



Colposcopy Staff Experience of 2018 Cervical Cancer Audit and Disclosure Process

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Executive summary

1.1 Background

- In 2021/22, the National Screening Service (NSS) established a consultation process with members of the 221+ patient advocacy group to capture their views and experience of receiving interval cervical cancer audit results in 2018.
- Following the process with 221+, the NSS team believed it important also to capture the experience of colposcopy staff in sharing the audit results. The aim was to give staff an opportunity to share their perspective and to understand their experience.
- The external researcher that who engaged for the 221+ project was engaged to co-design and document the research with colposcopy staff.
- In July 2022, NSS and colposcopy staff representatives established a working group to develop and oversee a consultation process and capture the views of staff who worked in colposcopy services in 2018.
- The purpose was to understand and document their experiences and the impact that the audit and disclosure processes had on them personally and professionally, as well as gathering their advice on how audit and disclosure processes could be improved for patients and staff in the future.
- The research identified the need to rebuild trust between colposcopy staff and (i) their local hospital management (ii) the management team of CervicalCheck and (iii) the wider HSE senior management team. The need to rebuild trust between the wider population and the CervicalCheck programme was also identified.
- Arising from the consultation and research with colposcopy staff, five recommendations were made. These are described below:

1.2 Recommendations

The recommendations below are based on the data gathered during this research and reflect the experience of the research participants (52 survey responses and 25 focus group members). The staff surveyed described their experience of the cervical cancer audit and disclosure process in 2018.

Further, feedback from the research participants suggested that they believed that sharing the learnings from this project with staff across the NSS and the wider HSE was important.

Recommendation 1 – Communication and education plan on screening

Develop, implement, and monitor a communication and education plan for NSS that explains the benefits, limitations, and complexities of screening to all stakeholders, including the media and politicians.

- Ensure that the plan contains a communication and education strategy (including social media and other platforms), and outlines who is responsible for each action.
- It is essential that this plan is reviewed regularly and adjusted, if necessary, to ensure it includes up-to-date information to meet the knowledge needs of stakeholders.

Recommendation 2 – Cultural change plan

Develop, implement, and monitor a “just culture” for the NSS and wider HSE in response to adverse events and incidents in healthcare. This should accompany implementation of the Patient Safety Act:

- Acknowledge and communicate that adverse events are an expected part of healthcare provision. Acknowledge that adverse events and patient harm can occur without deficiencies in the care provided.
- Promote a culture where staff and management work as a united team and support each other, before and during periods of significant stress.
- Strengthen the sense of trust in the working relationships between colposcopy staff, their local hospital managers and Cervical Check/NSS.
- Improve staff engagement within the HSE so that those who work directly with patients feel more connected to the management team for their service. Encourage staff to share their insights on how best to take care of patients’ needs and how best to reduce the risk of potential adverse events.
- Increase the sense of psychological safety so that staff feel able to articulate, without fear, their concerns about sharing information in the aftermath of patient safety incidents. It is important that all open disclosure meetings with patients are planned, coordinated and that staff are supported and have incident-specific training before participating in these meetings. This is essential to avoid compounding patient harm.
- Encourage and normalise staff participation in therapeutic interventions and personal coaching to address workplace trauma, especially in the context of staff response to adverse events and patient safety incidents.

Recommendation 3: Crisis management plan

Develop a crisis management plan which guides the NSS/HSE response to future adverse outcomes in collaboration with key stakeholders which includes:

- Providing a space to discuss potential patient safety incidents and adverse outcomes before they happen.
- Acknowledging that the rushed and poorly planned CervicalCheck audit disclosure process in 2018 impacted negatively on patient care, and staff wellbeing.
- Incorporating lessons learnt in the CervicalCheck personal cervical screening review communication process across all services. Ensure that communicating the results of patient care reviews to patients who have experienced an adverse outcome is carefully planned, and cognisant of the risk of patient harm.
- Acknowledging the need for staff and patient supports in review situations, in particular before and after a discussion of patient care reviews findings.
- Acknowledging the potential for these discussions to precipitate a media or political crisis.
- Defining and documenting governance structures and processes in the event of future crises, as well as defining roles and responsibilities by having a strong crisis communications plan in place.
- Involving staff on the ground as a key stakeholder in planning the response to any future healthcare crisis.
- Ensuring that the management of any healthcare crisis incorporates high quality internal communications. If a call centre is required for concerned patients, this should be established and staffed separately to the service which provides care. Staff for this call centre need to be adequately trained and have dedicated communications expertise and support.

This plan should be communicated clearly to stakeholders and revised regularly to ensure staff are up to date on how it will be implemented.

Recommendation 4: Develop a review structure and communications plan for interval cervical cancer reviews

Develop, implement and monitor an approach to discussion of interval cervical cancer audit results that is uniform, structured and clear.

The plan should include:

- This should also include a standardised method of classifying the quality of care.
- A training plan for staff involved in discussion of interval cancer review findings to ensure that those involved are supported to share results of the reviews in an evidence-based, standardised manner which is supportive of patients.
- Preparing patients for the potential results of an interval cancer audit in advance of these results being available.
- Support for patients and staff prior to, during and after the discussion of audit results. This should be personalised to individual patient needs.
- Sharing the review process and communications plan for discussing interval cancer review results with other services, to ensure that patients receiving review results across all areas of healthcare benefit from the learnings from the 2018 CervicalCheck crisis.

Recommendation 5: Develop a plan to help staff communicate transparently and in a trauma-informed way after an adverse outcome.

The plan should include:

- Ensuring that HSE policies include communication strategies for (i) adverse events associated with patient safety incidents, (ii) unexpected adverse outcomes where no patient safety incidents were identified (iii) adverse events when it is unknown whether a patient safety incident has occurred, and investigation is ongoing.
- Exploring how to share with wider HSE staff the experience of colposcopy staff involved in the 2018 disclosure meetings, including how these experiences impacted on their future engagement with patients.
- Education and guidance for staff on how to build their confidence and maintain their psychological safety when communicating with patients who have experienced an adverse healthcare outcome.
- Consideration of the impact that fear of litigation has on staff performance, confidence, and their interactions with patients.
- A review of the legal setting within which cancer screening operates in Ireland.

Introduction

2.1 Background

CervicalCheck, the national cervical screening programme, was established in Ireland in 2008. The programme began inviting women aged between 25 and 60 years to be screened every three years between ages 25-44, and every five years between 45-60 years. Between 2008 and 2018, around 3,000 women in Ireland were diagnosed with cervical cancer, of whom around 40% had never been screened.¹ During this time, around 56,000 women had high-grade cells detected and treated - cells which develop into cancer if left untreated. 1,482 women had cervical cancer detected via screening and colposcopy, 1,296 of whom had previously participated in the CervicalCheck programme.

A cytology audit for women diagnosed with invasive cervical cancer in the first eight years of the CervicalCheck programme (2008 - 2016) was undertaken as one measure of quality assurance and in line with best international practice. The audit highlighted discordance with a previous cervical screening test in 221 cases. This rate was consistent with that found in the audit of the English cervical screening programme. However, there was inconsistent disclosure of the results of the CervicalCheck audit.

In response to publicity surrounding the CervicalCheck audit, the then Minister for Health commissioned an independent Scoping Inquiry into the CervicalCheck Screening Programme, which was published in September 2018.³ All of the recommendations of this report are now implemented.⁴

The report criticised the way disclosure of the audit results was handled by colposcopy clinicians and by the healthcare system in general.³

In 2021/22, the National Screening Service conducted a consultation and research process with members of 221+ patient advocacy group to capture their views and experience of the interval cancer audit disclosure processes that took place in 2018.⁵ This consultation process included quantitative and qualitative research carried out by independent charity Quality Matters. The research showed that the events had resulted in patients losing trust in the screening programme, and recommendations were formulated on how to re-build trust. The research report made recommendations about how audit and disclosure processes could be adjusted to improve the experience for people receiving interval cancer audit results in the future.

Following the process with 221+, the next step was to capture the experience of colposcopy staff, to understand their experience of sharing audit results with patients and give staff an opportunity to share their perspectives. In July 2022, NSS and staff representatives established a working group to guide a consultation process and capture the views of colposcopy staff who worked in the service in 2018. For consistency, Quality Matters was again engaged to carry out the research element of the consultation. The purpose of the research was to understand and document staff's experiences of the cervical cancer audit and disclosure processes and to gather their advice on how audit and disclosure processes could be improved in the future.

2.2 Process and overall approach

A working group consisting of colposcopy staff, NSS representatives, an independent therapeutic facilitator, and an independent researcher, was established. Over eight workshops, the working group collaborated to design a research process that provided staff who were working in colposcopy during the events of 2018, an opportunity to have their voice heard. The external facilitator and researcher were hired to ensure integrity and independence in the process. All colposcopy staff who were working within the 15 colposcopy clinics during the events of 2018 were invited to participate in a research focus group, a 1-1 interview, and/or an online survey.

A collaborative research process was used. i.e., the working group piloted and edited the questionnaire, discussed analytical findings, encapsulated the findings, and translated the learnings into recommendations.

The working group consisted of the following people:

5 colposcopy staff

3 NSS staff, including a coordinator

Independent therapeutic facilitator

Independent researcher

The research was a way to engage healthcare staff and translate their experiences into meaningful recommendations that can be used to improve future communications of healthcare reviews and disclosure processes in a way that benefits both patients and healthcare staff. This research supports the approach of the HSE in open disclosure and developing a just culture for staff.

The chosen approach, i.e. encouraging people who have been involved in traumatising events to engage in research, was inspired by principles found within restorative practice, which emphasises the importance of offering those involved in a conflict or dispute a forum for dialogue, and expression of the emotions related to the past/present conflicts and challenges.⁶

2.3 Aim and objectives of research

The aims of the consultation and research process were (i) to document the experience of colposcopy staff during the events of 2018 and (ii) to provide learnings for how to improve the process of communicating review information to patients. This learning was used to help implement recommendations made by the HSE Expert Reference Group, established in 2019 to “define the future audit processes and review guidance for interval cancers in the National Screening Service based on international evidence and best practice”. CervicalCheck launched a new process for personal cervical screening reviews in April 2023.⁷

The specific objectives of this research were:

- To document the experience of colposcopy staff in disclosure of interval cancer audit results.
- To understand what would have improved the process.
- To formulate recommendations for improved practice in the future.
- To consolidate learning with that of the 221+ consultation to ensure an improved process that meets the needs of patients and staff.
- To consider any identified learning within the context of a restorative practice approach.

Research methodology

The research used a mixed-methods approach. This included focus groups, qualitative in-depth interviews, and an online questionnaire sent to all colposcopy staff. The mixed-methods approach was chosen to secure a rich in-depth understanding of the topics, combined with a more robust dataset on how many people had certain experiences. Furthermore, it was deemed important to give people different options for ways to participate, according to their preferences. The online questionnaire consisted of a mix of closed and open-ended questions, thereby incorporating both qualitative and quantitative items.

The qualitative research consisted of:

Two face-to-face focus groups in Dublin

One face-to-face focus group in Cork

Two online focus groups

One online 1-1 interview

The research scope was co-designed from the outset of the project. As such, the researcher was an active member of the working group, along with the facilitator. Each step of the research was discussed and agreed by all members. The process took place over eight meetings.

To effectively agree the research framework and instruments, the following process was undertaken:

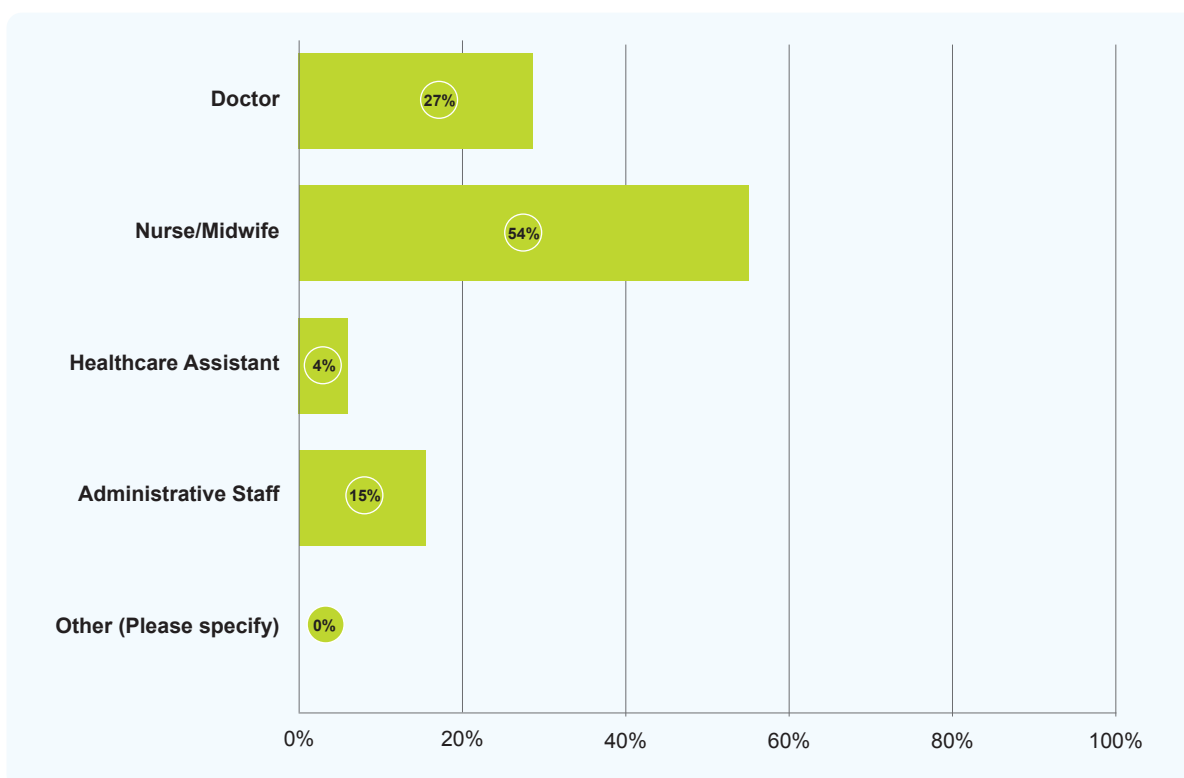
- 1) Consultation with the working group to discuss the scope and aim of the research.
- 2) The drafting of a research framework document that reflected these discussions. The chosen method was agreed among the group members.
- 3) Drafting of research instruments that explored the research questions.
- 4) Feedback on research instruments and final sign-off by all members of the working group.

3.1 Quantitative research design

The survey was developed with a mixed-methods approach, incorporating both qualitative and quantitative items. Once the survey was developed, tested, and finalised, it was distributed to potential participants by members of the working group. The survey was designed to ensure that potentially identifiable information was not gathered. Additionally, all qualitative data was screened so no identifying information was present, before being included in the analysis. The survey was hosted on the SogoSurvey platform by a multiuser link. All data was double password-protected and kept on a secure system.

A total of 52 professionals completed the survey. Figure 1 shows details of participants regarding their professions; as seen in the table, 4% of participants were healthcare assistants and 15% were administrative staff. The lower number of these professionals was discussed with members of the working group, who explained that not all units have dedicated healthcare assistants, and that both healthcare assistants and administrative staff tend to move roles more frequently than nursing and medical staff. Thus, it is likely that a significant proportion of healthcare assistants and administrative staff who currently work in colposcopy were not working in the field in 2018. The working group were happy that the target group for this research was appropriately reached.

Figure 1: What is your profession?



3.2 Qualitative research design

The qualitative research consisted of five focus groups (FG) and one 1-1 interview. All focus groups had a duration of two hours. The 1-1 interview had a duration of one hour.

Location	Date	Number of participants
Online focus group	25th January 2023	3
Online focus group	25th January 2023	2
Dublin focus group	1st February 2023	4
Dublin focus group	1st February 2023	5
Cork focus group	2nd February 2024	10
Online interview	3rd March 2024	1
Total		25

A total of 25 staff members participated in the qualitative research. A semi-structured interview method was used in focus groups/interview to determine participants' personal experiences and views of future solutions. The process aimed to ensure that personal experiences and stories were shared in a space of empathy and trust.

Participants were recruited through the working group, either by direct contact or emails distributed to all colposcopy staff. The criteria for participation were that staff had been working within the colposcopy units during the events of April 2018 and the months afterwards. Participants were contacted in line with an agreed recruitment and engagement strategy. This included the working group members passing on details of the participants to the researcher, who arranged an initial call or email to fully explain the research, ensuring they had time to digest the implications of engagement, and were making a full and informed decision.

3.3 Analytical approach and process

Several analytic methods were used. For the quantitative data, the majority of data was summarised using a descriptive approach. This data was then incorporated into a wider discussion and analytically combined with the qualitative data using a narrative synthesis approach. The data obtained through the interviews comprised a collection of subjective, complex, and interlinked stories, experiences, and situations. To allow for this complexity, the qualitative research was undertaken using a phenomenological approach as a methodological framework. Put simply, phenomenology can be defined as an approach to research that seeks to describe the essence of a phenomenon by exploring it from the perspective of those who have experienced it. As such, phenomenological research identifies and explores the content of a given human experience in a way that allows for a high level of complexity and subjectivity.^{8,9}

The interviews were partly transcribed for analysis to secure accuracy in the analytical process. The findings were distilled into themes that stand as the main insights of the research. The trustworthiness, validity and reliability of the analytical process was built by using the following techniques:

- Categorisation of raw data according to the topics and overall aim of the research. Where relevant, topics were broken down into themes to reflect the nuances and complexity of participants' lived experiences.
- Ongoing independent review of identified topics and themes by the other members of the research team to reduce the risk of biases and/or losing out on relevant details that might act as 'blind spots' for the researcher.

3.4 Ethical considerations and confidentiality

As the aim of the research was to carry out a service evaluation, it was not needed to seek ethical approval from the HSE Reference Research Ethics Committee (RREC).¹⁰

However, a number of ethical concerns were identified in undertaking this research, which were considered in detail with prevention and response strategies identified for each:

Risk	Prevention/Response
That highly sensitive or challenging experiences would arise, causing participants to feel triggered or retraumatised	Facilitator and researcher were trained in trauma and trauma-informed research methods. Facilitator and researcher were attentive and responsive to any signs of emotional distress or discomfort. When needed, the facilitator would offer the participants a break which provided them with a chance to collect their thoughts. The facilitator and researcher encouraged participants to opt out of any questions that made them feel uncomfortable and/or overwhelmed.
Participants would be reluctant to participate due to fear of information being subjected to FOI requests	Participants were reassured that the information would be held by and only seen by the Quality Matters research team.
Participants would hold back information because of fear of being identified through the research	Participants were fully informed about the aims of the project and the fact that their contributions would go into a research report, and would not be identifiable.
Participants would not feel fully informed	In order to ensure participants were fully informed of the research at all stages, the following points were discussed: Pre-interview • A review of the project aim • A reminder regarding confidentiality • A reminder regarding ongoing voluntary nature of their participation and option to withdraw/decline to answer • Explanation of the researcher's notetaking and what would be done with their information Post-interview: Participants were thanked for engaging in the research and next steps were explained. They were offered a check-in to see how they were feeling, and reminded to seek support as appropriate.

3.5 Limitations

While a considerable amount of effort was given to encouraging colposcopy staff to engage in this research, either through the online survey, focus group or 1-1 interview, some professionals did not wish to participate. This reluctance impacted the balance in colposcopy units represented and not all units participated in the research. Several emails were sent out to potential participants to encourage engagement, followed up by phone calls from members of the working group to ensure that all potential participants felt they had the chance to engage. However, as it was at the core of the research to encourage voluntary participation and engagement, the reluctance to participate was fully accepted.

Research findings

4.1 Main findings

Quality assurance and audit disclosure prior to 2018

Interval cancer audit is one measure of quality assurance in a cervical screening programme. Staff described that discordant results were expected to occur in an audit as screening has limitations and should never be understood or promoted as a diagnostic tool. Standard clinical practice at the time did not consider disclosing the outcome of an audit beneficial to the patient as it would not change their treatment outcome. Furthermore, staff had concerns that informing patients of the audit results could do unnecessary harm. Thus, some participants in this research considered the idea of disclosure to be problematic from a clinical care perspective, and worried that it could potentially cause additional stress for patients.

Arrival of audit results but no clear guidelines and support

Open disclosure was not implemented as a standard procedure for audit results in 2018. Colposcopy staff recalled that when letters with audit results started arriving in 2016, no clear directions were given on what to do with the results. A significant number of staff research participants were worried about the lack of clear guidelines on what to do with these results. A subgroup of the staff (14% of survey participants and three staff from the focus groups) described that they raised formal concerns. However, these people did not experience that their concern was taken seriously or considered important by their managers.

Staff abandonment

The massive public attention that arose around audit and disclosure in April 2018 stood out as a memorable point for the staff. This was followed by a period of immense stress, chaos and confusion. They did not receive clear or sufficient information and advice during the events, and most of their information came through the media. They were, however, given instructions to disclose audit results to every patient as fast as possible. Staff did not feel prepared to deliver the results to patients because this was not standard practice. The lack of clarity on the disclosure process resulted in staff feeling abandoned and in need of more support and guidance from hospital management, the CervicalCheck programme, and the wider HSE. The experience of not being supported has left staff with a reduced sense of trust in the system. It was their perception that there has been insufficient opportunity to have the voice of staff represented in the narrative of the crisis. An opportunity to tell the clinical story of what happened could help identify how to respond more effectively if a similar situation happened in the future in the HSE.

Lack of support and follow up for patients

It also caused staff enormous concern that there was no information or advice available in the system on where and how to refer patients for support in the aftermath of disclosure meetings. These meetings were experienced as very distressing for patients as well as for staff. The team were not equipped to provide support to patients who were experiencing high levels of emotions like shock, anger, and disbelief. The staff felt blamed for causing the cancers and experienced being accused of intentionally hiding information from their patients. Research participants described how the fact that they felt unable to adequately support their patients compounded their distress.

Fear

The staff described an increased sense of fear and cautiousness in the way they communicated with patients. This negatively impacted on their relationships with patients. Staff described that they felt that they lost their warm and personal connections with patients that had been normal prior to 2018. Staff believed they used to be trusted by patients but that trust has been diminished by the events of 2018.

Workplace morale

Staff who participated in this research reported that the workplace atmosphere and team morale was negatively impacted by the 2018 events. They felt isolated and would have benefited from more guidance and support from local management, CervicalCheck and the wider HSE. Participants believed that the way the media and politicians reported the events escalated the situation, resulting in staff feeling publicly shamed and scapegoated. Furthermore, staff remain frustrated and sad that the narrative that largely dominates the public sphere, to this day, is that the staff maliciously hid information from patients. They believed this hinders the public's understanding of the fact that there will always be cases where cervical screening doesn't pick up abnormal cells no matter how efficient and quality assured the service is. There was a real concern that the negative publicity will prevent women from accessing screening and colposcopy services. They also expressed concern that the level of litigation will mean that the free population screening programme is not financially viable in the future. Overall, the research illuminated the need to rebuild trust between staff and the management team of CervicalCheck and between the wider population and the CervicalCheck programme.

4.2 Detailed findings

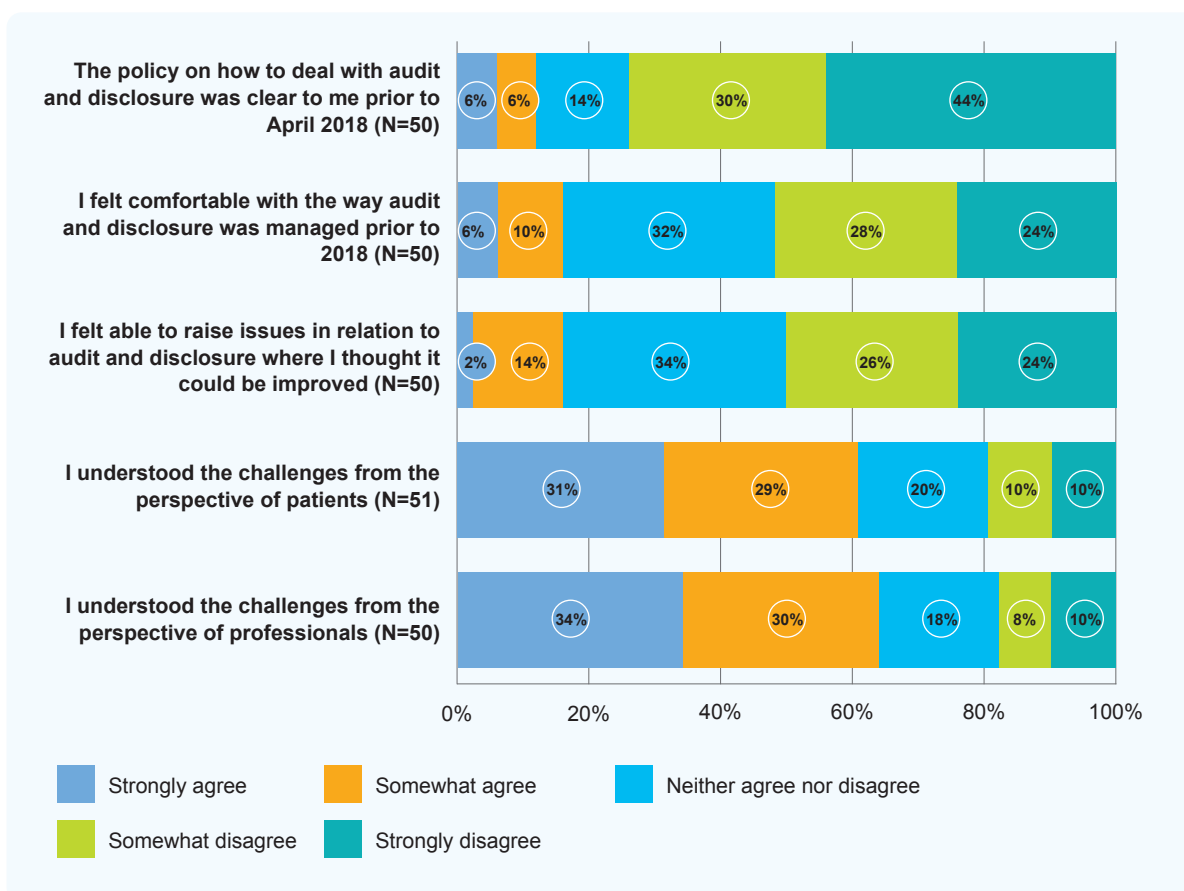
Arrival of audit results caused concern and confusion

Prior to 2018, disclosure was not implemented as a standard procedure for audit results and staff who participated in this research explained that there were no clear guidelines to follow to disclose audit results, which is reflected in Figure 2 below. This shows that almost half of survey participants (44%) strongly disagreed with the statement that there was a clear policy on dealing with interval cancer audit and disclosure in 2018. Additionally, more than half (52%) did not feel comfortable with the way it was managed prior to 2018. In addition, 50% did not feel they were able to raise the issues they were concerned about. These viewpoints were also expressed strongly in the focus groups, where participants described that, starting in 2016:

‘A couple of letters arrived here and there, saying “your patient has been in an audit; think what you would like to do with the results... if you think it would do more harm to the patient to disclose, don’t do it!” (...) it was all very fluffy. Everyone managed the letters as they felt right.’

As pointed out in the quote above, the letters were not directive but rather encouraged the consultants to decide whether to inform the patient or not. Most of the letters were filed in the patient charts, as professionals did not see any rationale to do otherwise and had not been given clear or direct instruction to do anything else. This approach was based on their belief that the results would not benefit patients from a clinical perspective, as the results would not change their outcomes or impact on their course of treatment.

Figure 2: To what degree do you agree with the following?



The events of April 2018

Participants repeatedly referred to one weekend in April 2018 as a memorable point in the events. Some participants recalled hearing stories in the media mentioning cervical screening leading up to that weekend while others heard from colleagues that something ‘big was going on’. Overall, the way professionals became aware of the events was diverse, with no unified communication from a higher authority targeted directly at professionals. The description of how participants experienced those days in 2018 was consistently described as “filled with panic”. This description was repeated across survey and focus group participants. Looking back on the events, professionals recalled many different emotions, thoughts and experiences. Despite some minor differences, a clear pattern of shared responses emerged from the data as summarised in the table below:

Description of atmosphere in workplace	Perception of the overall process and rationale	Emotions reported by professionals	Quotes from participants	Perceived communication and support from Hospital Management Cervical Check and HSE
Panic	Mismanaged, rushed, time pressure, stressful.	Disbelief	'Disclosure will be frightening for patients and cause distress'	No instructions, support and/or guidance provided
Confusion	Uninformed/ not thought out/ unplanned.	Anxiety, fear		Unclear, inadequate and/or ambiguous communication
Chaos	Unclear roles and responsibilities	Anger caused by frustration and humiliation	'Disclosure of results is inappropriate and cruel'	Absence of management
Despair	Process not grounded in care and concern for patients	Vulnerability and sadness	'Will this undermine and damage the reputation of the cervical screening programme?'	No senior manager with responsibility for communication to patients or screening participants
		Disgust		
		Unprepared		
		Ambivalent, pushed to go against own belief and rationale		
		Overwhelmed and stressed		
		Unsupported		

Participants outlined that a major shift took place during the latter days of April 2018 as they were suddenly ordered to disclose audit results, including those already filed. However, they were not provided with any support on how to do this in the most appropriate and person-centred way. It was a shared perception that it did not matter how disclosure was done as long as it was done as fast as possible, as one participant described:

‘The one thing is that we suddenly were ordered to get our charts. We tried to locate files and answer questions. We were looking at charts, lists, date of births, whether patients were dead or alive (...) It was complete chaos.’

One major source of stress was the fact that the regular clinical work was also expected to continue at the normal pace. As the news about what was soon referred to as the ‘cervical screening scandal’ started spreading, the professionals’ daily work and communication with patients was increasingly impacted by these events. Patients started questioning the professionals’ expertise as well as the quality of the cervical screening programme in general. Meanwhile, previous patients and/or relatives would call the clinic or arrive in person at the hospital without an appointment and ask to have their results. People were worried that their previous results were wrong or that they could be one of the cases where discordance was identified. Colposcopy professionals felt that they were appointed as responsible for all the issues that were arising around audit and disclosure. This caused many staff to feel anger towards the system and a sensation of being scapegoated and blamed for events that took place outside the colposcopy setting:

‘We were so removed from the truth of the narrative, even our colleagues didn’t really get it. There couldn’t be all that stuff in the media if there was nothing dodgy going on within colposcopy (...) They didn’t understand that the only problem we caused was that we didn’t communicate the audit results to the patients.’

As illustrated in the above quote, and echoed among most participants, it was felt that the dominant narrative, both among patients and the general public, portrayed colposcopy professionals as acting with a hidden and malign intent. In a broader perspective there is a significant clash between professionals’ view on audit and disclosure of results on one side (“audit results are for quality assurance and disclosing them can potentially have a negative impact on the patient’s wellbeing”) and the communication that took place in the media/among the public (“audit results have been hidden from patients with a malign intent”). It is the common perception among participants that the media nudged this change of focus and sparked the anger aimed at colposcopy staff. Staff do not feel that it was communicated to the public that the treatment outcome for patients was not impacted by whether audit results were disclosed or not.

Disclosure meetings

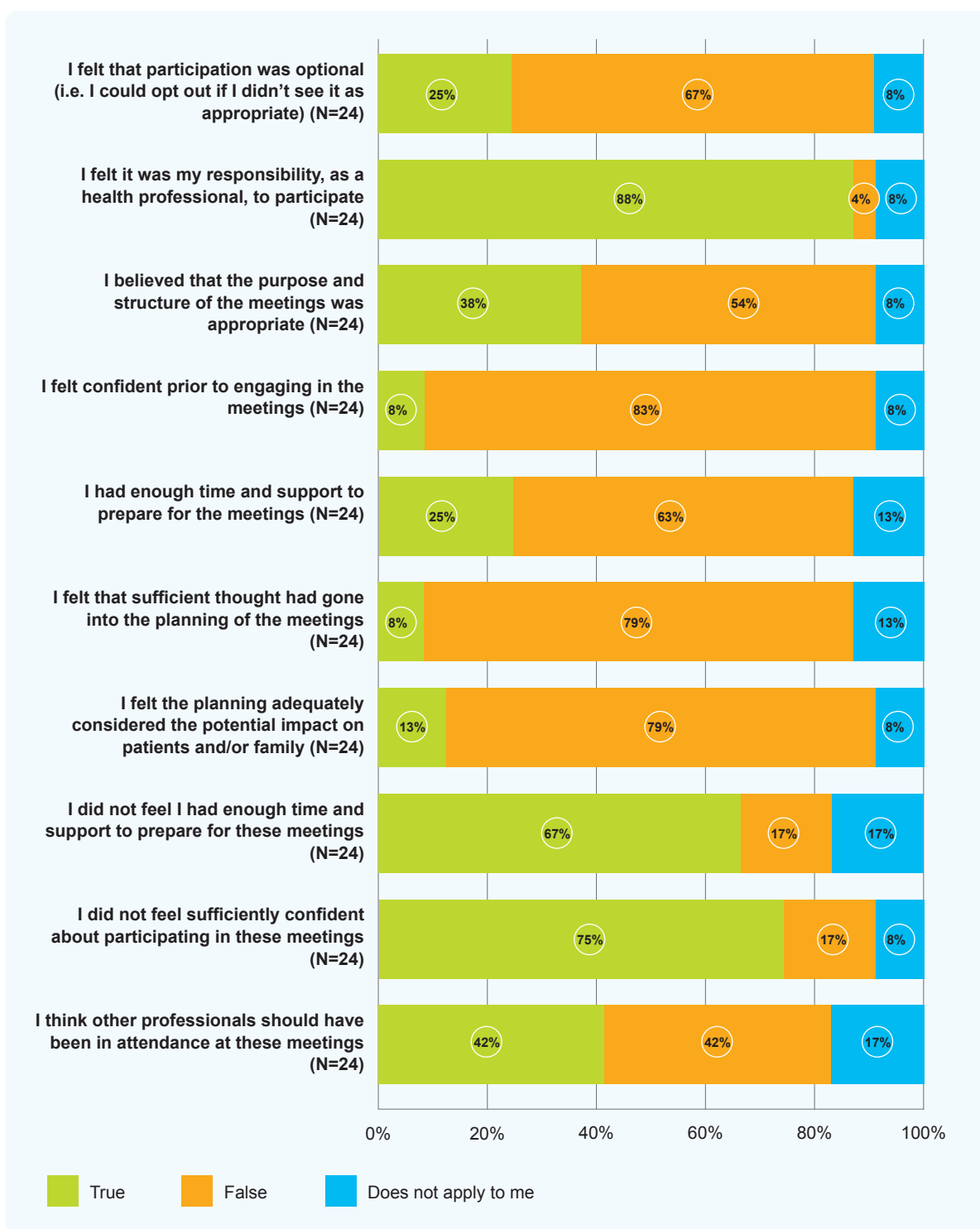
Approximately half (49%) of survey participants and half of focus group participants participated in the audit results disclosure meetings. When reflecting on these meetings, a key theme was that they felt rushed and were not well planned. The description of the disclosure meetings was, in general, very similar to that of the overall process with words such as rushed and unorganised repeated. Most professionals who participated in the meetings felt that participation was mandatory. The overall perception was that little attention was paid to the content and sensitive nature of the meetings, with the clearest goal being to get the results communicated to patients as fast as possible.

'We had to contact all our patients but were given no directions. It was hard because no one explained why it was happening, and why it was instigated. We did not have the language to do it and were not prepared for it at all.'

The consequences of this pressure were that professionals went into meetings feeling unprepared about how to communicate with patients, and how to handle their reactions. Some professionals described that they experienced a change in the character of the meetings, where the behaviour, reactions and atmosphere changed quite significantly over a short period of time. This is explained in the following quote:

'The first meetings were amicable. Patients seemed to understand the background and situation and were grateful but after a while they would ask for a second meeting, usually bringing a solicitor along. Their behaviour had changed to anger, shouting, and blaming us for having caused the cancer.'

Participants' narrative about how they experienced the disclosure meetings was mirrored in the survey results, as illustrated in Figure 3 below. In summary, these numbers indicated that 54% did not find the structure and purpose of the meetings to be appropriate, 63% did not feel they had enough time to prepare for the meetings, 75% did not feel confident about participating in the meetings, 79% did not feel that sufficient thought had gone into the planning of the meetings and 79% did not feel that the planning of the meetings adequately considered the potential impact on patients.

Figure 3: What best describes how you felt about participating in the disclosure meetings?

When reflecting on the disclosure meetings, professionals explained that they did not feel prepared for the level of emotion from patients. The extreme discomfort experienced during the meetings left professionals in a state they referred to as shock and trauma. They felt they were being placed in an unfair, powerless position, as they had to engage in a process they felt lacked integrity, contextual understanding and sensitivity for the people involved, including both professionals and patients.

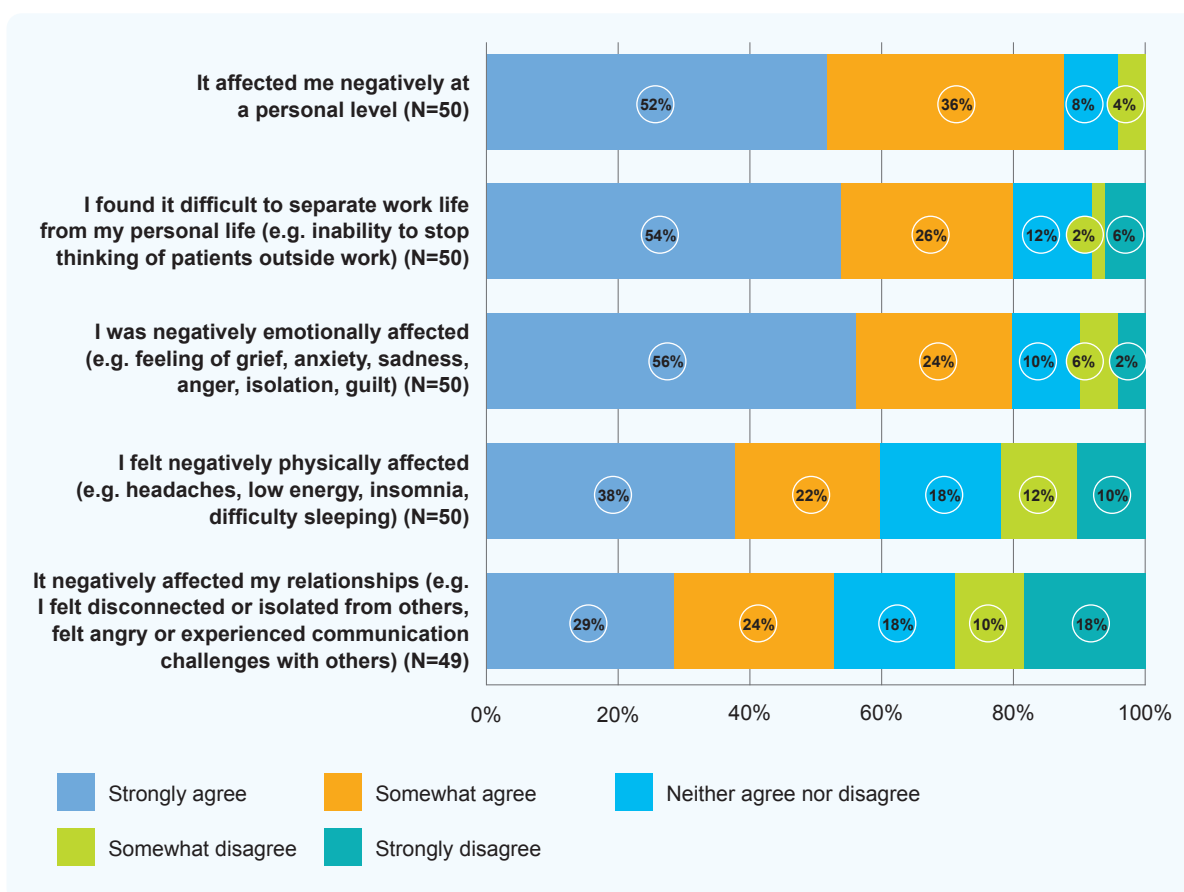
Impact on mental health and wellbeing of the 2018 events

The majority of participants in both survey and focus groups reported that the events in 2018 shocked them to a degree where their mental health, and to a lesser degree physical health, was impacted in a negative way. The sudden shift and abrupt disturbance in the daily work of professionals, reached far beyond professionals' work life and into their private sphere. This resulted in an unfamiliar insecurity among staff related to their professional identity and self-perception as colposcopy professionals. They described that they felt blamed and doubted, not only from their patients but also from colleagues outside colposcopy, as well as from relatives, friends, and people they would meet in everyday life. Participants recall that they felt ashamed to be associated with cervical screening. This experience is outlined below:

'People who knew we were working in colposcopy would start writing about us on social media. You wouldn't want to disclose where you were working, you would not go into a conversation with anyone. It was humiliating. We used to be so passionate about colposcopy but my beliefs were shaken by the whole thing.'

The most common emotions that occurred were sadness, hurt, anger, anxiety, isolation and guilt, as indicated by numbers in Figure 4. These themes were also widely expressed in the focus groups.

Figure 4: When answering the following question, please think about the degree to which the audit and disclosure events had an immediate personal impact on you (please check all that applies):



On a concrete level, the events of 2018 led to extreme work pressure for colposcopists. HSE management set up call centres for patients in case they were worried about their results, having followed the news in the media. Many of these calls were directed to the colposcopy clinics. Participants recall that they were not provided with additional resources to take these calls and thus had to deal with the large numbers of patients calling, in addition to normal clinical duties, as this participant recalled:

‘We became a call centre. Everyone that had ever attended the hospital were transferred to us and the solicitors started ringing. I never switched off, it was the last thing I thought off before going to bed and the first thing I thought of when I woke up. And the only support from management was a call in the evening asking how many patients we had seen or spoken to (...) When it all collapsed CervicalCheck became ghosts, they were just gone and we were left to ourselves.’

For the majority of participants, the traumatic experiences related to the events in 2018 were not dealt with at the time, due to time pressure. They reported that the local hospital management and CervicalCheck were not considered responsive and supportive during the events or in the aftermath. As one participant described, the pain and trauma has not yet healed and has only been superficially dealt with:

“It feels like putting a plaster over a wound that continues to fester underneath.”

It was the general perception that more repair and therapeutic support is needed to deal sufficiently with the past experiences.

Impact on relations between patients and professionals

Professionals explained that they are very passionate about their field of work and are proud of the quality of the cervical screening programme for women in Ireland. Some of the focus group participants have worked most of their career in colposcopy and have been happy and proud to see the cervical screening programme being implemented successfully. They expressed pride that the programme has helped to save the lives of many women in Ireland since its introduction. Staff also described that they generally felt a strong bond with their patients, based on the frequent visits during treatment. However, apart from a few participants who did not have any disclosure meetings taking place at their unit, there was a shared perception that, while professionals still believe strongly in the quality of the screening programme, how they relate to patients has changed. It was a frequently raised theme, particularly among doctors, that following the 2018 events, the bond between patients and professionals had been weakened, and communication with patients had become more cautious and distant. According to professionals, this is due to two different factors:

First, some professionals felt more insecure when dealing with their patients and reacted to the fact that they felt their role in the eyes of patients had changed due to their experiences of 2018. For some of the participants, they described still meeting patients who thought they were responsible for causing their cancer, and who questioned their professional integrity, as noted by one participant:

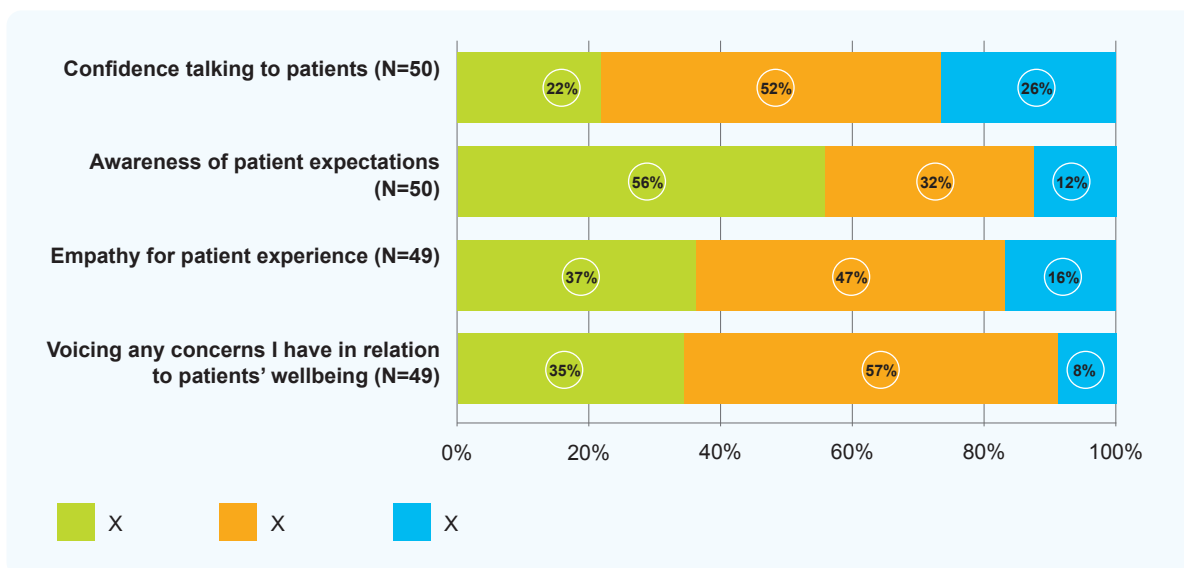
'From one moment to the next they (the patients) saw us as perpetrators. We went from being the ones that tried to cure them to the ones that had caused the cancer (...) Some patients believed that we had thrown their smear tests in the bin. We still meet that scepticism although it is five years ago now.'

Second, the fear of litigation is widespread and has increased significantly since 2018. This has a direct impact on communication with patients and the way professionals navigate their interactions. Many spoke about being constantly aware that anything they communicate to patients could be used in a future litigation and are therefore very cautious about communicating information. This cautiousness impacts their communication style, leading to reduced verbal communication and what is referred to as a somewhat robotic/mechanical approach, and reduced informal discussions/advice between colleagues:

'It Impacted my confidence dealing and talking with patients. I am almost afraid to explain too much now.'

Figure 5 shows data on professionals' confidence and empathy with patients. While 22% felt that their confidence talking to patients had improved, 26% say it had disimproved. Conversely, 37% reported improved empathy with patients while 16% reported disimproved empathy.

Figure 5: What best describes how the events of 2018 have impacted on your work in the following areas?



88% of survey participants and the majority of focus group participants answered that they were more concerned about potential litigation than they were prior to 2018 and reported that this impacts how they communicate with patients. 33% reported having lost motivation/interest in their job, while 31% said they were more motivated/interested in their job. There was no significant correlation between participants' feedback and professions, while a narrative analysis of data suggests that the outcome was associated with other factors such as individual experiences during the events of 2018, and the support received from immediate colleagues at the time.

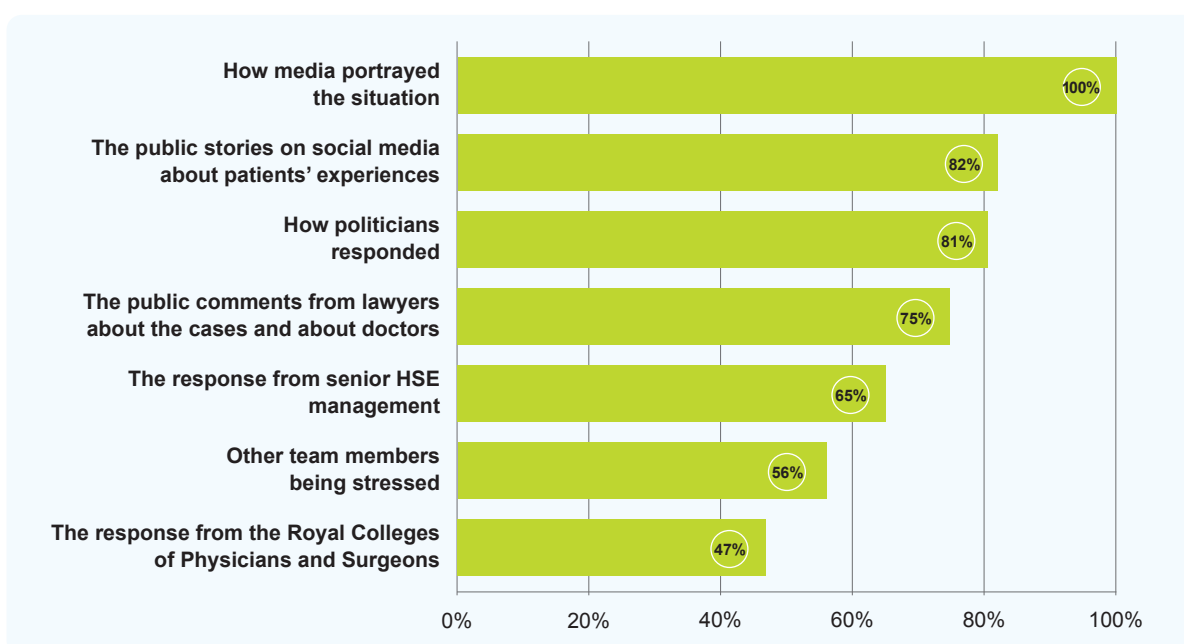
Impact on team morale and workplace atmosphere

92% of staff surveyed stated that team morale and atmosphere in the colposcopy workplace was negatively affected by the 2018 events. A narrative analysis of the interviews identified that the events led to exhaustion, stress, tension, confusion, isolation, anger and disillusionment among colposcopy staff, which severely damaged the workplace atmosphere. Many participants reported that they had close colleagues who decided to leave the service due to the events, which both resulted in extra workload and a general sadness among those who stayed. Overall, this review indicates that the events continue to have a negative impact on the atmosphere today.

It was the dominant perception that the media held a large responsibility for the negative impact on team morale and workplace atmosphere, as shown in Figure 6. Participants believed that popular media escalated the situation and exploited the distress of the women involved in their reporting. Professionals criticised the media for portraying the events in what they considered an unjust and irresponsible way, by suggesting that all interval cancers were associated with negligence. Participants felt that the media ignored their own responsibility to accurately communicate the nature of screening, including the limitations. They also reported that the media failed to communicate the fact that patient prognosis and treatment outcomes were not impacted by the non-disclosure of audit results, as the women involved in the audit had all been diagnosed with cancer before the audit took place. It was a shared belief that the way the media told the story had a detrimental impact on patients' engagement with the programme and on the credibility and ongoing implementation and success of the cervical screening programme. Participants also felt there was a negative impact on the reputation of professionals and a devaluation of their expertise and integrity. Indeed, when the story broke in the media, an initial reaction of sadness and worry among professionals was directly linked to how this would negatively impact the programme, going forward, as this quote describes:

'CervicalCheck was mentioned in the media and that is when it hit me, that all our good work will be wasted, our reputation will be damaged.'

Figure 6: Please order the following factors according to the negative impact they had on team morale and atmosphere in your workplace, starting with the most negative



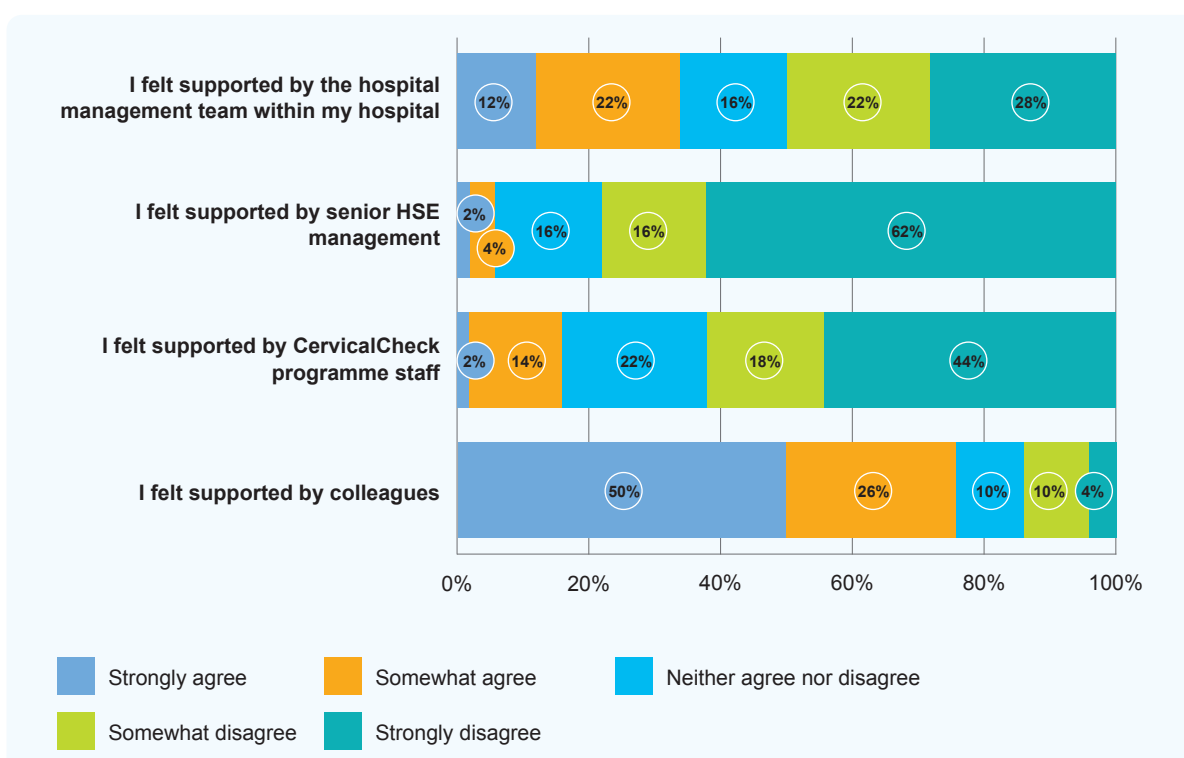
Another crucial factor that professionals reported causing significant distress at the time of the events was the way politicians responded. It was felt that politicians mainly repeated the media's approach and narrative and that they distanced themselves from any responsibility to accurately portray the benefits and limitations of screening. Instead, politicians took actions that directly positioned the colposcopy staff and the laboratories as primarily responsible for all interval cancers. Political responses included apologising on behalf of professionals and offering an additional free smear test to all women in the screening age range. Participants described the lack of awareness about the consequence of these actions and that the lack of downstream laboratory and colposcopy resources to cope with the number of women availing of the free extra test could have led to the collapse of the screening service. Participants explained that these actions undermined the trustworthiness of healthcare professionals further.

Support

There was consistent agreement across interviews and surveys that the level of formal support during and after the events was inadequate. 10% of survey participants reported not receiving and not needing any, 18% said that they did not receive any support although they needed it. The numbers and feedback from focus groups clearly indicated that most support was informal and received from colleagues (57%), family (53%) and friends (27%). It was highlighted frequently that staff's reliance on each other for support and comfort was crucial not only for own mental health but also for the screening programme to survive.

As shown in Figure 7, the perceived level of support from senior HSE management was particularly low, with 78% reporting that they did not feel supported. 62% of survey participants did not feel supported by CervicalCheck programme management and 50% did not feel supported by the management team within their hospitals.

Figure 7: Which best describes how you felt about the support you got after the audit and disclosure events?



The lack of support from local hospital management and the CervicalCheck programme was a key theme across focus groups and survey. Participants described the impact as being a feeling of being 'left alone' after the events of April 2018. This sentiment is summed up in the following quote:

'There was a lack of support on all levels, from Cervical Check to hospital management, no guidance on how we could communicate the results to the patients and deal with the fact that we felt sad for the patients: they were never just a name or an audit number but in the end you gave into autopilot.'

As the above quote describes, which is reflective of the narrative analysis of survey data and focus group discussions, the lack of structured support and guidance left professionals in a state of despair and powerlessness where they did not feel they were able to care sufficiently either for their patients or for themselves during and after these events. Most participants described that their inability to comfort patients was a strong stressor. This inability was caused by two factors: First, professionals did not feel prepared for the reactions from patients and did not feel able to support them. They reported not knowing where to refer patients to seek support. In addition, professionals were afraid that what they said during the meetings could implicate them in future legal proceedings. As illustrated in the following quote, professionals did not feel that the whole process was carried out in a responsible or considerate manner:

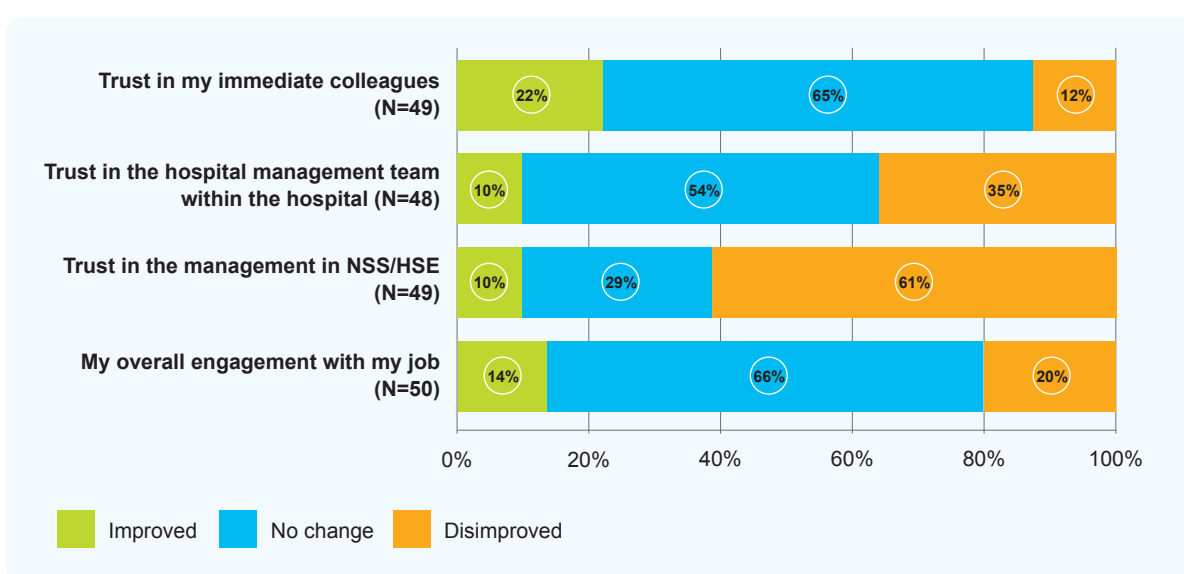
'There should have been a representative from the HSE present to support staff and patients. When asked by patients "what happens now?" all we could say was "we don't know". There was no information, no feedback, nowhere to tell patients to go and get help.'

When asked to reflect on what they lacked most during the events, participants consistently pointed to the absence of structured and frequent communication with local hospital management, CervicalCheck, and HSE as the biggest problem. What was needed, according to participants, was: briefings on the overall strategy; feedback meetings to discuss the situation and events as they developed; regular check-ins focusing on professionals' experiences, concerns, and mental health; and clear and direct guidance on what actions to take. Participants expressed disappointment and anger about the communication, and contact with management/authorities, which was perceived as inconsistent, erratic, and poor.

Impact on trust

The notion of trust and distrust was a recurrent topic in both survey and interview data. Thus, it was clear that one major consequence of the events in 2018 was that it led to a breakdown of trust. Participants defined trust in this context as encompassing accountability, honesty, transparency, clarity, and integrity. As seen in Figure 8 below, professionals' trust in the management in NSS/HSE disimproved for 61% of survey participants while trust in hospital management disimproved for 35%. From a positive perspective, trust in immediate colleagues improved for 23% of participants. This was also clearly reflected during the focus group discussion where a major theme was that the help, support, and comfort received was due to colleagues.

Figure 8: What best describes how the events of 2018 have impacted on your work in the following areas?



4.3 Unmet needs and suggestions for improvements

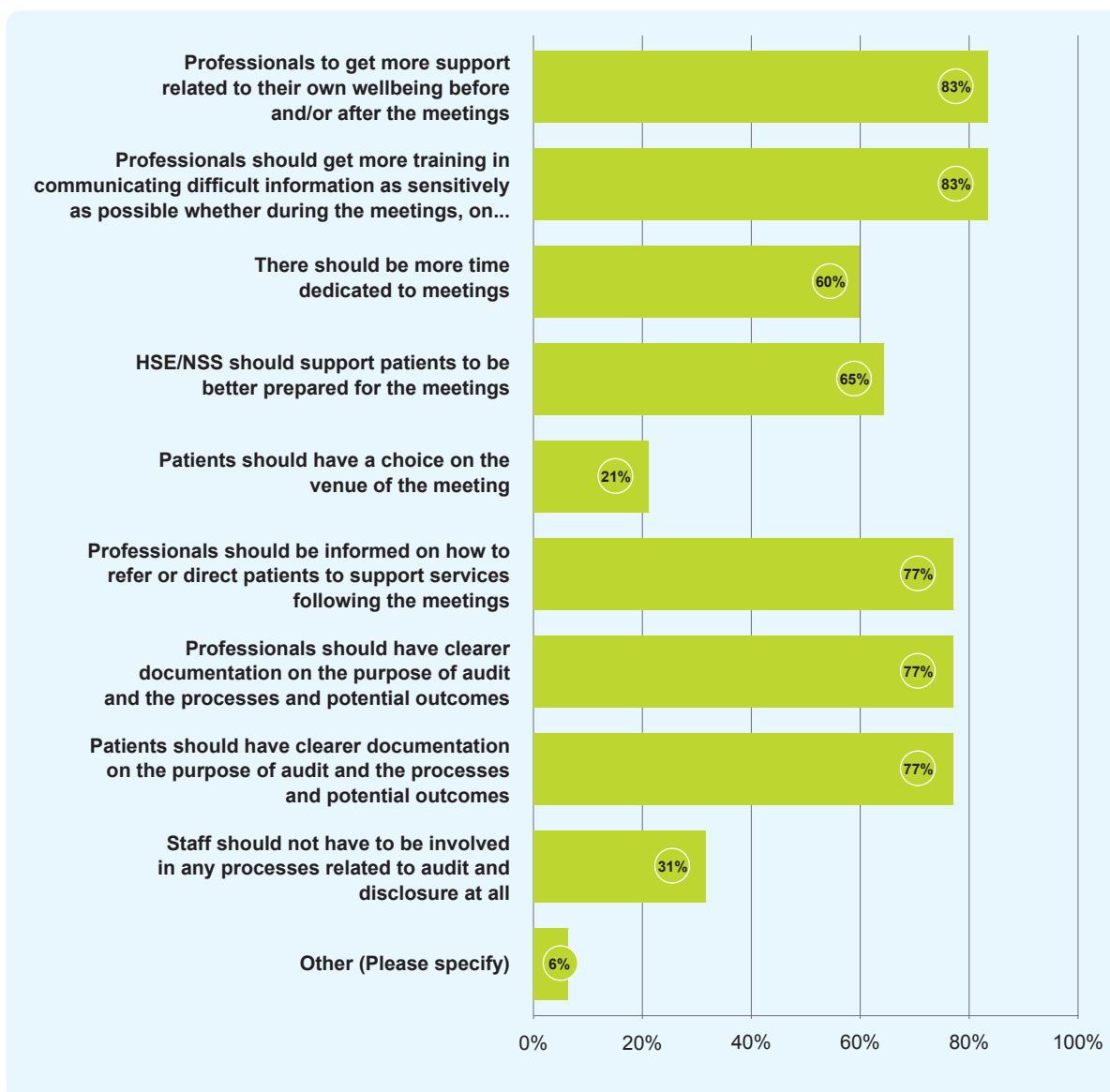
Overall, it was clear that trust, both on a personal, interpersonal and systemic level has not been restored to a degree that participants consider sufficient. Indeed, at the time of this research, colposcopy staff did not believe enough initiatives have been taken by hospital management, HSE or CervicalCheck to rebuild their trust. The way the events were portrayed broadly in society was considered unidimensional. Professionals did not feel that their experience had been explored, in terms of the impact of that experience on patients, or that the full details of what happened had ever been discussed. They wished to have their experiences of the past events communicated broadly, to their local hospital management, other colleagues, politicians and the public in general. However, the staff acknowledged that this research gave them an opportunity to share their experiences with each other and give feedback to CervicalCheck programme management, to ensure a better experience for patients in the future. They also expressed a desire to share the learnings from their experience more widely.

During the focus group discussions, and equally reflected in the survey data, it was a consistent belief that there was no robust crisis management strategy in place within the NSS/HSE, should a similar crisis occur in the future. This belief had some direct consequences for professionals. Firstly, they felt that their lived experiences had not been fully acknowledged by the HSE management, media and politicians, and the sense of being scapegoated had continued. Secondly, it perpetuated a notion of insecurity and worry in the participants' daily life as they did not feel assured that things would be dealt with differently in a potential similar future situation. There was a request for a forum for open and transparent discussion between colposcopists, local hospital management, CervicalCheck and the wider HSE management regarding the past events, and how learning from this could be used to improve care of patients and staff in the HSE services.

When reflecting specifically on the improvement of audit and disclosure processes, the table below shows that the most significant requests were related to preparation, support, and training for professionals and support for patients. In summary, 83% agreed that professionals should get more support before and after the disclosure meetings and preparation/training in communicating in the most sensitive way to patients. 77% agreed that there needs to be clearer documentation of the purpose of audit and potential outcomes provided to both at professionals and patients. Focusing specifically on the care of patients, 77% agreed that they need information on how to refer patients to support services after the disclosure meetings. 60% said that there should be more time dedicated to the meetings and 65% agreed that HSE/NSS should support patients to be better prepared for the meetings. This working group research was presented to the CervicalCheck Interval cancer reviews steering group and it contributed to the design of the CervicalCheck personal cervical screening reviews. These reviews were introduced in 2023 and are available to all patients who develop cervical cancer after having previously attended for screening or colposcopy within the programme.⁷

The narrative analysis of the qualitative data on how to improve audit and disclosure supported the findings of the survey (outlined in Figure 9). This pointed to the need for a range of conversations and policy responses, to ensure that staff feel heard and supported, and that faith and morale is restored within the workforce.

Figure 9: What measures should be implemented to ensure that future audit and disclosure is as good as it can be? (Please check all that applies)



Summary of research findings

Prior to the events related to cervical cancer audit and disclosure in 2018, cervical cancer audit was understood by staff to be a procedure conducted solely for quality assurance. They understood it to be designed on system improvement and were aware that it did not impact treatment outcomes for patients. Participants described that finding abnormalities on review (discordance) was expected to occur, as it is an inevitable part of screening. Because the sensitivity of cytology is approximately 75%, there will always be abnormalities that are not detected. Some of these will develop into cancer and may be visible in a future retrospective cytology review. Participants stressed that, due to these limitations, screening tests should never be understood, or promoted, as a diagnostic tool.

Participants recalled that letters with the results of audit started arriving in 2016 without clear directions on what to do with the results. As the audit results would not impact the patients' treatment outcome, professionals concluded that, from a medical perspective, it was not relevant or helpful to disclose these results to patients. Furthermore, some professionals were concerned that disclosing the results could cause patients unnecessary pain and upset. When the stories about cytology discordance on reviews hit the news in April 2018, this was a memorable point for the research participants. The following period was described as a time of immense stress and chaos. The dominant experience reported was that staff felt abandoned by their local hospital managers, CervicalCheck and HSE management when the news broke. They described a feeling of being left in the dark and they had to seek information through the mass media as there was no communication targeted at them as professionals from any of their managers.

Research participants described that without warning or preparation, they were asked to go through patient charts and disclose audit results to every patient as fast as possible. Staff did not feel prepared to do this and were not given any training or advice on how to communicate these results to the patients in a sensitive trauma informed way. The overall feedback was that the disclosure meetings felt rushed and not well planned. The litigious aspect of the cases soon became dominant and professionals experienced a pressure from solicitors calling and requesting documents.

Professionals recall meetings with patients where they were blamed for having caused the cancer. The disclosure meetings were described as a traumatising experience for both professionals and patients, which have had lasting consequences, especially in relation to the negative impact on trust in professional relationships. Thus, participants believed that the events have negatively impacted their relationship with patients. They reported that they have increased fear of litigation, and have become more cautious and distant in the way they communicate. For doctors particularly, the events have resulted in an altered relationship with patients, and they described frequently meeting patients that remain sceptical and seem to have reduced trust in the cervical screening programme. The negative impact on the reputation of the screening programme causes great regret among staff as they are proud of the high quality of the screening programme that has helped to save the lives of many women in Ireland since its introduction.

Participants reported that they mainly received informal support during and after the events in 2018. Although they received support from family and colleagues they reported that insufficient formal support was offered to them. Due to the perceived lack of formal support, professionals had reduced trust in hospital management, CervicalCheck and the wider HSE. They did not perceive that they have been able to voice their opinion, have their experiences acknowledged, and they did not believe that enough initiatives have been taken to establish a robust strategy should a future healthcare crisis occur. During the focus groups and interviews, most participants explicitly expressed appreciation of being given the opportunity to talk about their experiences and share their viewpoints in a safe space.

While participants described that there was a very high level of care and support exchanged between colleagues during and after the events, the workplace atmosphere and team morale was impacted negatively. They reported that the media reporting significantly contributed to their low morale and stress. Participants believed that the way the story was told was unidimensional and blaming, particularly placing the fault on colposcopy staff. They reported that they were upset at the lack of balanced reporting about the basic facts of screening and the fact that false negative results are unavoidable. There was also shared agreement that the way politicians responded further cemented the one-sided way of narrating the events, leaving out details that were crucial for the public to understand the complexity of what had happened.

Conclusion

Living through traumatic events or situations, especially those that continue over an extended period, can harm relationships. When a person feels overwhelmed, it can influence interactions with others because their sense of safety and security are perceived as being at risk.¹¹ Participants in this research reported that they experienced the events of 2018 as traumatic as they witnessed how upset, angry and anxious their patients seemed while feeling powerless to help them. The participants' distress was compounded by the experience of being ordered to share audit results without any training, guidance or understanding of how to do it in a way that would not further add to patient harm.

Going through the events of 2018 without a clear roadmap left participants feeling nervous and uncomfortable, and they started questioning their ability and their value to their patients. Through a trauma informed lens, it can be expected that staff, under such immense pressure from all sides (management, politicians, media, public and other staff), go into survival mode because of a natural physiological response to either fight, flight, or freeze.¹² Most people impacted by the audit and disclosure process in 2018 will have experienced a threat to their sense of safety in the world, although how this shows up in their behaviours and interactions may differ. To move out of survival mode towards safety and connection, drawing on principles from Restorative Practise, requires a process of repair to help ensure that people can return to their sense of feeling valued and trusted.¹³ This research process offered staff an opportunity to voice their experience of 2018 as part of a repair process that moves beyond blaming and promotes reconnection. Moreover, the intention was to learn from their experience to develop practices that support future communication of patient care reviews, in order to ensure the minimum amount of harm to patients and staff. Through the learnings in this report it was hoped that future crises in healthcare could be avoided or mitigated through better communication of information with staff, patients and stakeholders.

References

1. Royal College of Obstetricians and Gynaecologists (RCOG) (2019). Cervical screening in cases of cervical cancer in Ireland between 2008 - 2018: RCOG Independent Expert Panel Review. Available from: www.gov.ie/en/publication/a4e567-expert-panel-review-of-cervical-screening/
2. The National Screening Service (2020). Expert Reference Group Interval Cancer Report CervicalCheck. Available from: <https://assets.hse.ie/media/documents/interval-cancer-report-cervicalcheck.pdf>
3. Scally, G. (2018). Scoping Inquiry into the CervicalCheck Screening Programme. Final report. Available from: <https://www.gov.ie/en/publication/aa6159-dr-gabriel-scallys-scoping-inquiry-into-cervicalcheck/>
4. The National Screening Service (2023). Implementation of Dr Scally Reports: A Review by the National Screening. Available from: https://assets.hse.ie/media/documents/Implementation_of_Dr_Scally_Reports_-_A_Review_by_the_National_Screening_Service.pdf
5. Quality Matters (2022). Consultation with 221+ Members Research Report. Available from: https://221plus.ie/app/uploads/2023/03/QM_221-Report.pdf
6. Carroll & Reisel (2018). Introducing restorative practice in healthcare settings, first edition... Available from: <https://www.taylorfrancis.com/chapters/edit/10.4324/9781315613512-16/introducing-restorative-practice-healthcare-settings-janine-carroll-dan-reisel>
7. The National Screening Service (2023) CervicalCheck now providing personal cervical screening reviews. Available from: <https://www2.healthservice.hse.ie/organisation/nss/news/cervicalcheck-now-providing-personal-cervical-screening-reviews-04-april-2023>
8. Neubauer BE, Witkop CT, Varpio L (2019). How phenomenology can help us learn from the experiences of others. *Perspect Med Educ*;8(2):90–7.
9. Noda M & Oyama Y (2021). How Can We Understand and Describe “Non-Narrative” Narratives? A Qualitative Study of Workers with Recurring Sick Leave. *Jpn Psychol Res* 63(4):297–309.
10. HSE (2024). Ethical Approval for Research in the HSE & its funded organisations. Available from: <https://hseresearch.ie/research-ethics/#Projects-that-require-approval-by-a-HSE>
11. Center for Substance Abuse Treatment (2014). Trauma-Informed Care in Behavioral Health Services. (Treatment Improvement Protocol (TIP) Series, No. 57.) Chapter 3, Understanding the Impact of Trauma. Available from: <https://library.samhsa.gov/product/tip-57-trauma-informed-care-behavioral-health-services/sma14-4816>
12. McEwen B (2007). Physiology and neurobiology of stress and adaptation: central role of the brain. *Physiol Rev* ;87(3):873-904. doi: 10.1152/physrev.00041.2006
13. Gavrielides, T. (Ed.). (2018). *Routledge International Handbook of Restorative Justice* (1st ed.). Routledge. <https://doi.org/10.4324/9781315613512>



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