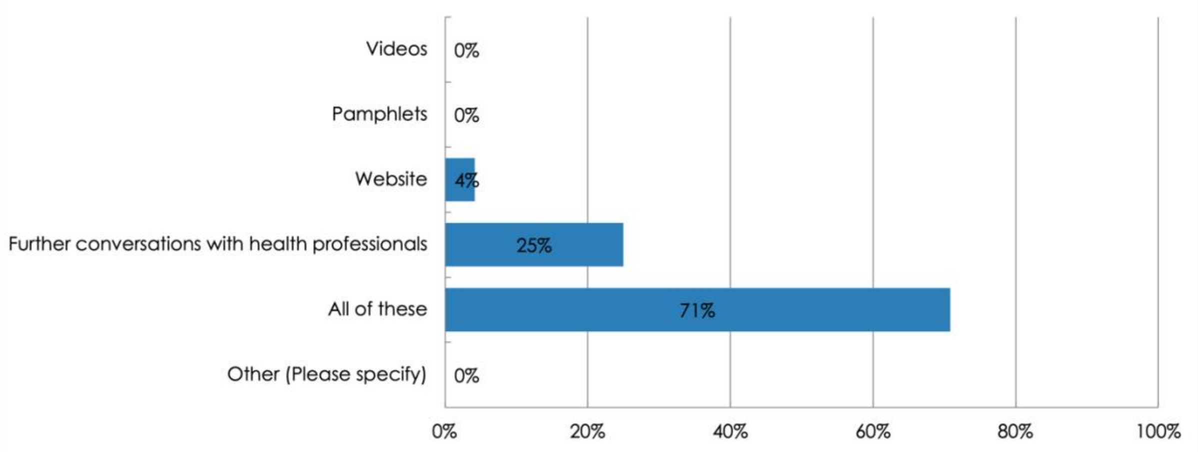
Almost all participants requested that all women who attend screening are made aware that screening is not a diagnostic tool. It should be highlighted that women who have regular screenings can still develop cervical cancer even if the tests have not detected abnormal cells/changes. This information should be provided when the screening test is conducted in a language that is easy to comprehend. Furthermore, participants stressed the importance of making women, and GPs, aware that they should act promptly on symptoms, independent of the result of their last screening.

6.3 Audit

Following a diagnosis of cervical cancer, the participants wish to have as much information as possible, and through various channels, about the process of audit. The audit needs to be properly explained in a simple, understandable way, i.e. that at some point the slides will be reviewed for educational purposes and quality control, as well as what happens with discrepancies.

> *'The more information about the auditing made available to patients, the better understanding they will have of the process'*

FIGURE 2: "How would you prefer information about the review/audit processes to be given (in addition to professionals explaining the process)? (select one option from list below")



6.4 Patient-requested reviews

All participants stated it was important women were informed that they can request a review of their screening tests. As shown in figure 3, the majority of participants prefer to get this information at a face-to-face consultation with the treating doctor, which as highlighted in the qualitative interviews and discussions with the Engagement Group also gives them the opportunity to have any questions clarified. All participants found it important to have choices throughout the patient-requested review process (figure 4) and in this context to be able to decide which medical professionals disclosed the results, what types of issues they would be informed of, how to receive the results and to be able to choose not to be informed with the possibility to find out later, on request (figure 5). As indicated in figure 6 there was a strong wish to have access to a key contact person to seek information from while waiting for the results of the review. Overall, the data documents a wish for future processes to include an option for personal contact with healthcare professionals and to have as many choices as possible throughout the process.

FIGURE 3: "How would you like to receive the information on the patient-requested reviews? (select one option from list below)"

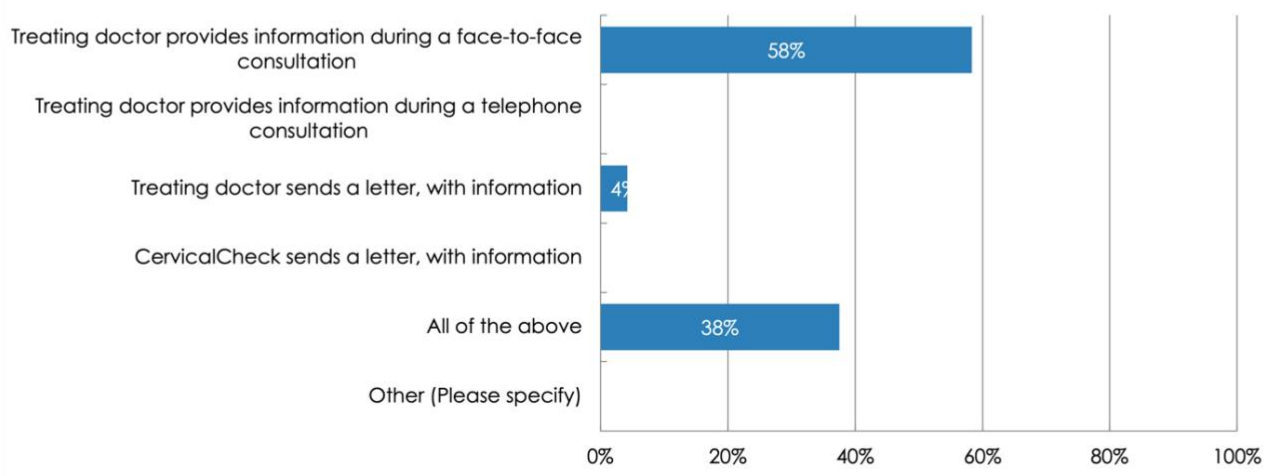


FIGURE 4:"How important is it for you to have choices throughout the patient-requested review process?"

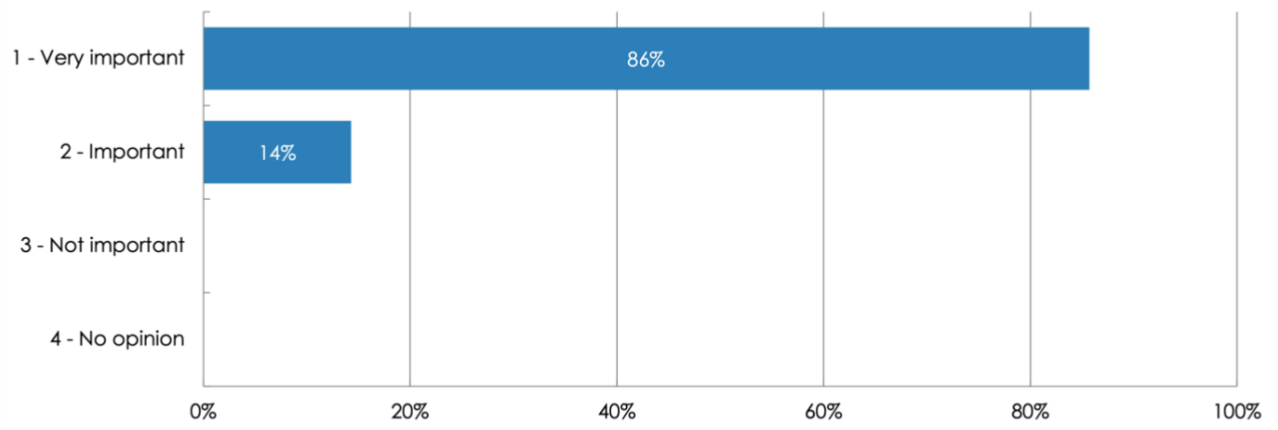


FIGURE 5: “If you choose to request a review, how important is it for you to be able to decide”

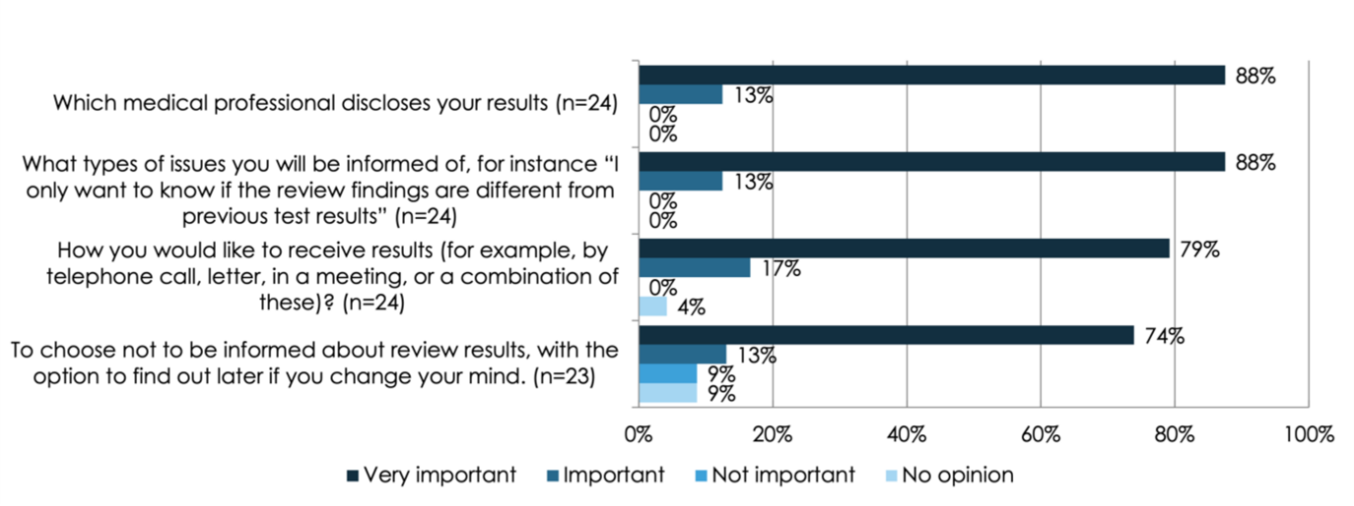
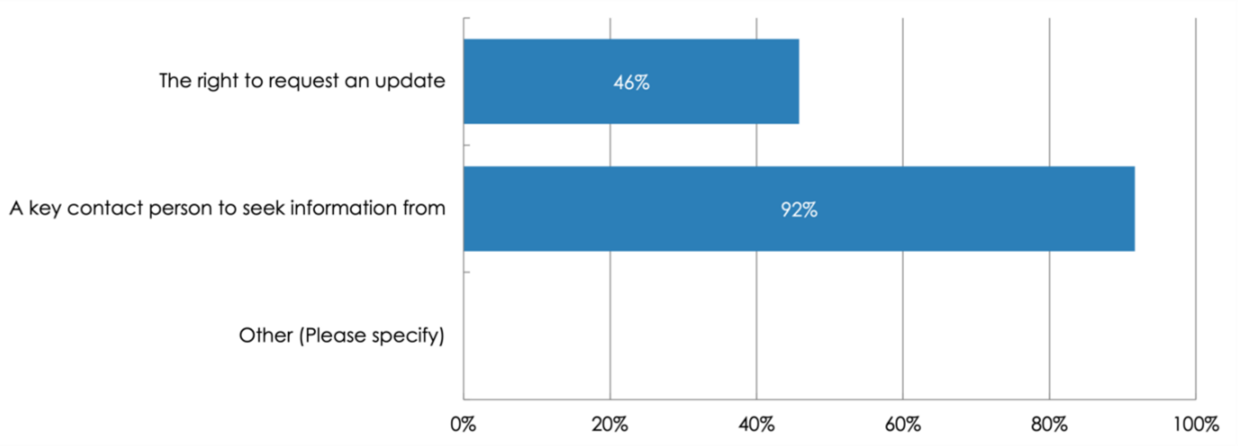


FIGURE 6: “What options would you like to be available whilst you are waiting for review results?”



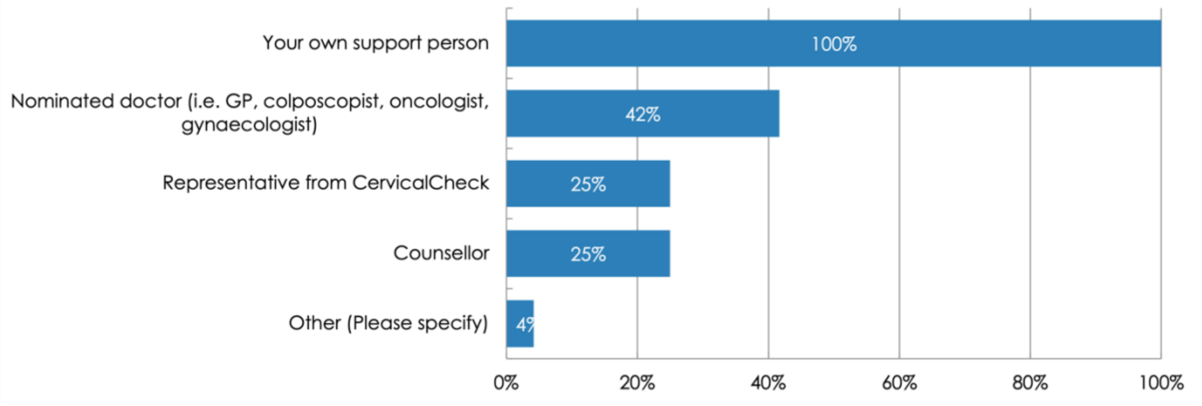
6.5 Disclosure

6.5.1 Preparation and attendees

As all participants associated the process of disclosure with shock and disbelief, it was considered crucial to prioritise preparing patients for this experience. According to participants it is particularly important to encourage the patient to bring a support person and to clarify with them what will happen and what will be discussed at the meeting. As shown in figure 7, and as expressed through the qualitative feedback as well, patients wish to be able to bring their own support person when having their results disclosed. A support person is not only important in the role of providing care and compassion during the disclosure meeting, but also in the period afterwards where the patient needs extra support and care.

> *´You should be informed in advance that you should have someone with you, have someone talk to you after to help deal with the consequences'*

FIGURE 7: "Who should be able to attend the meeting relating to your review results? Select all that apply"



Participants requested having clear information about the purpose of the meeting before the actual disclosure takes place, as the general experience is that it is difficult to comprehend new information given the sensitive topic. Furthermore it is advised that a part of the disclosure meeting is dedicated to preparing the patient for the time ahead as a lot of emotional challenges and issues tend to arise in this period. Thus, it is important that patients are made aware that emotional reactions are likely to occur, and that they have sufficient information about *where* and *how* they can get support, help and advice in this period.

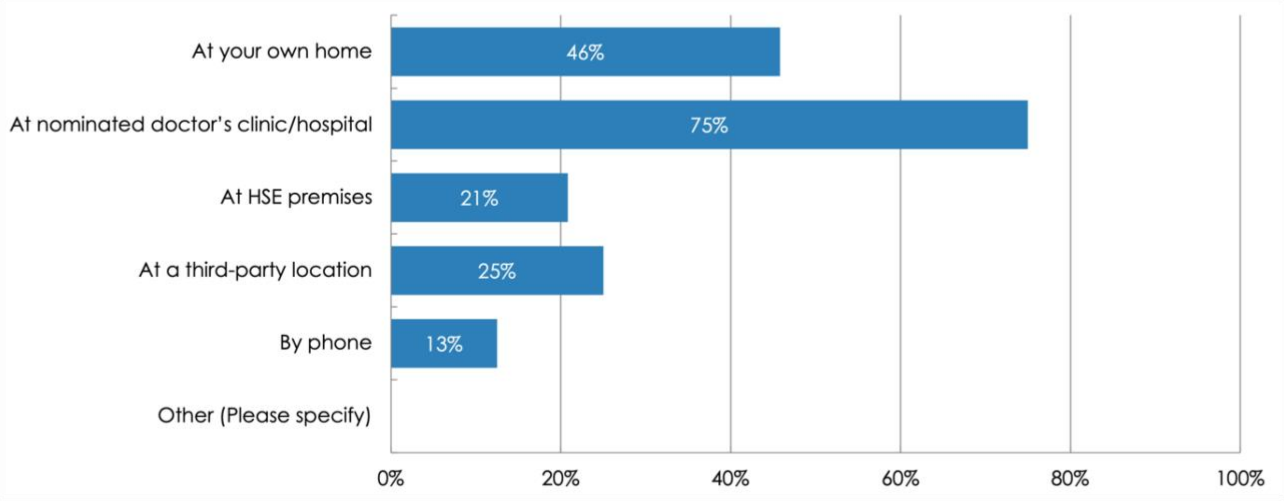
> *'I would have liked to have been given a chance to be better prepared and not just landed with a lot of information that clearly I was too distraught to take in. And to have been given a better report to take away, read and take in. I should have been told to bring someone with me to prepare me for what they had to say´.*

> *'The patient should be provided with all the information and be provided with a contact if they wish to discuss it further, once the shock has sunk in'*

6.5.2 Location and healthcare professionals

All participants requested that more consideration is given to *where* and *how* disclosure results are presented to the patient. As shown in figure 8, there is agreement that the results should be given face-to-face and not via phone while almost half of participants think that it should be possible to choose to receive the results in own home.

FIGURE 8: "What options should be available in terms of where you would like to get the results of your patient-requested review? Select all that apply"



Participants recommended a strengthened sensitivity to the contextual setting of the disclosure so that the meeting is not held in a busy outpatient department of the hospital but in a more tranquil setting. It is also very important that there is sufficient time set aside for the meeting so that the patient is given enough time to think, reflect and ask questions.

'There should be specific time set aside for it. Results maybe should be given in an area of the hospital that is quieter and not in a busy OPD clinic'

The approach, attitude and behaviour of healthcare professionals present during the disclosure meeting have a strong impact on patients' experience of the meeting. Participants wish that the staff present are respectful, caring, empathetic, understanding, considerate, involved, knowledgeable, and patient. Within these descriptions lies a deep wish that among patients to be given a personal treatment in a safe space where they feel confident to ask questions that can help clarifying doubts and make the situation less confusing and frightening.

'If they could explain exactly everything through the process, let the woman ask as many questions as she likes and be more compassionate'

'Communication is not one way. Listening takes time. Reviews and audits are very important. Disclosure is about being present and willing to listen. Not just ticking a box. We are not just parts. We are a collection of stories and experiences that can affect how we deal with diagnosis etc. Disclosure should not be seen as just a once of engagement but a process'.

'More empathy. And a little bit of kindness.'

'Listening. Ability to adapt to the needs of women. Don't dismiss their concerns. Don't treat us like we are invisible'

6.5.3 Communication/language

Following the evaluation of the participants' disclosure experience, one focus area in the improvement process should be the use of a clear language. Using technical/clinical words has an excluding effect and hinders a smooth dialogue in which the patient feels confident. Language should be kept simple, informative, 'for everyone', and should be thorough and honest. It is important to aim for an equal distribution of power between patient and healthcare professionals, especially in terms of knowledge;

the patient has to feel confident that nothing is kept secret and that she has access to exactly the same information as the doctor.

Tell the truth instead of using slippery words to help them wriggle out of their responsibility to us, patients. For example, they should say 'your smear has been misread' instead of 'discordance in your smears'

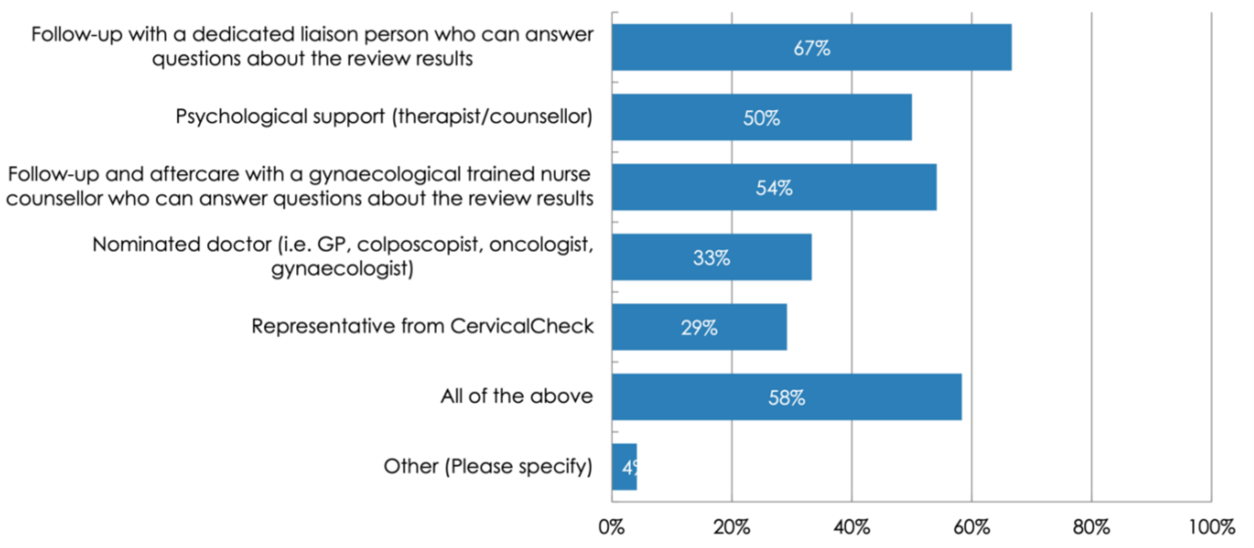
'If a doctor knows something about YOUR body that you don't then you need to be told(...) they shouldn't be playing God!'

'It has to be thoroughly explained in simple English, no big words used'

6.6 Post-disclosure – support and feedback

All participants expressed a need for support following the disclosure of results as this was considered a particularly difficult time where a lot of questions arise as well as challenging psychological experiences for women. As shown in figure 9 more than half of the participants agreed that a full range of supports should be available. The data shows that professionals with specific knowledge about the review results as well as professionals who offer psychological support are found particularly relevant to include in support offers.

FIGURE 9: "Once the outcome of the screening review results have been shared, what supports do you think should be available to patients? Select all that apply"



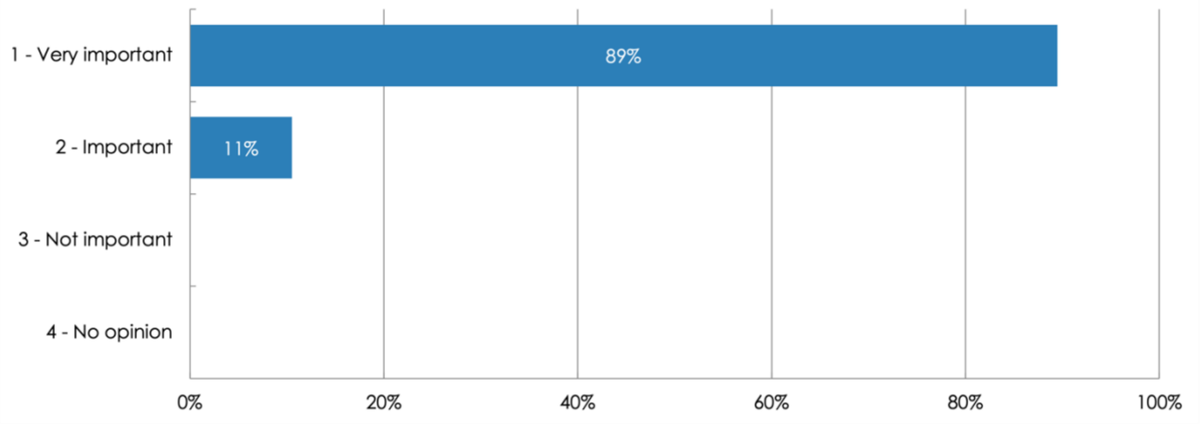
In terms of other initiatives than those mentioned in Figure 9, the qualitative data provides other suggestions for improving support/access to support after the disclosure with a priority of financial support to help out with transport costs, costs for accommodation if having to spend a night close to where the treatment/therapy takes place and costs of childcare.

'Help with finances(…) if I have to travel, and may require a stopover and the cost of the person travelling with you doubles this'

'Yes, provide a lift to the hospital appointments or help with the expenses of driving to hospital and parking fees. In my case, my partner has to take a full day off work to take me there'

As part of the post-disclosure process, there is a significant wish, as seen in figure 10, to have an opportunity to provide feedback to CervicalCheck in order to support evaluation and monitoring and to ensure that women are given a voice in this process in a long term perspective.

FIGURE 10: “How important is it that the patients can provide feedback to CervicalCheck relating to their experience of patient-requested reviews and disclosures?”



7 Recommendations

7.1 Key principals

The following principles are identified as core to the patient-experience to consider when planning the improvement of the processes:

Empowerment and respect through transparency and choice

- The system needs to be transparent and ingrained in a culture where the patients have an empowered position. In practise this means that the women are supported, as needed, to be able to make informed choices and that staff is encouraged to share information. Failing to do so distributes power unequally which is detrimental for building trust in the treatment and system.

Empathy, personal contact and care

- The importance of professionals’ showing empathy and care must be acknowledged and considered in future changes as this directly impacts patient wellbeing, stamina and resilience during the patient journey.

Structure, organisation and clarity

- It is crucial that there is coherence across the patient pathway and that nothing appears random. All the steps should be aligned across the involved professionals so that patients feel they are ‘in good hands’
- All information and communication must be clear, concise and inclusive and professionals should provide genuine opportunities for patients to ask questions.
-

7.2 Specific recommendations

Specific recommendations for improvement of the patient experience accompanied by their rationale:

Overall process

Recommendations	**Rationale**
HSE to establish systematic training of relevant professionals on ethical and empathetic patient engagement on audit and disclosure. This could include themes such as: • Trauma Informed Care and Psychological informed environment • Training on Active Listening and Ethical Disclosure	The majority of participants outlined that they found their overall experience of this process as impersonal and unempathetic, lacking understanding of individual needs and reactions and without sufficient time for questions or clarity of information. Training for professionals will benefit patients but it will also work to acknowledge that the process can be difficult for everyone involved, including medical professionals. There are a range of models and approaches which can ground the need for empathy and kindness in an evidence based framework
There should be recommendation that patients attend meetings with a support person, and timing and communications should facilitate this	A support person can provide an extra level of support for the patient throughout the process, this was a clear recommendation from women consulted

Screening

Recommendations	Rationale
HSE/NSS to undertake an initiative with GPs/sample-takers regards the limitations of screening and how important it is that the limitations are properly explained to women when their tests are taken. The key points are that: • The GPs/sample-takers must make sure that the information about the limitations of screening are communicated in a simple language and provide patients with written material about it that the patient can bring home. • GP/sample-takers should advise patients to react promptly on symptoms, even if the screening test does not indicate abnormalities. • The best practice responses for GPs when patients present with symptoms and have negative screening results	The majority of participants were not made aware of the limitations of screening until they were diagnosed with cervical cancer. When screening is perceived by patients or medical professionals as a diagnostic tool it can delay time of diagnosis which may have grave consequences such as: • The cancer progresses • The patient needs to have more invasive surgical procedures • It can eventually reduce the chance of survival

Audit

Recommendations	Rationale
HSE/NSS to establish a system that ensures that the topic of audit is raised at an appropriate time following the diagnosis of cervical cancer. Information on audit should be provided to the patient by a medical professional in simple, empathetic language and combined with further access to information according to patient preferences such as: • Videos • Website • Pamphlets • Invitation for the patient to have further conversations with professionals about the process of audit	No participants recall being informed about the audit. This was experienced as being ethically wrong and disempowering. Participants in the research recommended that thorough and easily comprehensible information on audit will help establish a needed level of transparency within CervicalCheck

Patient-requested reviews

Recommendations	Rationale
The treating doctor should provide information about the patient's right to request a review. This should be done in a face-to-face consultation as a standard of care, at the discretion of the patient • As part of this communication it is important to inform the patient of the potential outcomes of the review in a plain, simple, empathetic English • HSE/NSS to inform the involved professionals that is it very important for the patients' wellbeing that understanding and respect for the wish to have a review of results is shown • It is important that record keeping of old test results is well-organised and timely In regards to reviews, the following choices should be available to the patient: • *Who* she would like to disclose the results • *What* issues she would like to be informed of, e.g. "I only want to be informed if the results are different from previous tests" • *How* she would like to receive the results of the review Whilst the patient is waiting for the results, she should have: • A key contact person to seek information from • The right to request an update	Participants wish to have as many options as possible to choose between in regards to the patient-requested reviews so that they feel involved in the process and have clarity and control over information that concerns their health as this directly affects their feeling of bodily integrity and personal agency For HSE/NSS to re-build trust and improve patients' wellbeing it is crucial that women are acknowledged as experts of their own health and bodies, and therefore have access to all information they need

Disclosure

Recommendations	Rationale
An appropriate healthcare professional should prepare the patient, in empathetic language, about what will happen at the disclosure. This can be done through a phone call or a letter. • The patient should be encouraged to bring a support person to the meeting The patient should be given choices on where to receive the review results; • There should be an option to choose a nominated clinic/hospital • HSE/NSS to find a way to involve the GP for example by making it possible for the patient to schedule the disclosure meeting in the GP clinic	Research participants were clear that it is important that the patient is as well prepared as possible to reduce the risk of traumatisation that the majority of participants describe being subjected to
At the meeting professionals need to use simple language, show empathy and understanding, be calm and give plenty of time for the patient to ask questions The attending professionals should provide a detailed transcript of meeting and send this to patient afterwards if requested while also giving the patient the option to receive the transcript later	When the disclosure gives the impression of a mechanic procedure it neglects the patients' needs and wellbeing while it also damages the trust and perception of CervicalCheck If patients feel rushed, they are not encouraged or do not feel confident to ask questions
The attending professionals should prepare the patient for the post-disclosure process: • Explaining what common emotional reactions people can have • Presenting the patient with the opportunity to have a call organised from a support worker to offer psychological support and answer any questions • Providing the patient with contact details for a support person in case she needs urgent support	In order to show holistic care for the patient, it is necessary that that the system cares for the patient after disclosure as this is reported as being when issues arise and is therefore a time when women need help and support

Post-disclosure

Recommendations	**Rationale**
HSE/NSS to strengthen support services offered to patients. This includes: • Arranging calls from a relevant professional who can answer questions and can provide psychological support to deal with emotional aftermath of audit and disclosure processes • Providing the patient with an opportunity for counselling • Providing opportunities for additional meetings with relevant medical professionals as required	It is necessary for the system to acknowledge that the patient journey is prolonged by the disclosure of results; a lot of especially mental support is needed in this phase Taking responsibility for this support will help establish HSE/NSS as caring and responsive of women's needs

Ongoing review and cultural change

Recommendations	**Rationale**
HSE/NSS to provide patients with an opportunity to give feedback to HSE/NSS relating to their experience as patients. Complaints should be registered and there should be systematic follow-up on these cases HSE/NSS to establish an evidence based process to ensure permanent cultural change in relation to the way women are engaged with in terms of screening and diagnosis of cervical cancer, including: - Vision and values clarification, engagement and communication processes established, standards or requirements clarified, training or guidance provided - Monitoring systems developed to test whether necessary change has occurred. - Establishment of quality control process/quality system that provides annual status and statistics. The results should be accessible to the public	All participants agreed that the opportunity to give feedback to NSS/CervicalCheck is important and can contribute to a transparent, inclusive and well-organised system A well-established, professional feedback procedure will show that there is a wish going forward to improve the system with a patient-centred perspective at the core of change A systematic approach to feedback will make it possible to monitor, follow and compare cultural change over time and on a national scale.

8 References

221+ Patient Support Group (n.d) Retrieved from https://221plus.ie/about-us/ [Accessed 31 January 2022].

Ben-Tovim, D. I., Dougherty, M. L., O'Connell, T. J., & McGrath, K. M. (2008). 'Patient journeys: the process of clinical redesign'. *The Medical journal of Australia*, 188(S6), S14–S17. Available at: https://www.mja.com.au/journal/2008/188/6/patient-journeys-process-clinical-redesign [Accessed 31 January 2022].

Gualandi R, Masella C, Viglione D, Tartaglini D (2019) 'Exploring the hospital patient journey: What does the patient experience?' *PLoS ONE* 14(12): e0224899.Available at: https://journals.plos.org/plosone/article/file?id=10.1371/journal.pone.0224899&type=printable [Accessed 31 January 2022].

HSE/National Screening Service (2020) *Expert Reference Group Interval Cancer Report CervicalCheck*. Available at: https://www2.hse.ie/file-library/cervical-screening/interval-cancer-report-cervicalcheck.pdf [Accessed 31 January 2022].

9 Appendix

9.1 Overview of the Engagement Group

The group of women from 221+ included: - Grainne Culliton - Karen Lavelle - Aiste Vekrike
221+ Coordinators: - Ceara Martyn - Winnie Donoghue
HSE staff: - Estelle McLaughlin - Caroline Mason Mohan
Independent Consultant: - Nadine Ferris France
Quality Matters Researchers: - Anne Thyssen Vestergaard - Mercedes Hoad Moussa

9.2 Interview guide for qualitative interviews

Introducing the session

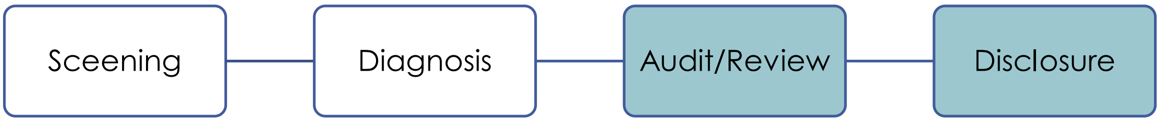
The interviews will be semi-structured.

The aim of this project is developing a set of recommendations to inform the development of the audit and disclosure processes relating to cervical cancers.

The purpose of the consultations is to develop recommendations which are women and patient-centred and based on the lived experiences and valued perspectives of participants.

Input from women and families who have been through this experience will help other women going forward.

If we look at the patient journey, mapped below, it is at the audit (review) stage and the subsequent disclosure of the audit results that this our discussions centre upon. That said, while we will try to focus discussions on these themes, we acknowledge there are factors in various stages of a patient's journey that interact with the specifics of audit and disclosure.



We expect that conversations and ideas will flow into areas that don't necessarily relate to audit/disclosure. While these won't form part of the recommendations of this project, these ideas are valid and important meaning that any emerging themes which become evident will be recorded and reported back to 221plus who will engage members further on these topics.

As the topic is highly sensitive and linked to many traumatic experiences it is crucial that the interviewer works to create a space of security and kindness. Participants must not feel pressured to contribute.

Note: This guide will need to be modified for interviews which involve relatives of

Deceased women. For the wellbeing of all women and their families it is recommended that participants who have lost loves ones partake in consultations specifically dedicated to them.

Guiding principles and policy context

The interviewer introduces herself and explains the purpose of the study and that the information shared will be summarised and reported anonymously

Individual story

Aim: To understand the patient journey in a holistic perspective including starting point and end points.

Interviewer asks the participants if she is comfortable sharing her story as a cervical cancer patient. She is invited to share only what she is comfortable with and to include anything that she finds relevant.

‘Disclosure’

The moment of disclosure

Aim: to give the participants the possibility to share their experiences and to ground participants in the process which we will be exploring in depth.

> ‘Let us try and go back to that point when you experienced the disclosure, if possible. I encourage you close your eyes and take yourself back to that moment
>
> It might have been a telephone call, or a meeting.
>
> Can you remember that first point of disclosure, how did it happen and what were you feeling at that moment?

If comfortable, participants are invited to share their experience of the <u>first point of disclosure</u> and the <u>feelings</u> from that experience they can remember.

Digging deeper – disclosure experiences

Aim: to give the participants the possibility to share their experiences and gather information about these which can be grouped thematically.

> *Can you identify issues or problems that you encountered in that disclosure experience? Alternatively, if there were positive aspects to that experience, I would also like to hear about those too.*

‘Blue sky-thinking’; building a better system together

Aim: To identify how the system could be improved and what participants would like to change in the future

> *‘Let’s drop away from that story of your disclosure now, as we turn instead to how you would like things to be different…*
>
> *‘I would like you now to enter a more* ***solution-focused mindset****. So, for a little while, let us leave society as we know it and go to a place where the main priority is wellbeing and caring for people, regardless of finances, logistics or other limitations.*
>
> *When people in this society suffer from illness, such as cancer, the overall focus is on making the experience as least traumatizing as possible.*
>
> *I would like you to describe how the <u>disclosure process</u> would look in this caring society. Again, if you could think about this in the context of audit and disclosure.*

> *Think about how you would like the process to be for other women who go through a journey as a patient diagnosed with cervical cancer. Please, do not think about what you think is possible but instead how it ought to be, if the goal is to put the needs of the patients at the centre of the process.*

Better outcomes for women

> *'Now, imagine that what you've described as the ideal scenario with regards to disclosure and audit was your reality.*
>
> - *How would you be standing differently now?*
> - *Would you be in a better place?*
> - *What difference would this have made for you, and how?*
> - *How will it help women facing this situation in the future?*

Thank you and follow up support available

Thank you for your sharing and insight on this difficult topic. Your time will help 221+ advocate for better healthcare for Irish citizens. If this session has bought up feelings of anger or upset, please reach out to 221+ who are available to provide support. They can be contacted by phone on **01 2316 648** or by email, **info@221plus.ie**.

9.3 Survey Questionnaire

How should the audit and disclosure process be? This is an opportunity to have your voice heard.

Welcome

This short survey was developed jointly by members of 221+ together with the HSE. Its purpose is simple:

- To make sure that the experience of audit and disclosure is better for women who will go through the process in the future.

This survey takes around 5 minutes to complete. It aims to understand your experience of auditing and disclosure and your thoughts on how these can be improved. Findings will be presented in a report to the HSE in February 2022.

Your answers and input will be used to understand how the processes around audit/review and disclosure can be changed in order to put women's wellbeing first so that the experiences of 221+ members are never repeated among other women in Ireland. This is an opportunity to improve things for women going forward.

Thank you for participating.

Background

In 2019, following the failures of the CervicalCheck Screening Programme, and 221+ advocacy efforts in response, an Expert Reference Group was established to address one element of quality assurance i.e. how best to conduct audit by clinical experts of cancers arising between screening visits . You can read more about this here. As part of this, an Engagement Group comprising 221+ members and HSE staff came together to design a process to consult with members of 221+.

Audits are the processes in place to review the effectiveness of a screening programme through the review of cervical screening histories of patients diagnosed with cervical cancer in between screenings. **Disclosure** refers to how a patient is informed of the results from an audit of their screening history.

Please skip any question you are not comfortable answering

EXPERIENCE OF SCREENING, REVIEWS/AUDIT AND DISCLOSURES	
1. When participating in CervicalCheck screening, the limitations of screening were explained to you. Is there anything you would like to share in relation to this? **Free text**	- Strongly agree - Agree - Disagree - Strongly disagree
2. If you feel comfortable sharing this here, please describe your own experience with the audit/review and disclosure processes. **Free text**	
3. What three words best describe the process of review/audit and disclosure you experienced?	1. input answer 2. 3.
4. Please describe what you would like to be different in regards to review/audit and disclosure. **Free text**	
5. If you were planning the review/audit and disclosure processes, what three words would **you *want*** women to use to describe the experience?	1. input answer 2. 3.
INFORMATION ON REVIEW/AUDIT PROCESSES WITHIN CERVICAL CHECK	
Two types of screening audits within CervicalCheck are recommended: **'Patient-Requested' case reviews** which can be requested by a patient who has been diagnosed with a cervical cancer in between screenings and **'Clinical audits'** which assess quality and standards by reviewing the patients' screening history without patient details being visible to the reviewing clinician 6. How would you prefer information about the review/audit processes to be given (in addition to professionals explaining the process): *[Select one]* a) Videos b) Pamphlets c) Website d) Further conversations with health professionals e) All of these f) Other……	
7. If you would like to comment or provide more detailed answers on question 6, please do so here: **Free text**	
INFORMATION AND OPTIONS FOR PATIENT-REQUESTED REVIEWS	
8. How would you like to receive the information on the patient-requested reviews? *[Select one]* a) Treating doctor provides information during a *face-to-face* consultation b) Treating doctor provides information during a *telephone* consultation c) Treating doctor sends a letter, with information d) CervicalCheck sends a letter, with information e) All of the above f) Other__________	
9. How important is it for you to have choices throughout the patient-requested review process?	- Very important - Important - Not important - No opinion either way

10. If you choose to request a review, how important is it for you to be able to decide: (clarify the scale for the reader of this doc). a) Which medical professional discloses your results b) What *types* of issues you will be informed of, for instance "I only want to know if the review findings are different from previous test results" c) How you would like to receive results (for example, by telephone call, letter, in a meeting, or a combination of these)? d) To choose *not* to be informed about review results, with the option to find out later if you change your mind.	For each decision option, rate importance: - Very important - Important - Not important - No opinion either way

11. Are there any other areas in which you should be able to choose and decide the process and way forward? **Free text**

12. What options would you like to be available whilst you are waiting for review results?: *[Select all]*
   a) The right to request an update
   b) A key contact person to seek information from
   c) other ___________

RECEIVING REVIEW RESULTS: 'DISCLOSURE'

13. What options should be available for sharing results of Patient-Requested reviews with a patient? *[check all that apply]*
   a) A trained nurse counsellor arranges phone or face-to-face appointment
   b) CervicalCheck sends a letter to GP, with information
   c) CervicalCheck sends a letter to GP, with information and option for follow up with Cervical Check trained nurse counsellor, who arranges phone or face-to-face appointment
   d) A trained nurse counsellor liaises with treating physician in advance and shares all relevant information
   e) other ___________

14. What options should be available in terms of *where* you would like to get the results of your Patient-Requested review? *[check all that apply]*
   a) at your own home
   b) at nominated doctor's clinic/hospital
   c) at HSE premises
   d) at a third-party location
   e) by phone
   f) other ___________

15. Who should be able to attend the meeting relating to your review results? *[check all that apply]*
   a) Your own support person
   b) Nominated doctor (i.e. GP, colposcopist, oncologist, gynaecologist)
   c) Representative from CervicalCheck
   d) Counsellor
   e) Other_______

FOLLOW UP, SUPPORT AND AFTERCARE

16. Once the outcome of the screening review results have been shared, what supports do you think should be available to patients? *[check all that apply]*
   a) Follow-up with a dedicated liaison person who can answer questions about the review results
   b) Psychological support (therapist/counsellor)
   c) Follow-up and aftercare with a gynaecological trained nurse counsellor who can answer questions about the review results
   d) Nominated doctor (i.e. GP, colposcopist, oncologist, gynaecologist)
   e) Representative from CervicalCheck
   f) All of the above

g) Other_______	
17. Can you think of any issues (for instance transport and childcare) that make it difficult for women to access these supports? **Free text**	
FEEDBACK	
18. How important is it that the patients can provide feedback to CervicalCheck relating to their experience of Patient-Requested reviews and disclosures	- No opinion - Not important - Important - Very important
OTHER SUGGESTIONS FOR IMPROVEMENTS	
19. Can you think of other measures than can ensure that review/audit and disclosure processes prioritise the interests, rights, and needs of women? **Free text**	

Thank you for your time, sharing and insight on this difficult topic.

If answering these questions has bought up feelings of anger or upset, please reach out to 221+, who are available to provide support. They can be contacted by phone on 01 2316 648 or by email, info@221plus.ie

Independent charity, *Quality Matters* was commissioned to co-design this survey in collaboration with 221+ members and the HSE. The information you provide is securely stored; only accessible to Quality Matters and deleted once the research report is written. The survey is **completely anonymous** – what you choose to share will not be identifiable to you, and you won't be asked for any identifying information.