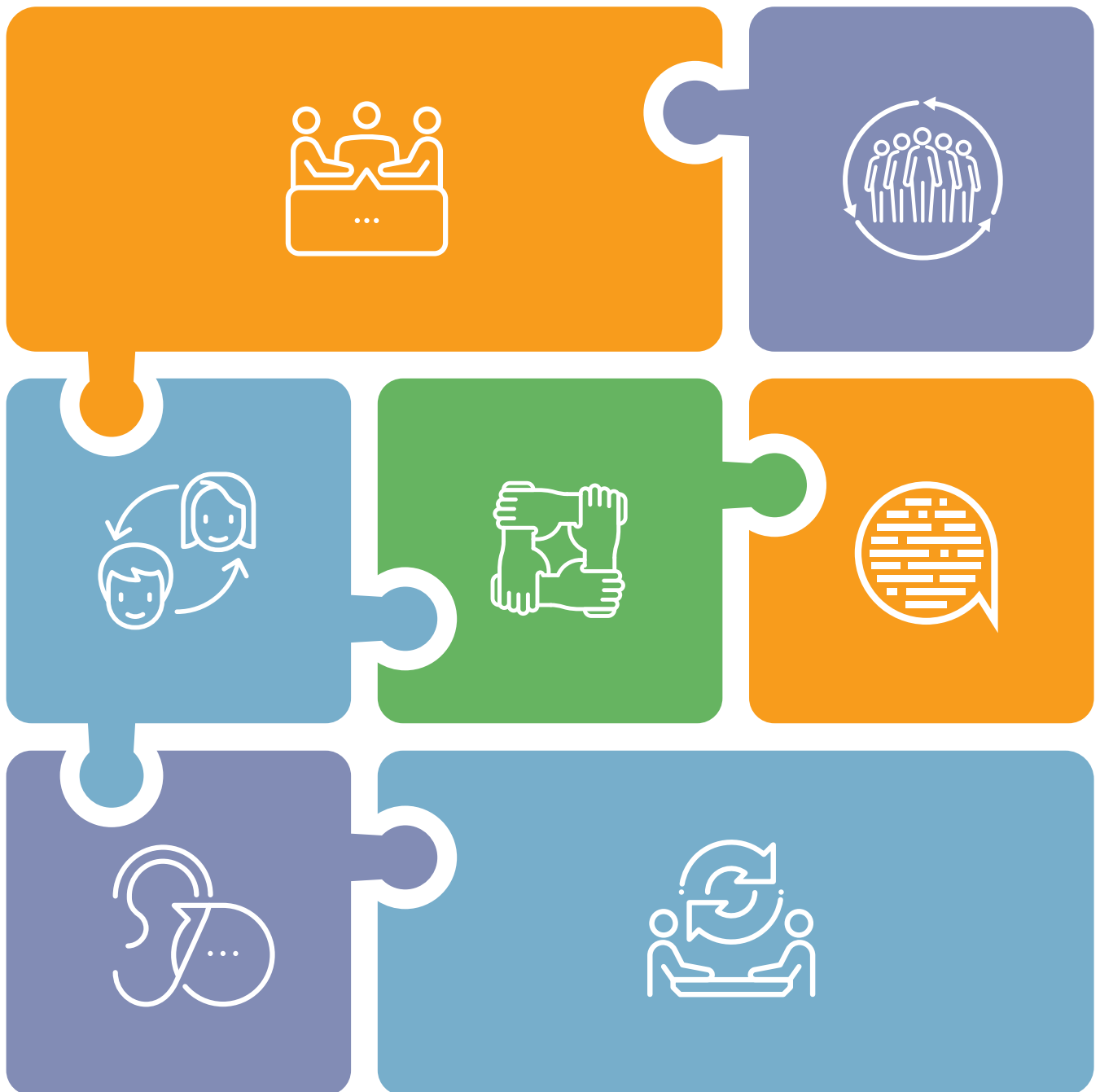




An tSeirbhís Náisiúnta Scaghtástála
National Screening Service

National Screening Service

Patient and Public Partnership Strategy 2019-2023 Progress Report



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Glossary

ERG	Expert Reference Group
FIT	Faecal Immunochemical Test
HCP	Health Care Professionals
HPV	Human Papilloma Virus
HIQA	Health Information and Quality Authority
IC	Interval Cancer
NSS	National Screening Service
NSAC	National Screening Advisory Committee
PPP	Patient and Public Partnership
PPP reps	Patient and public representative(s)
PREMS	Patient Reported Experience Measures Survey
TNA	Training Needs Analysis/Assessment

Foreword

Patient Panel Representatives

As Patient and Public Partnership representatives (PPP reps) at the National Screening Service (NSS) we are committed to working as volunteers together with NSS staff to achieve our mutual goal of delivering a quality screening service.

Guidance, policy and programme delivery can be complex, unclear and driven by a mix of scientific and governing factors that do not necessarily align with what really matters to people using services. So we are delighted that the Patient and Public Partnership (PPP) now exists and brings real people, and what matters to them, into the heart of the screening services. We acknowledge that change cannot happen overnight, and that commitment and respect are qualities needed to work together with an open mind to deliver a world class screening service.

It is apparent to us PPP reps that when NSS involves and listens to those who need, use and care about the services available to them, through the new partnership we are experiencing, NSS staff better understand population health needs and respond to what matters most to people.

Although PPP is in its infancy, it is fantastic that we are already working in partnership with NSS staff to develop a clear and shared view of how to identify effective and efficient ways of designing and delivering quality screening services.

We are proud to be patient representatives. We take our responsibility seriously which includes representing all service users across the four screening programmes. In our experience as patient representatives, we can see that the NSS is creating a model of PPP that could be copied and used in other national health services; to make a difference in decision-making around service planning, operation and proposals for changes to healthcare.

Working together, we can make a difference and that difference can include you.

Breda, Mary and Moira, patient representatives



Director of Public Health, NSS

Just over two years ago, I was honoured to be a part of developing the first PPP strategy. Now I am proud to see the changes PPP has brought to NSS. I am very grateful to the PPP representatives for the time and expertise they have brought to the first half of this implementation project, and to the staff champions in the national screening programmes who have worked in partnership whilst supporting other staff to put the patient at the centre of all we do.

We set out to ensure that services meet your needs and are truly person-centred. To do this we needed to understand what it feels like to use our services and what gets in the way. Of particular importance to us was to ensure that information is provided in a way that is accessible to you and helps you make the right screening decisions for you.

Together we have made great progress in achieving the aims set out in the strategy. We have looked at two main ways to make sure that the patient voice is having an impact. The first is to make sure that patients are involved in priority projects. The second is to make sure that any project we do is informed by our goal of person-centred care. There have been NSS-wide projects established to improve how we involve PPP reps, assess your experience of using services, and improve how information is created and shared. This report shows the breadth of what has been done across the whole of the NSS.

“The people who experience screening bring to us a different and highly valued perspective – the reality of what it is really like. Working in partnership with representatives allows us to test ideas and co-create solutions with the people who matter”

Fiona, Chief Executive, NSS

Demonstrating our commitment to patient partnership, ‘involvement’, along with ‘trust’ and ‘governance’, are the three NSS priority pillars. Indeed, we are clear that trust is hard to achieve without public involvement, and that the work completed to date has brought value not only to NSS, but crucially, to the people who use our services.

Thanks again to all of those who have inputted to this report. I look forward to continuing to implement the PPP strategy, strengthening our processes, and continuing to improve NSS services for the people who use them.

Caroline, Director of Public Health

Executive summary

The first National Screening Service *Patient and Public Partnership Strategy 2019-2023* was published in November 2019. The PPP strategy set out the plan to strengthen patient and public partnership and to ensure services meet the needs of users and are delivered through the HSE values: care, compassion, trust and learning.

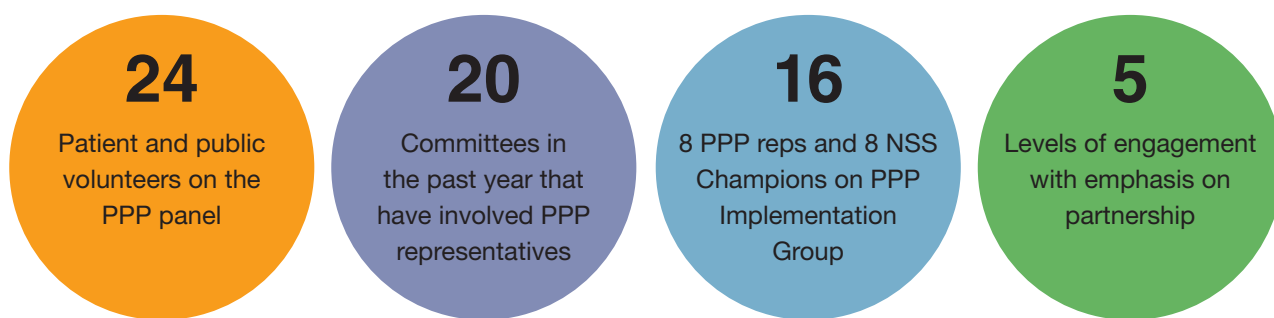


Figure 1: Patient and Public Partnership highlights

Working in partnership with patients is a critical part of achieving person-centred care. They bring a wider perspective that positively influences service design, delivery and evaluation. By providing their input, patient representatives directly help services to be better at addressing patient needs and care. This mutual partnership helps build trust between the patient and the healthcare services and leads to improved experiences and health outcomes.

At the mid-way point of the strategy implementation, this report highlights what has been achieved and aims to identify the priorities for the remainder of the strategy. Overall, we have found that the systematic change towards a 'person-centred' culture is demonstrated in the numerous projects across all of the NSS programmes that have engaged in the PPP process.

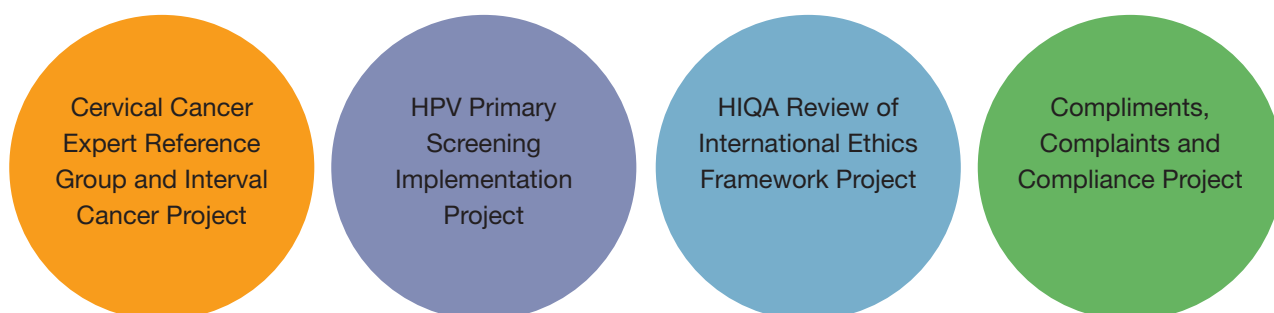


Figure 2: Patient and Public spotlight case studies

Introduction

This report summarises the activities progressed since the PPP strategy was launched in 2019. The strategy is being embedded across the four NSS population screening programmes: CervicalCheck, BreastCheck, BowelScreen and Diabetic RetinaScreen; and the NSS’s corporate and supporting functions. The report demonstrates the progress made in implementing the PPP strategy, and the attainment of the strategic aims through meaningful collaboration and partnership.

It also touches on the challenges experienced with the implementation of the strategy. It is important that we reflect so that we can continue to learn and improve to ensure we are working in true partnership with patients and the public, to improve NSS services.



Figure 3: PPP vision and mission

Achieving the PPP strategic priorities

This progress report demonstrates the commitment to PPP from the volunteers and staff in the NSS. The report reviews progress made on the three strategic areas of work (see Figure 5), highlighting key actions underpinning the delivery of these priority areas. A lot has been achieved over the past two years and we look forward to continuing the work to fully implement the actions set out in the strategy.

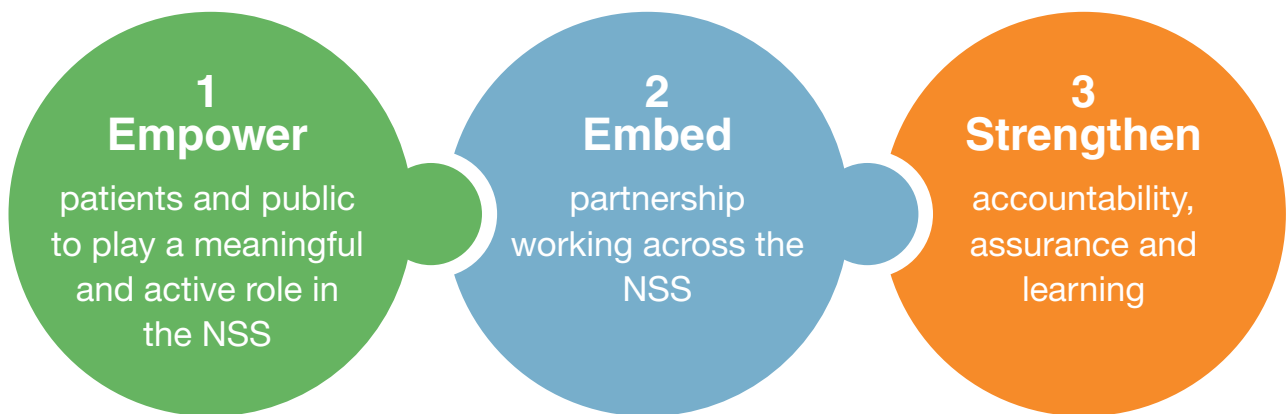


Figure 4: PPP strategic action areas



Figure 5: Summary of Patient and Public Partnership strategy actions

Summary of Patient and Public Partnership representatives, feedback

The following comments have been made by PPP representatives who have worked on a variety of NSS projects.

“The quality of the people involved was great – a very dedicated team of staff, all trying their best to get everything done and to improve the screening services.”

Tom, PPP representative

“The ERG and Interval Cancer Project has shown positive partnership in meetings...that share decision-making power with patients and the public to inform design and policy, a welcome and essential shift from what was happening before the introduction of PPP.”

Moira, PPP representative

“At one session – we felt that decisions had already been made without consulting the PPP reps. As a result of this, there was discontent amongst the PPP reps. We fed this back to the chairperson and it was addressed appropriately.”

Brigid, PPP representative

“It is useful to have PPP reps on projects, but it is important that it is not tokenistic.”

Breda,
PPP representative

“When I agreed to be a patient rep I was very concerned that I was simply there to tick a box. It has been a pleasure to discover that this hasn't been the case, and in fact patient involvement is now being viewed by many in the service as vital.”

Grace, PPP representative

“Another PPP rep and I gave feedback on a letter. They took our advice on board and reviewed the letter. We felt what we were saying was appreciated and listened to.”

Brigid, PPP representative

“I was really happy to contribute to the HIQA project. The process was unique and provided me with an opportunity to represent those whose voices are not heard, yet they are so relevant. It allowed me to be open and understand the process, embrace it, be part of it, and freely contribute to it. I felt seen and heard.”

Lora Ruth,
PPP representative

“I feel that there is a great willingness on the part of all members to be inclusive and I would like to think with time we can support the engagement of members of the Syrian community to play an active part on the committee also.”

Linda, PPP representative

“If Covid has taught us anything it’s that trust is so important. When patients and the public see themselves represented prominently on areas of development and decision-making, it strengthens that vital trust.”

Grace, PPP representative

“It was difficult getting used to the language. There were lots of abbreviations that I didn’t understand. The ERG report had an abbreviations section that I found very helpful but new PPP reps could be intimidated by the language.”

Tom, PPP representative

“PPP on these important projects is more than a tokenistic gesture; it provides a real and substantial benefit to all stakeholders. I have experienced trust between the NSS staff, medical professionals, and the PPP rep involvement.”

Moira, PPP representative

“If you have the time and the interest, then just go for it. Listening to everything going on helped give me confidence and I personally gained from being a PPP representative.”

Breda, PPP representative

PPP Implementation Group

To oversee implementation of the PPP Strategy, the PPP Implementation Group was established in March 2021, following a pause during Covid-19. The group is responsible for co-designing solutions and approaches to implementation and evaluation across the three strategic priority areas, with particular focus on how PPP should be structured in the NSS.



Figure 7: PPP Implementation Group photo taken on 6th May 2021

The PPP Implementation Group contains a combination of patient and public representatives, and NSS staff. The PPP Implementation Group governance structure is described in Figure 8.

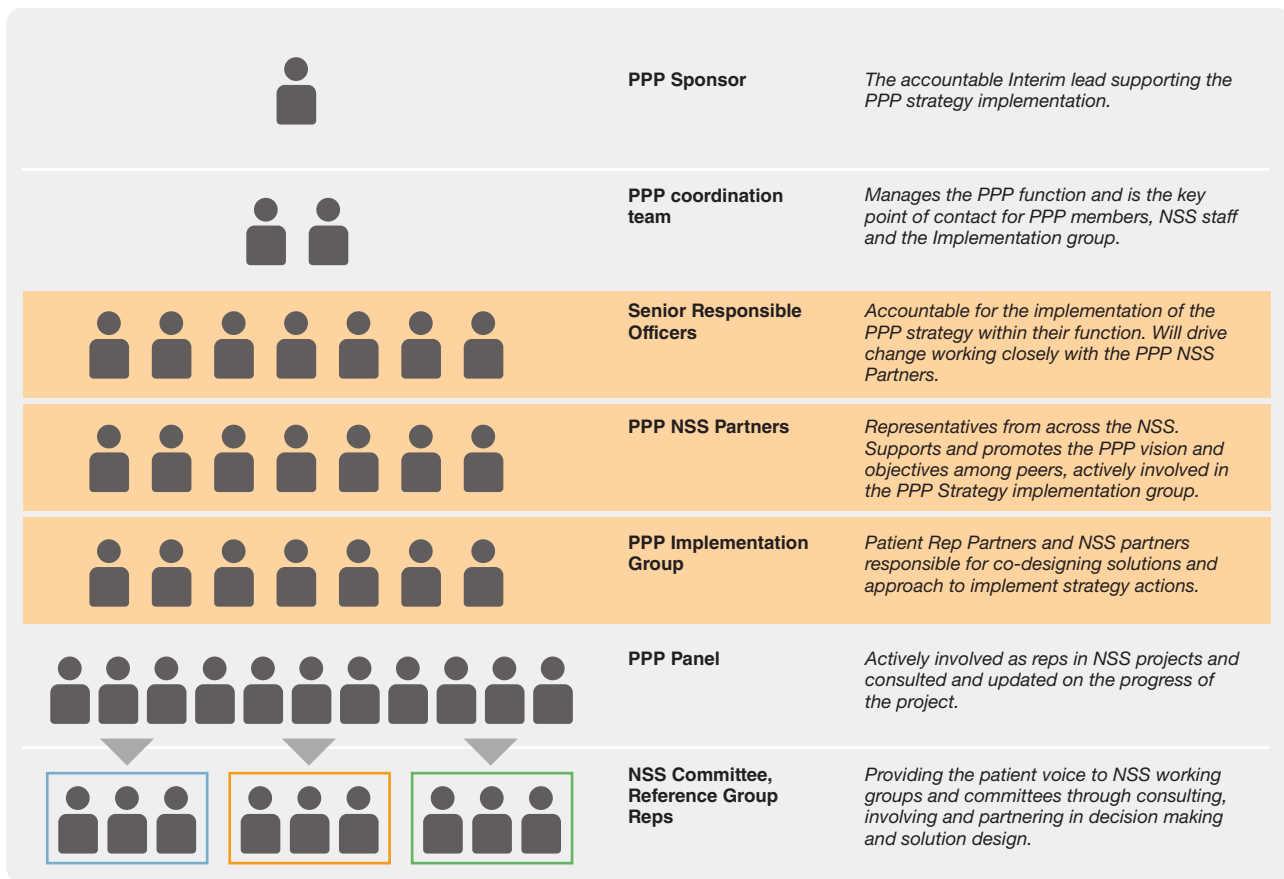


Figure 8: PPP governance and structure within the NSS

In 2021, a series of meetings and four PPP Implementation workshops were facilitated virtually via the Zoom platform to jointly oversee implementation of the strategy, and co-design numerous components of the PPP action plan. This work included consultations to jointly develop and agree permanent ways of working. These included structures, communication strategies, roles and responsibilities; and outlining exactly how the PPP functions, and what supporting tools and processes are needed to successfully embed PPP across the NSS (see Appendix 2).

The role of an NSS Partner (formerly NSS Champion)

An NSS Partner is a trusted member of the NSS team that advocates for and promotes PPP within the NSS. The NSS Partner shares the PPP vision within their team as they embrace the cultural and organisational change.

“It has been very reassuring to see how our PPP reps have settled in so quickly. They have contributed greatly to the development of roles, responsibilities and communication strategies of the PPP...it has proven very beneficial to hear what worked well previously and what we should consider doing differently going forward”

Brenda, Head of Client Services, NSS

A PPP representative's perspective

Breda, PPP representative on PPP Implementation Group

“My role as a PPP rep is to observe, contribute and help guide the process as we continue to improve our screening service.

To date this has mainly been a positive experience. Meetings between patient representative and NSS staff have been constructive, energetic and respectful of all our views.

It has been acknowledged that not everything goes to plan and that processes can, at times, be slow. However, together we make strides when we listen, respect and learn from each other's points of view. We are making progress with our plans to recruit more representatives from the public, and to make the service more accessible and user-friendly for all service users.

We are a work in progress; we are still developing. We respect and seek out opinions and suggestions that may help us deliver an improved and all-inclusive gold standard service that will serve the population for many years to come. My time here has been educational, challenging and rewarding.”

Next Steps for the PPP Implementation Group

During the first two quarters of 2022, the PPP Implementation Group will focus on co-developing and finalising the PPP Operating Model (or Ways of Working). Once the new PPP permanent structures have been established, new PPP representatives will be recruited and will receive complete induction and training programmes that have been co-designed with current PPP Implementation Group representatives. The new co-designed ways of working will likely involve two tiers of involvement: a PPP Panel and a PPP Network. This will offer a variety of ways to be involved in ongoing NSS business or short-term projects. The existing implementation group (which was time-limited) will come to an end, and the new permanent PPP Panel and PPP Network will continue on with delivering PPP within NSS.

“Co-designing the PPP ways of working is an opportunity to achieve true partnership. The fact it will result in a long-term approach bringing patients closer to NSS decision-making, and will influence across all corporate goals and priorities is an exciting prospect for the future of NSS services. The next phase will focus on broadening diversity of representation so that we can bring many different voices to the table and incorporate their views to the work of the NSS.”

Estelle, PPP Project Lead, NSS

NSS Committees

Since the launch of the strategy in 2019, PPP has been adopted by numerous priority and high profile projects, and is becoming embedded in NSS routine ways of working. PPP representatives provide the patient voice to these NSS projects, working groups and committees through different levels of involvement (see Appendix 1) including consulting, involving and partnering in decision-making and solution design.

Spotlight Case Study

Primary HPV Screening Implementation Project

In 2017, a HIQA health technology assessment recommended HPV screening as the primary method for the prevention of cervical cancer in Ireland. Planning for transition from cytology screening to HPV primary screening commenced within the NSS and the HPV Primary Screening Project began in 2018.

A steering group was assembled to oversee, direct and monitor the project and its numerous different workstreams and to ensure it was completed in a timely manner while maintaining the highest standards of quality and care.

“It was my first project as a PPP rep – I mainly observed for the first few meetings, but I became more confident as time went on”

Breda, PPP representative, HPV Screening Project

Two PPP representatives were members of the project Steering Group.

“The PPP reps asked the difficult questions that needed to be asked. They asked through their language and they were representing the voices of the people of Ireland.”

Gráinne, Project Lead, Primary HPV Screening Implementation Project

The diversity of the Steering Group and the inclusion of PPP representatives ensured strong governance and strong collaboration. The PPP representatives presence on the Steering Group helped ensure that the voice of the people of Ireland was heard.

Following on from the success of PPP involvement in the Primary HPV Screening Implementation group, CervicalCheck recently recruited two PPP reps to sit on the CervicalCheck Quality Assurance committee. The PPP reps joined the committee in January and February 2022.

Key messages from PPP representatives

The importance of making PPP reps feel comfortable and using simple language that is easy for everyone to understand – avoiding medical jargon.

“the meetings could be daunting initially, but do your homework before the meeting and as time goes on you gain confidence. They were all very welcoming and there was no awkwardness or intimidation”

PPP representative, Primary HPV Screening Implementation Project

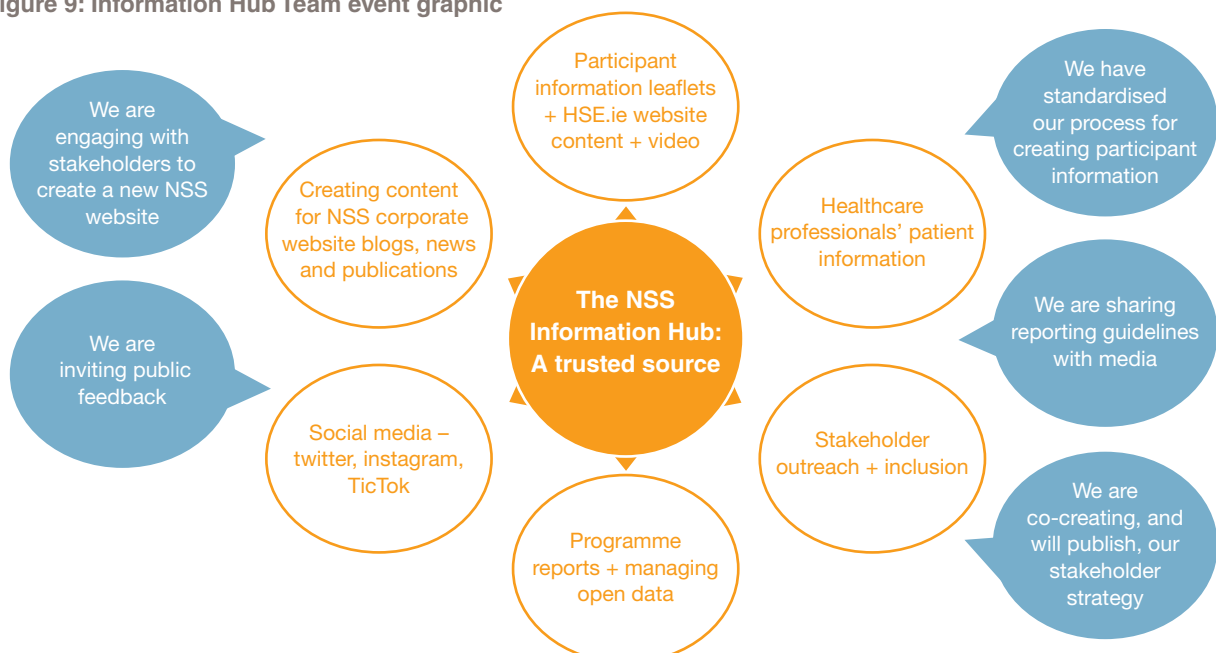
“there were issues with the usual medical jargon and ‘HSE Talk’, they were using a lot of abbreviations without giving a thought”

PPP representative, Primary HPV Screening Implementation Project.

The NSS Information Hub

The NSS is piloting a new function called the Information Hub which is a collaboration between the Communications and Public Health departments. The Information Hub aims to transform the way the NSS and the screening programmes communicate with the public, service users and healthcare professionals. The Information Hub will apply standardised and evidence-based approaches to the review, development and communication of screening information, and will play a key role in improving openness and transparency both within NSS and beyond. Included in the pilot is the application of a new standardised and evidence-based process for the review of information materials including letters and leaflets, as well as the development of a number of blogs to support NSS programmes and activities. The Information Hub will help ensure that content is accessible and understandable to all audiences and will enable people to make informed decisions about engaging in screening services. The Information Hub supports key actions within the PPP strategy by providing tailored information that meets users needs, promoting openness and transparency and having patients at the heart of the development process.

Figure 9: Information Hub Team event graphic



Training needs assessment for PPP representative and NSS staff

In order to work in equal partnership with patients and the public, a crucial component is to provide training and development opportunities to support people to play active roles. We recognise that PPP representatives are experts by experience. We must ensure that they have the necessary skills, confidence and knowledge of the relevant policies and systems to be able to play active roles. In 2021, a training needs assessment (TNA) was conducted using focus groups and an online survey. The TNA report and the recommendations following on from the focus groups and survey will guide the content of the inductions and introductory training planned in 2022. The information gathered from the TNA will help us tailor training to specifically meet the needs of the PPP panel members and NSS staff.

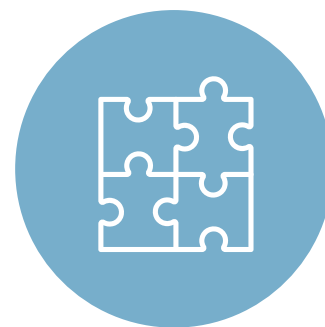
“By conducting the focus groups and survey, participants were able to articulate their views and provide suggestions to inform the Training Needs Analysis process. As per the PPP strategy, we are working in equal partnership with patients and the public and recognising they are experts by experience. We want to ensure that they have the necessary skills, confidence and knowledge to be able to play active roles and having co-designed training will support this”

Kathryn, Senior Health Promotion Officer, NSS



Strategic Area 2:

Embed partnership working across the NSS



‘Create a culture of person-centeredness and partnership working at every level of the organisation.’

Person-centred culture

The vision for the PPP is “to improve health outcomes through inclusive, high-quality, person-centred screening services where the voices of participants are included in decision-making”. To achieve a meaningful patient and public partnership, we require a shift in the traditional culture of care, to the creation of partnership.



Figure 10: Graphic from a PPP Implementation Group workshop

The efforts and inclusion of PPP across numerous NSS projects since the commencement of the PPP strategy, demonstrates the NSS commitment to embedding PPP into the culture and ethos of the organisation. The PPP Implementation Group is currently identifying actions that can be taken to ensure effective governance for PPP moving forward, and how best to instil a positive culture within the NSS that embeds PPP as a normal way of working.

“Our programme participants are the reason NSS exists. They are not external to our business, they are our business. We must put the service-user at the centre of everything we do to ensure we can provide the best quality services that meet their needs.”

Fiona, Chief Executive, NSS

Summary of NSS staff feedback regarding PPP involvement in NSS

The following comments have been made by NSS staff who have embraced PPP involvement on a variety of NSS projects.

“As an NSS Partner, we need to ensure that the PPP reps have the supporting tools and training to assist them in having meaningful engagement at meetings.”

Brenda, Head of Client Services, NSS

“It’s important for PPP reps to meet the team as it shows that we are not a faceless organisation, and that we are a team of focused staff coming in to work everyday to try our best to improve the services.”

Gráinne, Project Lead, HPV Primary Screening Project

“At every committee meeting we tried to keep the PPP reps involved. Making sure they had an opportunity to contribute and get a chance to speak.”

Nóirín, Chair, Interval Cancer Implementation Project

“It is vital the PPP reps have a trusted link person with whom they can share their concerns, issues and ideas of better ways of working. This creates a safe and trusted way of working, and it has proved to be successful in the IC Project.”

Antoinette, Senior Project Manager, NSS

“Because of the complexity of screening – PPP reps need proper inductions. If someone is willing to give 2.5 hours of their time per month supporting a project, then it’s important that they have good insight into the project and their roles and expectations as a PPP rep.”

Gráinne, Project Lead, HPV Primary Screening Project

“PPP involvement is essential. We need the patient voice present in everything we do. Their presence on our committees adds depth and invaluable perspective.”

Nóirín, Chair, Interval Cancer Implementation Project

“The time and energy that they [PPP reps] devote to this project is unpaid, voluntary and comes from a place of doing good for others. PPP reps need to have focused actions, so that their time, which is a precious commodity, is made the most of.”

Antoinette Senior Project Manager, ERG Project

“What was lovely was that everyone was really focused on the common goal of providing a better service for the people of Ireland. There were no egos around the table.”

Gráinne, Project Lead, HPV Primary Screening Project

“I look forward to continuing moving towards our defined next steps which includes recruiting more patient representatives who will receive a complete induction and training programme.”

Brenda, Head of Client Services, NSS

NSS Communications Strategy

The NSS communications strategy is focused on building and maintaining trust. A joint Communications and Public Health Information Hub (as discussed on page 16) is embedding the drivers of trust – intent, respect, inclusion, integrity, competence, openness and fairness – in our communications work. The trust mantra, ‘nothing about us without us’, places the people we care for in screening at the heart of our communications processes. The PPP reps bring the voice of the public and our participants to our comms work. Trust is built, firstly, through being trustworthy. By bringing the PPP reps into our decision-making processes, we are providing others with good evidence of our trustworthiness. We believe that involving citizens is key to building trusted environments.

Communicating in screening is about informing and educating. However, before we can do this we have to listen, and gain knowledge and understanding from the people who have the experience of the screening process. In our work with the PPP reps we have aimed to collaborate as equals, reflecting on their unique and valuable perspectives, and embedding their feedback with consideration and care.

NSS corporate website development

“NSS communications is developing a new corporate website for NSS. It will be a source of evidence-based information about population screening in Ireland. A PPP representative was recruited to support the website development. Our PPP rep was key to the research phase of the website content development. In a one-to-one interview she advised on content which our research company termed ‘gold-dust’. With this PPP input the website is evolving as a channel through which the public can engage with and provide feedback on our work. This feedback will be evaluated and inform our future work.”

Fiona, Communications Manager, NSS

Spotlight Case Study: Cervical Expert Reference Steering Group and Interval Cancer Implementation Project

In October 2020, the HSE welcomed the publication of the Expert Reference Groups (ERG) Interval Cancer (IC) Reports and their recommendations for the future management of interval cancers across all three cancer screening programmes. An interval cancer is a primary cancer diagnosed after a negative screening test, but before the next screening test is due, or within a period equal to a screening interval for a person who has reached the upper age limit for that screening programme. The Interval Cancer project involves programme-specific implementation groups, a communications and a legal framework group.

As was the case in the ERG project, this project has embraced the patient and public representative voice from the outset, in the knowledge that the PPP reps provide invaluable perspective throughout the complex implementation of all ERG recommendations.

“it is hugely important to understand the training and the role of PPP – we are there for a national perspective, not a personal perspective”

Brigid PPP representative

The CervicalCheck Implementation Group has two PPP representatives, so that the needs of cervical screening programme participants are considered. The group is also engaging directly with those who have been impacted by an interval cancer. An interval cancer patient and public representative advisory forum has been formed. This is an open discussion forum to gather valuable feedback on particular elements of the Interval Cancer project.

Several PPP representatives have moved from the ERG project into the IC Project on their own request. This has proven to be a smooth transition for them despite being involved in a highly complex and challenging project. The fact that they wished to continue to be involved confirms their value to, and the importance they place on, the project.

The culture in the NSS to embrace PPP has evolved positively over the past few years. The chairs of the implementation groups on these project are committed to ensure the power share of the project members is equal. This ensures that the patient and public's perspectives are heard and considered. This important work is helping to re-build trust and confidence in the screening programmes while supporting transparency.

Key messages from PPP representatives

Having an effective chairperson is essential to the success of meaningful PPP involvement

“Susan (Chairperson) was great- she was a really good chair, was open, and listened. I found it helpful to take some conversations offline – it was easier to get to know each other and gave her an opportunity to run things by us – especially sensitive matters.”

PPP representative on Cervical ERG and Interval Cancer Group

“Nóirín (Chairperson) was great – she would always say ‘I want to hear from the PPP reps, what do you think about that’ – She really listened to us and took our opinions on board. No one ever cut me off and I was always given the opportunity to speak.”

PPP Representative on Cervical ERG and Interval Cancer Group

“Professor Mac Mathuna (Chairperson) was very good. He always tried to include me in things, always asked if I had any questions or anything to include in discussions. I felt like my voice was heard.”

PPP representative on Bowel Screen ERG and Interval Cancer Project

The power share and dynamic at meetings can be a challenge

“Initially at meetings, some healthcare professional can be cautious around us (PPP reps) and can hold back slightly, however, with a good Chairperson that dynamic is quickly eliminated.”

PPP representative on Cervical ERG and Interval Cancer Group

“At one session, we felt that decisions had already been made without consulting us (PPP reps). As a result of this, there was discontent amongst the PPP reps. We fed this back to the Chairperson and it was addressed appropriately.”

PPP representative on Cervical ERG and Interval Cancer Group

A PPP Representatives Perspective

Moira, PPP Representative on Cervical ERG and Interval Cancer Implementation Group

“These are two priority projects which have successfully embraced essential public and patient involvement. Having a model of ‘person-centred’ healthcare, set up with the purpose of increasing understanding of service-user needs, is essential to creating more responsive policies and greater health equity.

The project has shown positive partnership and inclusion in meetings, forming participatory spaces that share decision-making power with patients and the public to inform design and policy. This is a welcome and essential shift from what was happening before the introduction of PPP.

It was hugely helpful to me that in advance of the audit of the Interval Cancer Project, an induction meeting provided all public and patient stakeholders involved in the project with overviews of the NSS, Public and Patient Participation, and clinical audit practices; as well as time to define roles and expectations of public and patient representative members ahead of the project. All of this contributed to the implementation of patient and public partnership as a routine way of working throughout the project.

I have experienced meaningful involvement on these projects, I have been invited to contribute to the work and to regularly comment in meetings. I have felt heard and appreciated. NSS staff have taken time to check that I have understood certain aspects of the project, and have given me opportunities to say what is going well and what the challenges are.

I have to always remember, that despite having a respect, and an understanding of NSS work, that I am wearing my patient representative hat and need to view everything from the patient’s perspective and need to respond with relevant feedback. I sometimes see both sides of a situation and can find myself looking really hard to find a solution in favour of the public and patient. The respect that is afforded to me in return makes it all hugely worthwhile.”

Strategic Area 3:

Strengthen accountability, assurance and learning



‘Ensure there is social accountability for NSS services and that participation and monitoring leads to learning and improvement’

The systems and organisational changes already achieved within NSS, demonstrate the implementation of key actions within the PPP strategy such as strengthening accountability, assurance and learning across the NSS. Progress in these areas can be demonstrated with the inclusion of PPP reps on Quality, Safety and Risk, and Quality Assurance committees. It is also shown in the creation of new systems that ensure feedback processes are in place to listen to the voice of the people using services, and that they inform change.

Patient-Reported Experience Measure (PREMs) pilot project

The NSS aims to understand and continually improve the screening experience of those participating in our screening programmes. BowelScreen is the national bowel cancer screening programme. The BowelScreen Patient-Reported Experience Measure Survey (PREMs) project will gather realtime feedback from people going through their screening pathway. People with a negative screening (FIT) test and also, those with a positive test, and who have a colonoscopy, will receive the survey. This is a proof of concept project where feedback will be sought via an online survey that will be circulated via text message. This quality improvement project will attempt to capture feedback quickly from our patients. The anonymised data gathered will be used to identify areas within the programme that work well, areas for improvement, and where else this methodology could be used across the NSS. The project will be implemented between April 2022 and December 2022. In the future, PREMs have the potential to be implemented across all NSS screening programmes to help improve patient experience and to drive greater efficiencies.

Spotlight Case Study: HIQA Review of International Ethics Framework Project

The National Screening Advisory Committee (NSAC) outlined that an ethics framework will provide an important structure to support evaluations and deliberations in relation to population-based screening programmes. The HIQA 'Review of international ethics frameworks used in policy-making in the context of screening' involved two PPP representatives. The review aimed to identify ethics frameworks used internationally for policymaking in the context of screening and to use this information to help develop an ethics framework for assessing population-based screening programmes in Ireland. The final HIQA report was published in 2021.

"I wanted to try to ensure that the patient is kept at the centre of everything. It's very important that when a patient, or indeed any member of the public, is reading something from HSE or HIQA on general health, that they can understand what is being said/communicated. It's also very important that they feel it's relevant to them."

Keith, PPP representative

Key messages from PPP representatives

The importance of having a diverse and inclusive PPP panel

"Representing the views of the African and migrant community helped in providing a different cultural perspective, view, and understanding which is very important in this changing and diverse Ireland. I learned a lot from the project, which has also inspired me to educate myself more on the area of ethics and research. It was indeed a very positive experience."

PPP representative on HIQA Review of Ethics Framework project

Spotlight Case Study: Compliments, Complaints and Compliance Project

Service-user experience starts from a person's first contact with the NSS, and continues for a long time after. The Compliments, Complaints and Compliance project captures service-users' feedback on their experience of using our screening services, and aims to reassure them that what they have to say about their journey has a meaningful impact on the way the NSS designs and delivers our services. The project focus is on constantly improving patient and participant experience and outcomes, while ensuring compliance with policy and statutory requirements.

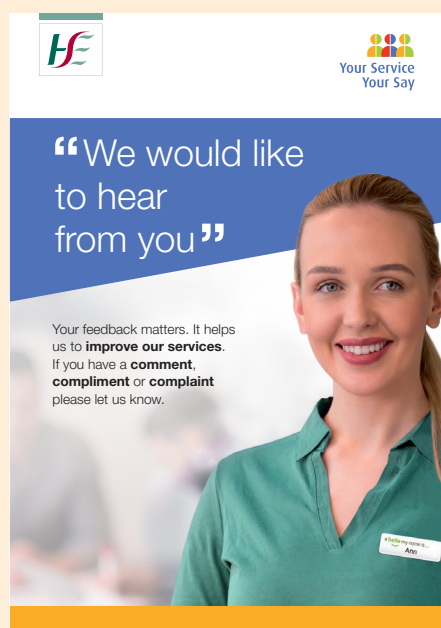
The systems and organisational change being introduced in this project, are also necessary to establish consistency in systems and processes, including the recording and management of patient complaints, compliments and feedback. The NSS Complaints and Compliance team has begun rolling out Stage 1 of the HSE's 'Your Service Your Say Policy' within the NSS to standardise and improve the pathways for service-user feedback.

These changes help ensure that the voice of the service-user informs the service design, delivery and improvement of services, and will help build trust and confidence in our screening service.

"Having robust feedback processes in place will allow us to really listen to the voice of our service-users when they tell us about their experiences with the NSS. The project aims to meaningfully partner with service-users through their feedback to identify learning opportunities. These will contribute to building trust and confidence that we are an organisation that values person-centeredness, patient safety, quality and learning."

Susie, Complaints & Compliance Officer, NSS

Figure 11: 'HSE Your Service Your Say'



A summary of other PPP actions completed across the NSS

-
- PPP was included as a priority area in the NSS Operational Plan 2021.
-
- PPP reps were involved in numerous projects (See appendix 3) across NSS such as the easy-read bowel and breast leaflets projects
-
- An NSS ‘Screening Masterclass’ for NSS staff was hosted in early 2021, to provide a comprehensive overview of the principles of screening through teaching and illustration of real world scenarios and incidents.
-
- A ‘Jargon Buster’ has been co-designed by the PPP Implementation Group.
-
- A ‘Barriers Report’ on recent NSS research conducted on the barriers to uptake of screening services in Ireland was compiled and circulated to PPP panel members.
-
- An ‘Options Paper’ on the PPP panel’s ‘Ways of Working’ has been circulated to PPP Implementation Group, patient partners, and NSS partners for discussion and sign-off.
-
- NSS is developing a new website, which will be a source of trusted information.
-

PPP strategy implementation challenges

While working towards achieving the actions outlined in the PPP Strategy, we have met certain challenges.

Communication

Covid-19 saw the PPP representatives adapt to the 'new normal', as face-to-face meetings and workshops were paused and were moved online. IT literacy and access to digital devices became a challenge for some PPP representatives, and extra support for the PPP representatives was provided to ensure they remained linked with the NSS committees and groups.

"Face-to-face engagements are essential at the start of a project to build and foster relations. However, the added time of travelling to and from in-person meeting can lead to involvement fatigue, and eventually lead to resignations. Ideally, a blend of both meeting formats would benefit the needs of all involved"

Antoinette, Senior Project Manager, NSS

Key messages from PPP representatives

the new ways of communicating had benefits and limitations

"Zoom is convenient to a degree. However, It can be difficult to come back in to a conversation at a virtual meeting. A good Chairperson can make you comfortable to come back in and respond to someone/something'. However 'face-to-face is best-over a cup of tea, and an informal chat, you can get to know people"

PPP Representative

"Online is great- it's very handy and everyone is always bang on time. However, there is no opportunity to chat to people over a cup of tea, to share ideas and to discuss things in more detail. I am travelling from the West – so a mixture of online and face-to-face would be great"

PPP Representative

Focus for 2022 and onwards

The progress achieved to date is due to the huge efforts of the patient and public representatives, and NSS colleagues. With the success and solid foundation from the first two years we look forward to the continued work as we embed PPP within all functions of the NSS.

Next Steps for the PPP Strategy

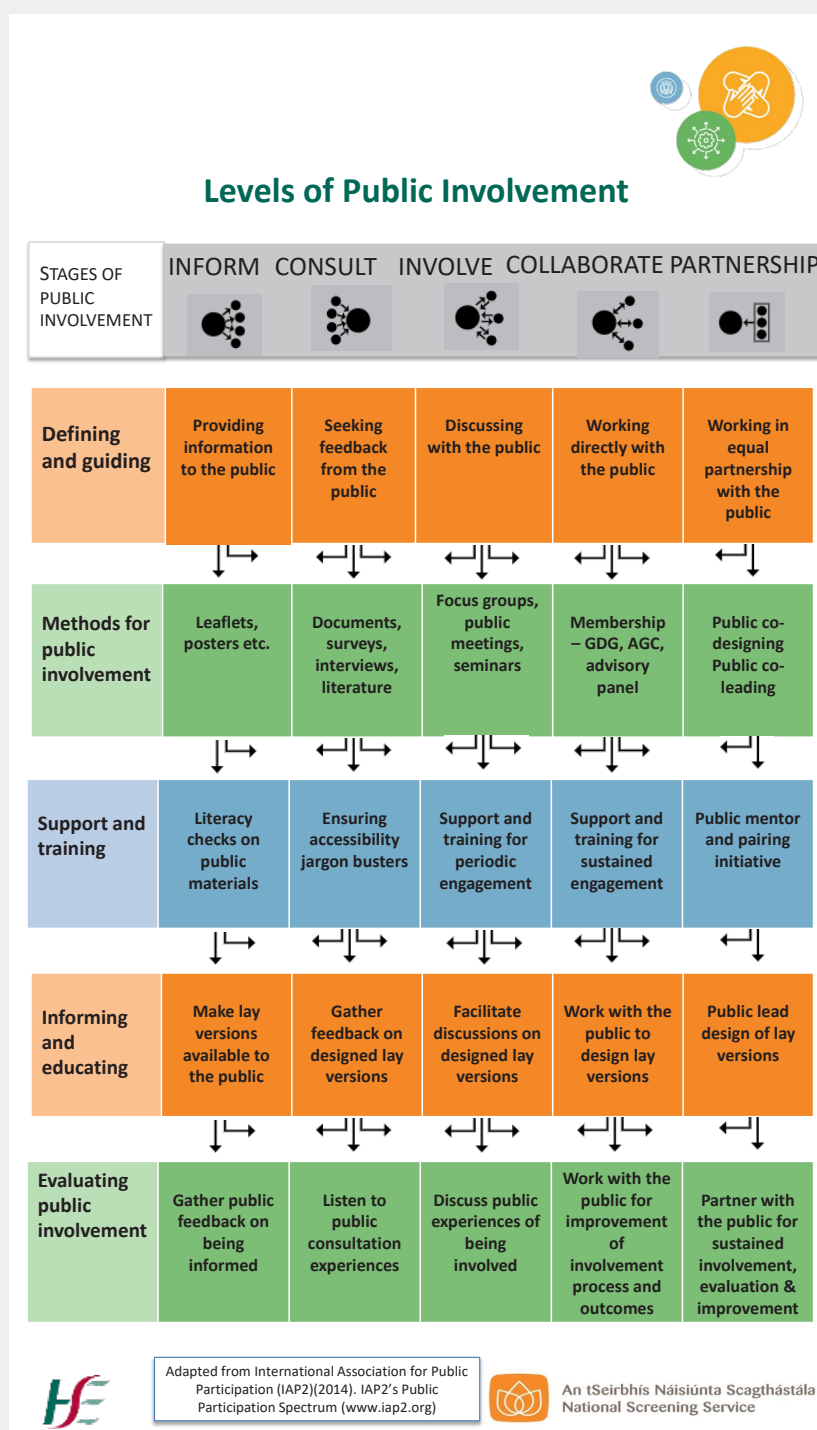
- Developing the PPP operating model to clearly outline how PPP should function on an everyday basis within the NSS, what the PPP permanent structures should be, define roles and responsibilities, and what work processes need to be implemented
- PPP toolkits and guides developed to support effective PPP implementation
- Transition the PPP Implementation Group into permanent ways of working in 2022
- An open recruitment campaign will begin in early 2022 to establish a diverse and inclusive PPP Panel and a PPP Network/Hub, with members from under-represented minorities
- Following on from the results of the Training Needs Assessment, develop and launch a new Induction and Training Programme in 2022
- A Patient-Reported Experience Measures project established in BowelScreen in 2022
- Continue to encourage and facilitate PPP representative recruitment on NSS projects, committees and groups, as appropriate
- Continue to embed PPP into NSS operational planning and facilitate NSS cultural change

Notwithstanding the challenges, we look forward to moving to the remaining stages of the PPP strategy. The NSS will continue to be committed to the implementation of the strategy. We would like to thank the PPP panel members and representatives and NSS staff for their dedicated commitment to the strategy, and to all stakeholders who have supported this work throughout its first two years.

References

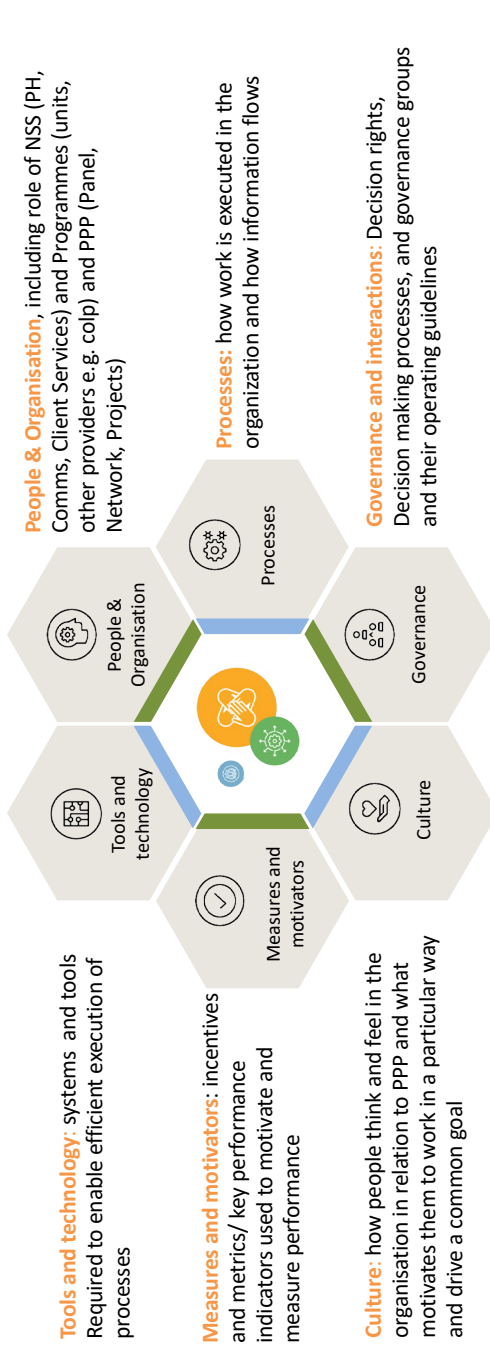
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Appendix 1: Levels of Public Involvement



Appendix 2: PPP Operating Model Proposal

PPP Operating Model



Appendix 3:

PPP representative Groups/ Committees/Projects

Table 1. PPP Representatives Involvement in current groups/projects		
Group	Status	Number of Patient/Public/ Community Groups*
Research with LGBT community (LINC group)	Active	2*
CervicalCheck Primary Care Group	Active	1
General PPP Panel	Continuous	24
COVID Restart Group	Closed	3
PPP Implementation Group	Active	8
NSS Quality Safety & Risk Committee	Continuous	2
Expert Reference Groups <ul style="list-style-type: none"> • Interval Cancer Steering Group • BreastCheck Interval Cancer Audit Implementation Group • CervicalCheck Interval Cancer Audit Implementation Group • Communications Interval Cancer Implementation Group • BowelScreen Interval Cancer Implementation Group • Legal Framework Group 	Active	
Communications User research and engagement:	Continuous	2
Breast Density	Active	
Elimination of Cervical Cancer	Pending	2
Information Hub project	Active	5
I-ARC Project	Active	2
CORE Research	Active	1



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