



HSE Patient and Public Partnership Conference 2023

● Foreword

The first annual HSE National Conference on Patient and Public Partnership took place in Dublin's Convention Centre on October 12 2023, bringing together patient advocates, healthcare professionals, policymakers and stakeholders.

This was a hugely successful and important landmark conference which was organised by patient groups and HSE staff working together. It was a wonderful opportunity to discuss, debate, listen and learn from each other. I was delighted to have had the opportunity to take part and to lead on this important work alongside many others including colleagues from the HSE's National Patient and Service User Forum, the Irish Platform for Patient Organisations, Science and Industry (IPPOSI) and Patients for Patient Safety Ireland.

This report on the event reflects the many contributions on the day including the challenges and opportunities and outlines the key learnings and recommendations. It covers the highlights from the day and the important next steps to be taken.

Opening the conference on the day HSE Chief Executive Officer, Bernard Gloster, spoke passionately about the need for a true partnership between those who need and use health services and those who deliver them

Joining the CEO on stage, service user and member of the HSE National Patient and Service User Forum, Christine Fenton, questioned how people can know when their voice has actually made a meaningful and tangible difference. Sustained, accountable, person-centred partnerships were identified as the goal, delivered by changes to culture and inclusion in structures,

In his speech Minister for Health, Stephen Donnelly TD highlighted how we know that health service staff working in partnership with patients and the public ultimately delivers better health outcomes.

I believe strongly that patient partnership and engagement is a fundamental cornerstone of healthcare and a critical component of a safe, people-centred service. Patients have a unique perspective which makes them invaluable partners in how we design, deliver and evaluate our health services. There is a growing recognition of the invaluable role that patients and service users play in shaping health care delivery, policy development and organisational governance. A lot of work is underway to increase partnership with patients. I acknowledge that much more remains to be done but believe there is now a solid foundation upon which to build a truly person-centred health system.

In conclusion I would like to thank all the members of the HSE Patient and Service User Forum, and the many other patient and service user organisations and individual advocates who played a role in organising this conference.

Joe Ryan

National Director Patient & Service User Experience.



Organising Committee Members

Anne Lawlor,

Chair of the Forum, Chair of 22q11 Ireland

Laura Kavanagh,

Co-chair of the Forum, IPPOSI

Kara Madden,

Chair of Patients for Patients Safety Ireland

Joe Ryan,

National Director, HSE Operational Performance and Integration

Iolo Eilian,

Assistant National Director, Patient and Service User Experience

Acknowledgements

Thanks to all the members of the HSE Patient and Service User Forum, and the many other patient and service user organisations and individual advocates who contributed to the preparation of the agenda and the event.

Special thanks to the HSE Patient and Service User Experience Office staff Mila Whelan, Nicola Williams, and Orla O'Reilly, as well as HSE Project Manager Julia Barry who supported the coordination and preparation of the conference.

● Executive Summary

On 12 October 2023, Ireland's inaugural Patient and Public Partnership Conference took place in the Convention Centre, Dublin. In a significant departure from previous events, the programme was co-created by the HSE National Patient and Service User Forum (an informal network of organisations and individuals with an interest in the health system, co-chaired by [IPPOSI](#) and 22q11), and the HSE Patient and Service User Experience Office and the HSE Operational Performance and Integration Directorate. Drawing a crowd of over 450 across online and in person attendance, patients and service users, their family members, carers and supporters, as well as patient and service user organisations and advocacy groups, were joined by HSE clinical and non-clinical staff from the national and regional levels.

Under the theme 'Creating Tomorrow, Together,' the conference aimed to explore the readiness of the health system to partner with patients and service users at a strategic level (rather than at the individual care level), including for service design and delivery; for policy and programme development and implementation; and for organisational change and governance. Discussions focused on the opportunities (and challenges) which partnership represents to give life to the HSE's values of care, compassion, trust, and learning and to co-design a person-centred health system, together.

Opportunities

Overwhelming support for taking a partnership approach to building our future health system was reiterated across all sessions. Adapting the well-used mantra, many called for nothing about us (the patient or service user) to be done without us. Lived experience was put forward as an area of expertise which is equally relevant in shaping strategy, policy, and performance as it is in directing individual care. Patient and service user voices need to be brought into each and every aspect of our health system, and these voices need to carry influence and be reflected in decision-making processes.

Challenges

Despite consensus around the many opportunities, it was widely acknowledged that there are cultural, structural, financial and practical issues that need to be addressed. Buy-in from front-line health and social care professionals is slow, given the current constraints within the health system and the enormity of their immediate environment. Progress towards partnership, like any big change process, requires time for mind-sets to change, for cultures to shift – we will not manage to transform our behaviours overnight. Knowing when to partner, with who, and how will take learning, perseverance, and trial and error. Patient and service user expectations around partnership must also be managed, with the rationale for partnership and the expected outcomes of partnership clearly defined. Clear communication, transparency, and honesty were mentioned many times, but these are not always a given. Even where partnership has gotten off the ground, other problems arise – including a lack of diversity in terms of age, gender and ethnicity among those partners coming forward, and the absence of a system for valuing and remunerating these partners for their time.

Benefits

The opportunities far outweigh the challenges, and the benefits of working in partnership with those who access our health system are well discussed. Patients and service users, and many health and social care managers and professionals, know that working in partnership ultimately delivers better health outcomes. And while there are public partners who will have had negative experiences within the health service, similarly, there will have been many who have had positive experiences; and all of these experiences should equally inform how we develop and improve our health system in the future. The local autonomy afforded by the move to six different health regions and the ongoing implementation of Sláintecare can benefit greatly from improving partnership with local communities.

A number of successful projects have already resulted in tangible outputs and improvements; in many cases these can be replicated or scaled up. The current approach to patient and public partnership is seen as “ad hoc” and piecemeal – a structured framework is required, one that would formalise this approach and ensure that the needs of all stakeholders are met. Measurements of its success are required, and these must be co-designed with patients and service users.

Next steps

The conference was hailed as a landmark discussion, one which built upon many years of hard work in bringing patient and public partnership to the fore. While it is acknowledged that much more remains to be done, there is now a solid foundation upon which to build a truly person-centred health system, with a stated commitment from the HSE to progress a

partnership approach so that patients and service users can have influence at all levels of the health sector – nationally and regionally.

- **Recommendations**

The HSE senior management commits to lead by example in relation to partnership

A HSE National Strategy around Partnership should be co-created with patients and service users to identify the steps needed to progress partnership in the next five to ten years. The strategy should formalise the HSE's approach to partnership and the HSE senior management commitment to partnership. The implementation of the strategy should be supported in service plans and budget processes. Senior managers should champion the implementation of the strategy and ensure progress is measured via performance indicators and across governance mechanisms, including the HSE Board and HSE Board Sub-Committees.

A partnership approach informs the co-development and co-implementation of all major national strategies, programmes, and policies

Progress towards partnership needs to start now. We cannot wait until the conditions are perfect for partnership. To mark a sea change in how we do business, we need to draw a line in the sand, stating that from here on, no national strategy, programme or policy will be developed without the involvement of patient representatives on decision-making bodies, and without the engagement of the broader patient community at key milestones along the way. Work in the health regions space, as well as in integrated care, enhanced community care, genetics and genomics, and digital health should pilot this new approach.

Partnership structures are included in the roll-out of the new health regions structure to embed partnership

Partnership is an essential part of a functioning health system, and the new health regions need to reflect this reality in the way they organise themselves. Each health region should have a partnership office, with an associated partnership action plan and budget for partnership activities in the local area. Health region partnership offices should be nationally coordinated to ensure quality, consistent, and sustainable approaches to partnership.

The HSE allocates expertise and resources grow its capacity in relation to partnership

A small office of three is currently leading the HSE's approach to partnership. Given the mammoth task involved in influencing culture, establishing structures, and growing capacity these resources are not sufficient and they do not demonstrate a commitment by the senior management to 'put their money where their mouth is'. The partnership agenda needs to be driven by people who understand the theory and the practice – this includes experts in public participation, public communication, and public training. It also includes roles for patient partners, such as the creation of Patient Directors. Patient facilitators, spokespersons, and educators are also required. Remuneration must be available to public partners in recognition of the time and expertise shared.

Conference Highlights



The conference, chaired by consultant paediatrician at Children's Hospital Ireland Dr John Fitzsimons, commenced with a focus on the potential of partnerships across health service design and delivery, policy and program development, as well as organisational change and governance. Dr Fitzsimons highlighted the diversity of the audience's situations and experiences, while commending the united vision, passion, and commitment towards partnership;

"We are all aligned today in our intention and the dialogue today is part of that process. We will be enriched from listening to each other". He introduced 'the platinum rule': treat others as they would like to be treated.

"Partnership with patients and service users' needs to be a cornerstone of how we work across our health system and broader health sector" HSE Chief Executive, Bernard Gloster



Opening the conference, HSE Chief Executive Bernard Gloster spoke passionately about the need for a true partnership between those who need and use health services and those who deliver them. He acknowledged that there is a danger of box-ticking, and he underlined that real patient and public partnership should be a journey of continuous improvement. There is no place for paternalism, and he emphasised that delivering a modern, fit-for-purpose health system requires a change in culture. To ensure the right care, at the right time, in the right place, he called for an honest relationship with the people involved, one based on real inclusion and real listening. "We need to actually live and do partnership, and not just talk about it." Setting out principles for partnership, his message was simple but clear "when we listen, have we heard, and the real test of our bona fides, did we act on what we heard".

Joining the Chief Executive on stage, service user and member of the HSE National Patient and Service User Forum Christine Fenton, questioned how people can know when their voice has actually made a meaningful and tangible difference. Sustained, accountable, person-centred partnerships were identified as the goal, delivered by changes to culture and inclusion in structures, and by explaining to those serving others that "Part of the solution to reducing your pressure is in the partnership".

Referencing the HSE Change Guide and the Health Act of 2004, Christine enquired about how new life could be injected into the provisions around public and patient participation.

Underlining that change would not happen overnight, the Chief Executive spoke about his intention to lead by example, and he announced plans to bring the Patient and Service User Experience (PSUE) Office to report directly into his office from 2024. Highlighting the restructuring of the HSE into six new health regions, he pointed to the potential for more local autonomy. “It will enable our local regions to determine the innovative services they need for the local population”.

Speaking about the evaluation of progress, Christine queried whether there were currently sufficient measures in place to assess the progress of partnership approaches across the HSE. The Chief Executive referenced ongoing work around the development of key performance indicators (KPIs), acknowledging that something “with more depth” is needed, and asking patients to join in identifying appropriate measurement tools. This invitation was later echoed by Caitriona Heslin, Assistant National Director, HSE Organisation Development and Design, who said a focus on quantitative measures must be matched with qualitative evidence. “You have to tune into what’s really important to people and the narrative of people’s lived experience should be part of how you evaluate services.”

“We know that health service staff working in partnership with patients and the public ultimately delivers better health outcomes. There is a way to go, but this conference is an important opportunity for discussion & debate” Minister for Health, Stephen Donnelly



Partnership has come a long way in the past two decades, and the Minister underscored the conference as “an important moment in the journey”. Stating clearly, “we know the patient experience matters”, he admitted that “this wasn’t self-evident in the past” and he acknowledged that “it is an extraordinary mark of the success that you have all achieved, that it is now seen as self-evident”. Demonstrating support for partnership, he added “from my perspective, and also on behalf of the Government, we are fully behind and fully support, the work you are doing in bringing about this very fundamental change”. Embedding this patient-centric approach to everything we do in health is different to rolling out a new service or opening a new building or introducing new legislation, he said. “It is about fundamentally changing the way that people think... it is much more difficult but ultimately more beneficial.”

The establishment of the Patient Advocacy Service has been a huge step, and the Minister committed to further investment in staff and resources for the service so that it can continue to expand, as well as raising awareness of its existence. Minister Donnelly also stressed the importance of listening carefully to what patients have to say as part of the National Patient Experience Survey and he emphasised the importance of identifying what is working within the health service. He also made reference to the Patient Safety Bill, and the Open Disclosure framework, and plans to advance a policy for remunerating patient and public partners.

Speaking plainly, “we use our health services when we are vulnerable, we need to empower the public and the advocate to bring about change in how we think, and that drives how we work”. Putting the patient voice at the centre of what we do, requires a “mind-set shift” in policy making and in care delivery. We need to invest in building trust.

“It requires major culture change for the patient’s ‘lived experience’ to be given equal weight alongside the expertise of clinicians” - Carol Munt, UK-based patient partner and advocate



[Presentation from Carol Munt](#)

Introducing “the story of 5 Ps” – Carol described public and patient partnership as ‘People with a Passion and a Purpose with a Place and a Payment’. This is the theory, but she cautioned that the reality is often different; partners are not always looked as people with experience, they may be looked as patients in gowns, in beds, in wards. She referenced the Royal Berkshire NHS Foundation Trust's PEET (Patient Experience Engagement Team) initiative. Citing the reasons for its success as varied but highlighting that chief among them was the decision to talk to patients, not when they are vulnerable and when they are in a hospital, but when they are on their own ground and when they are able to sit in a room with clinicians and with other decision-makers and have an equal contribution.

The biggest challenge is changing the culture; “it is a huge difference for the health service to accept that other people – other than themselves (professionals) – do actually know something about their condition”. “It’s not rocket science to work it out, we all have a different approach to things”, but the lived experience is “no less valuable”. Carol underlined the potential for patient partners to eventually become patient leaders or health system champions. Co-production stems from an equal partnership where people with lived and learnt experience work together with professionals from start to finish. Speaking about the Leading Together Programme, she summarised “it’s amazing what you can achieve when it doesn’t matter who gets the credit”.

Partnership – challenges and opportunities



Setting the scene to discuss challenges and opportunities around partnership, Joe Ryan, National Director for Operational Performance and Integration remembered his own introduction to partnership, and the learning curve he embarked on to really understand what partnership looks like, how it needs to be planned, and what is needed to make progress. Echoing the Chief Executive, Joe spoke about the need to “listen, and then act”.

Christine Fenton agreed wholeheartedly, citing positive experiences of partnership as those where you feel heard, where your contributions are valued and remembered and have influence. In contrast, negative experiences are those where there is listening, but there is no hearing and no acting upon what has been said – you are invited to share but you have no influence.



“Patients are uniquely positioned to understand the challenges that are there...but the challenges are not insurmountable, the benefits are huge” Joan Johnston, general manager of COPD Ireland, parent and carer.

Changing the culture to one that is person-centred and oriented is necessary but this must be underpinned by a standardised framework for patient partnership. Currently, the approach is ad hoc and “piecemeal”, working well in some areas, hospitals and projects, but not in others, where it is inadequate or non-existent. “I have had different experiences as a patient partner - some were very good and others needed some work,” Johnston said.

Establishing a register of patient advocates was a suggestion of Joan Johnston’s; the HSE could then easily and quickly match the right advocates to the right initiative or group. This would be similar to Boardmatch, which connects potential board members’ expertise with the right board. “Connecting the right patient with the right project is key.” Ensuring diversity among patient advocates also represents a challenge, one that must be tackled.

Bureaucracy and red tape has hampered these projects in the past, and patient advocates called for “sufficient autonomy” for those tasked with leading them. Sometimes members of the HSE are not allowed to share information with someone who isn’t an employee of the organisation - “that creates an inequality”.

The timing of partnership is also crucial and many conference attendees agreed knowing at what stage to bring in patients is a challenge. Patients and patient advocates are often invited in at a late stage in a project, and asked their opinion on something that has already been designed and developed. They should instead be asked to participate at the “ideas” stage. “We want to be in the room and tell you what’s important to us.”

The conference also heard there is a palpable sense of enthusiasm among HSE staff for the move towards patient partnership. Jackie Reed, National Lead HSE Health and Social Care Professions, said staff are keen to “embrace” this change, despite the challenges it presents. However, it is and will be a steep learning curve for everyone involved. The Patient Engagement Roadmap has provided much-needed guidance for staff but the introduction of a formal framework is required in order to meet the needs of all parties in the best possible way.



Clarity in terms of objectives and expectations should be there from the outset. Bríd Ryan, clinical lead, HSE ePharmacy, spoke of the need for “brutal honesty in what we say we are going to do”.



There was a high level of consensus on the need for a system of reimbursement/remuneration (beyond expenses) for patient and public participants. Both patient advocates and HSE employees acknowledged the time burden that this participation demands, and the practicalities of travel, childcare, etc. Confirmation by the Health Minister that such a system is in development was warmly welcomed across the board. It was noted that practical matters around these payments must be ironed out - for example, precisely which budget it comes from, or ensuring that it does not impact disability or unemployment payments, for example.

Additional benefits for patient advocates were suggested, such as the provision of relevant training. Joan Johnston cited one project where patient partners were given access to HSElanD, the health service’s online training portal. This could also act as an incentive for getting involved and provide added value for those that offer their time. Suggestions of specific training for both staff and patient partners was also suggested; for example, courses could be made available on HSElanD on how to do patient partnership for staff and how to be a patient partner.

“We are not under any illusions. Trust takes partnership and that takes time,”
Iolo Eilian, HSE Assistant National Director, Patient and Service User Experience Lead.



Many patients and audience members noted that the failure heretofore to provide a person-centred model of care has meant an undue burden has fallen on patient advocacy groups and charities, as patients seek advice, information and support that has been lacking during their experience in the health service.

**“There is a trepidation around something new that’s being introduced but that challenge is lessening as local evidence mounts as to the benefits that people with lived experience bring.”
Colm Harty, Patient & Service User Engagement Lead CHO6, QSSI**

There is a certain “nervousness” given the newness of this endeavour, said Laura Kavanagh, IPPOSI and HSE NPF co-chair. Patients can be nervous as they want their input to have value, while healthcare providers can be nervous about the unknown.

Colm Harty, Patient & Service User Engagement Lead CHO6, QSSI agreed citing the “fear of the unknown” when it comes to patient and service user partnership and the massive learning curve it involves. “There is a trepidation around something new that’s being introduced but that challenge is lessening as local evidence mounts as to the benefits that people with lived experience bring.” Building a patient representative committee so that patients with lived experience can be matched to the relevant projects is a key focus.

Structure is starting to take shape: Eight patient and service user engagement leads have been appointed and by the time all posts are filled there will be 20, located across the various HSE regions. The conference heard that these posts are a critical element in attempting to formalise structures and practices that support patient partnership. Harty acknowledged that they are breaking new ground but the goal is to “achieve longevity through the systems we create together”. The sheer size of the HSE as an organisation has historically been an impediment to change - and indeed the pace of change - but with the new regions and locally appointed patient and service user engagement leads, this should be less of a problem as local needs drive partnerships in those areas.

Harty discussed an example of a project in which patient engagement was paramount. This falls prevention project included a mapping survey, as well as a focus group including four patient partners and four staff. Outputs included a booklet, which he said adequately captured the lived experience of the patients who participated. One of the patients involved was Chris Healy, who has experienced several serious falls. He commented: “My voice was heard... I really enjoyed speaking to people who had been through similar and I felt no shame.” Healy advised the HSE to partner with people with valuable lived experience, not just because it is “the right thing to do”, but because they will gain valuable additional insights.

**“Conversations can be the trigger for change,” Caitriona Heslin,
Assistant National Director, HSE Organisation Development and
Design**

The health service has recognised and accepts the value of patient and public partnership, and staff are enthusiastic, but fundamentally changing minds and culture is still difficult to achieve. Caitriona Heslin, Assistant National Director, HSE Organisation Development and Design, outlined her work in building capacity and supporting the implementation of the Health Services Change framework, a policy that has been signed off within the HSE but also by their trade union partners. This Framework, which she said is “anchored in people’s

needs”, can act as a reference point and can support development that can in turn assist with change. This Change Framework itself is the result of a co-design process involving patients, service users, families, citizens and communities and staff.

As the health service embraces this change, Heslin emphasised the critical importance of dialogue. “Conversations can be the trigger for change and we need to foster lots and lots of conversations and through those, build the relationships and build the trust in order to give people a voice.” People are at the heart of change and the evidence on change is very clear, yet the HSE has historically underestimated the human factors in change. While improving processes and systems is essential, the evidence says 70% of the energy must be put into people and culture change. “Change levered from the outside in is much more powerful... we really do need to listen to the voice and listen to the experience.” Change is best when co-designed and delivered locally.

The challenge boils down to blending what people need with what is feasible on a practical and technical level, and financially viable, for the organisation. Embedding the cultural change is the crux of what the HSE is trying to achieve, supporting staff and teams to move forward with them on this journey.

“Good communication skills help us build rapport with our patients.” Wini Ryan, Programme Lead with the National Healthcare Communication Programme

Communication pervades every aspect of patient and public partnership and will be the foundation on which patient partnership is built. However, the quality of the communication is not always satisfactory to both parties. Mr Peter Gillen, surgeon and clinical advisor to the national healthcare communication programme, discussed the difficulties in changing culture when it comes to how communication typically happens within the health service - and in our everyday lives - and emphasised the need to have conversations where both sides are happy with the outcome.

Wini Ryan, Programme Lead with the National Healthcare Communication Programme, stressed the importance of using communication skills deliberately. Healthcare staff may either not be aware of these skills or else simply not using them; the training run as part of the programme is designed to address this. One-sided conversations can be common in the medical sphere; rather than a “shot put” approach, where the professional is just telling the patient some information, the frisbee approach is about interaction, collaboration, partnership, and building a relationship. For example, medical professionals should first find out what the patient already knows, because most of them will be an expert in their own condition. This will help the healthcare professional to identify the appropriate starting point for speaking to the patient, and allow them to match the language used by the patient. It is also critical to show the patient that they are listening. “Good communication skills help us build rapport with our patients.” A confounder is that healthcare can involve high levels of emotion and highly stressful situations but it is then that communication skills are critical in showing compassion to patients and families. Ryan pointed out that a patient will “always remember” the day that they received bad news.



“The broader the representation you have in any committee or project, the better the output is” Jo Shortt Assistant National Director, HSE Change Planning and Delivery.

The conference heard that the reorganisation of the HSE into six Health Regions represents a novel opportunity to provide integrated, locally planned and delivered that is easier to access and navigate for patients and their families. Patients and service user partnerships are to be recognised in a formal capacity within the structures of each Health Region and this project is ongoing, ready for completion upon the establishment of the different regions, explained Jo Shortt, Assistant National Director, HSE Change Planning & Delivery. A co-designed draft submission on patient partnership has already been drafted.

Patient and service user partners will be members of the Health Regions Programme governance groups, and are also members of the design work stream for integrated service delivery. Passion from patient/service user partners has been evident at all stages, and Shortt praised their steadfast commitment, even when ill or in difficult personal circumstances.

Yet there are obvious challenges and Shortt commented that the process was more challenging than they had anticipated. Managing expectations will be key. She echoed Heslin, saying that while patients may articulate the changes they would like to see, not all will be feasible, practicable or financially viable. Clear communication around the objectives of each project should help to avoid disappointment in this regard.

The issue of diversity and inclusion as it relates to patient and public partners cropped up again and again. One patient present, who has a neurological condition, noted that younger patients are less likely to get involved, whether it is peer support or patient partnership. More efforts must be made to involve people of all genders, ages, ethnicities and within all disease areas. “The broader the representation you have in any committee or project, the better the output is.” HSE representatives acknowledged it is a major challenge to address this, and reach patients and service users.

What partnership looks like may be different depending on our personal background or on our professional focus – but there are some common elements that need to be considered as part of most partnership initiatives. As the health service and patients find themselves on this journey, defining and aligning their partnership goals and approaches is a challenge in itself.

Partnership goals for Enhanced Community Care (ECC)

**“Capturing experiences of using and delivering services is a key part of how improvement is grounded in what matters to people,”
Elaine Newell, Project Lead, Enhanced Community Care Programme.**

Enhanced community care (ECC) involves enhancing and increasing community services and reducing pressure on hospital services, and it places a focus on health and wellbeing with a view to prevention, early intervention and self-care supports. The ECC programme has taken an experience-based co-design approach, creating the space for service users, carers, and staff to reflect on and share their experiences of a service and to work in partnership to identify and develop improvement priorities. Taking this approach to a national programme breaks new ground, although the merits of partnership have been tried and tested in various clinical settings and in other countries. As part of the ECC project, five co-working sessions produced a draft service improvement plan, written by service users and staff. It also led to two tangible service improvements: the Better Together poster, leaflet and feedback form, and a community specialist assessment report for the older person.

**“I am a firm believer that when we bring our issues and concerns to the powers that be, they do take it on board.”
Joan Kavanagh, Service User, Community Care Project**

Service users who took part in the project spoke of the need for compassion and mutual respect, removing the fear and trepidation many people may feel when entering in a healthcare setting. They praised how this patient partnership project was run, saying they felt there was no “power imbalance”, with everyone on an equal footing: “Everyone has something of value to add, everybody had a voice”. It was noted on multiple occasions that the use of online platforms such as Zoom and Microsoft Teams have democratised and opened up meetings to broader participation. Making meetings convenient was acknowledged as a small step that can have a big impact.



Partnership Goals for Clinical Programmes

“As is, our healthcare system is hurting both the people who work for it, and the people whom they seek to serve. If we want something different we have to do something different and to do differently we need to think differently so think partnership.” Anne Lawlor, Chair of 22q11 Ireland

Patients are the experts in their own condition, and they are ideally placed to provide peer-to-peer support, as well as to share their lived experience to inform how their care is coordinated and delivered. In partnership with clinicians and care coordination staff, the rare disease patient community associated with 22q11 has built a holistic model of care that has helped patients and families managing the condition. It offers support for those struggling to find the right care by connecting families with an experienced support group, where they can benefit from connecting with others who have similar lived experience. It also links patients and families into a clinical coordinator who explains the care pathway and tackles any questions or concerns at the earliest possible stage. “Although there are challenges within the system, this innovative model has been an important and welcome success for our patient and family community”, said Anne Lawlor, founder of 22q11 Ireland and chair of the HSE National Patient and Service User Forum.

By adopting this innovative model, early engagement and good communication with the coordinator has contributed to a reduction in clinic non-attendance and to a growth in trust and satisfaction among patients and families. The delivery of care is adapted to meet the specific needs of the community, and an ongoing process of active listening encourages flexibility and responsiveness to patient preferences and expectations.

The model is regarded as highly transferable, and suitable for implementation across a range of complex care conditions. Enthusiasm in the room for scaling up this approach was evident, and it was assessed as imminently feasible with the appropriate education, investment, and leadership. It was suggested that an Irish complex care centre could be established, one that is modelled and informed by both good practice and the lived experience of patients and families.

Partnership goals for research for care

“From the little germinating seed, great things have grown, and spread to other areas” Mandy Daly, patient advocate and founder of the [Irish Neonatal Health Alliance](#)

Patient and public partnership in clinical research is at a tipping point – its inherent value is finally being recognised. Developing partnership goals for person-centred research for care is the next hurdle. Since 2021, the [Health Research Board \(HRB\)](#) has funded [the PPI Ignite Network](#), which promotes and supports PPI in institutions across Ireland. Leader of the Network and Professor at the University of Galway, Sean Dineen, spoke of how the HRB

has “put its money where its mouth is” when it comes to PPI, stating simply but powerfully “PPI is just like ethics, you just need to do it!”

There have been many organic examples of PPI even before the current drive to include patients, services users and members of the public in research. Mandy Daly of the Irish Neonatal Health Alliance spoke about her experience of research in the neonatal space, indicating that advocates have helped draft research questions and research grant applications for the past eight years, as well as inputted into the design PhD programmes and research recruitment panels.

“We need to clearly explain to the public the value and benefit of research,” Avril Kennan, [Health Research Charities Ireland](#)

While PPI as an integral component of research is gaining momentum, there is a need to ensure a diversity of voices participate as there can be an “over representation” of certain people. To combat inclusion challenges, Health Research Charities Ireland (HRCI) – together with UCD – co-hosts a PPI liaison officer in their offices. This role helps to identify who are the public partners, where they can be found, how they can be engaged, how they can advocate with others, and how they can organise events that are accessible for patient and public partners.

Dr Maria Quinlan of the HSE Research and Development Team agreed that there is also a role for the HSE in supporting the growth of a diverse pool of partners – efforts could be made to link experienced partners with new partners, creating “safe spaces” for mentorship and personal development. Education and capacity building for patient and public partners is essential, but it is equally important for training to be provided to the chairs of committees, working groups, and other mechanisms who include partners in their processes. The IPPOSI’s patient education programme, which includes modules on clinical trials, health technology assessments, and medicines regulation, was highlighted as an example of patient-centred training.



Good governance was likened to the essential “pipework” enabling the achievement of successful partnerships, with all initiatives focused on co-designing and co-evaluating with partners. Ultimately, the end goal is for everyone to know what they are doing, why they are doing it, and what are our shared responsibilities in progressing partnership.

Many public and patient partners highlighted remuneration for sharing their expertise and time as key in rewarding patient and public participants for their and making them and their contribution feel valued. Practical issues need to be ironed out between the policy makers at the departmental level, as disability or pension payments should not be affected by remuneration received for partnership activities.

The core values of partnership in research were identified as the same as in any partnership – communication, honesty, and trust.

Bringing Partnerships to Life in 2024

“It’s about bringing patient voices into service design, development and delivery at the national, regional and most importantly the local level,” Dr Derick Mitchell, IPPOSI CEO



Achieving true patient partnership will require better structures, better culture, but, fundamentally, better decision-making that’s informed by patients’ needs, preferences and voices, said Dr Derick Mitchell, IPPOSI CEO.

“We need to map out how we link up and join up all the dots... It’s a puzzle to be resolved.” Jacqui Browne, HSE Board Sub-Committee Member, and advocate

All stakeholders in patient and public partnership in the health service must have a shared understanding of what it means, pointed out Jacqui Browne, HSE Board Sub-Committee Member and advocate. When we say patient and public partnership, do we mean patient engagement or participation or consultation? Defining what partnership means and ensuring everyone is at the same starting point will help to grow and develop the framework, move forward and determine future outcomes.

Brian O’Hagan, Northern Ireland Patient and Service User representative, told the meeting that any framework for patient engagement should be a “living document”, revisited regularly. A framework offers guidance on when to use patient partnership but also when not to use it - for example, in emergency situations. O’Hagan also spoke of the need for champions of patient partnership in the community, within patients, within carers, within frontline staff, and management as well as politicians.



“When you marry the lived experience with the clinical experience, it’s a match made in heaven.” Anne Lawlor, founding member and chairperson of the 22q11 Ireland Support Group

CONFERENCE AGENDA

<https://hsepatientconference.ie/agenda-2023/>

USEFUL READING AROUND THE THEME OF THE CONFERENCE

Health Act 2004, Part 8:

<https://www.irishstatutebook.ie/eli/2004/act/42/section/8/enacted/en/html>

Change Guide

<https://www.hse.ie/eng/staff/resources/changeguide/>

Better Together Roadmap

www.hse.ie/eng/about/who/national-services/partnering-with-patients/resourcesqid/hse-better-together-patient-engagement-roadmap-book.pdf

National Patient and Service User Forum – Our Vision for Partnership across our HSE
hsepatientconference.ie/wp-content/uploads/2023/10/Our-vision-for-patient-partnership-across-our-HSE-22.pdf

PPI Ignite Framework

<https://ppinetwork.ie/resource/ppi-ignite-network-values-and-principles-framework/>

CONTACT DETAILS

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