

**OUR VISION FOR  
PARTNERSHIP  
ACROSS "OUR HSE"**



**HSE National Patient and Service User Forum  
June 2023**

# NATIONAL PATIENT & SERVICE USER FORUM



## What do we do?

Our forum is a vibrant community of patient and service user organisations, disability and advocacy groups, individual patients and service users, and their family members, carers and supporters.

We meet every 4-6 weeks, either online or in person, to discuss issues which are of collective importance to the patient and service user community. Topics include plans for patient and service user engagement, integrated care, digital health, and health regions.

As members of the forum, we can request updates from HSE teams and offer valuable insights from a patient and service user perspective on programmes, processes and policies. We can also actively participate by joining co-design working groups, project oversight panels, programme advisory committees, and board sub-committees.

The forum is always welcoming new members, so if you are interested in partnering to shape a new health future for us all, please contact Nicola Williams, HSE Patient & Service User Engagement Office, [nicolaj.williams@hse.ie](mailto:nicolaj.williams@hse.ie).

## Who are the forum members?



**Anne Lawlor,  
Chair, 22q11**

**Laura Kavanagh,  
Co-Chair, IPPOSI**



**In 2015, several organisations and individual advocates, family members, carers and supporters came together to establish the HSE National Patient and Service User Forum. Each member brings with them a wealth of invaluable lived experiences and a deep knowledge of the health service.**

**Some of the organisations involved in founding the forum are listed below:**

- Disability Federation of Ireland
- Patients for Patient Safety
- Federation of Voluntary Bodies
- Diabetes Ireland
- Irish Heart Foundation
- Alzheimer Society of Ireland
- Age Action
- Irish Cancer Society
- National Women's Council
- Chime
- Asthma Society of Ireland
- Irish Platform for Patients' Organisations (IPPOSI)
- Family Carers Ireland
- Care Alliance Ireland
- SAGE Advocacy
- Rehab Care
- MS Society Ireland
- ACT for Meningitis
- Ability West
- iCAN
- Marfan Syndrome Support Group
- Alpha 1
- Feileacain
- 22q11
- COPD Ireland
- Amputee Ireland
- Jack and Jill Foundation
- Irish Hospice

What is our vision?

## PARTNERSHIPS ARE THE FUTURE

We believe that "the HSE" is "our HSE", and that we all have a responsibility to work together to build responsive, resilient, and respected health and social care services.

Part 8 of The Health Act 2004 underlines the importance of 'public representation and user participation' and it describes a range of mechanisms which can be established to support the work of the Department of Health (DoH) and the HSE.

As patients and service users, we stand ready to breathe new life into the implementation of this legislation, and to grow, support, and sustain partnerships with health service managers and health and social care professionals across the HSE, nationally and regionally.

We want to see patient and service user perspectives inform how we design and improve care, how we develop and implement policy, and how we govern and assess performance across our health service.

**#PARTNERSINVOLVED**

**#OURHSE**

“Our vision for partnership is for patients and service users to become **involved**, as little or as much as they want, across all areas of the health, social and community care sector in Ireland, starting with the HSE”

HSE National Patient Forum members

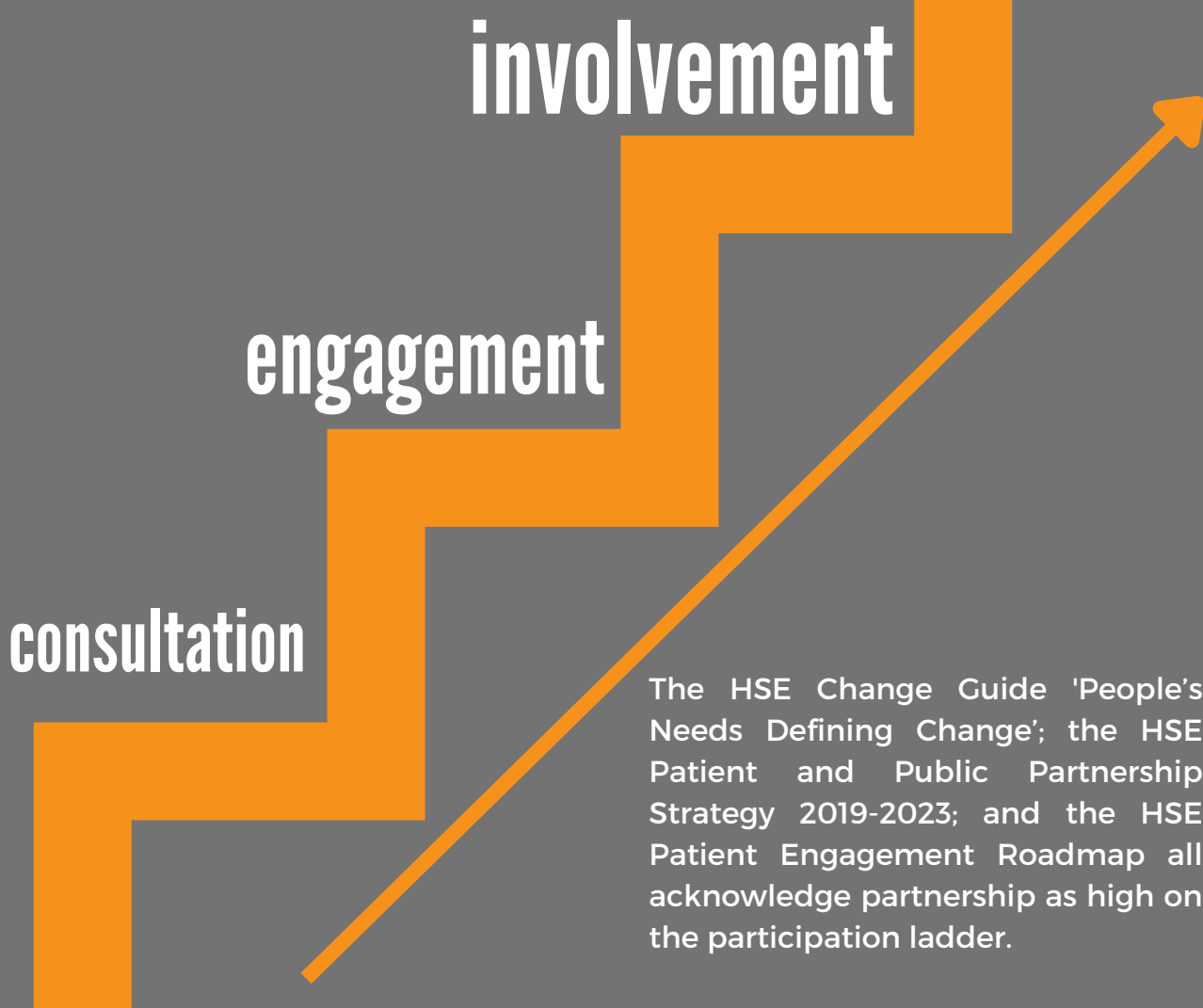


## What is partnership?

By focusing our energy and resources on creating **EQUAL, MEANINGFUL, and SUSTAINABLE** partnerships, we will build a health service **WITH** patients and service users which delivers **FOR** patients and service users.



# partnership



The HSE Change Guide 'People's Needs Defining Change'; the HSE Patient and Public Partnership Strategy 2019-2023; and the HSE Patient Engagement Roadmap all acknowledge partnership as high on the participation ladder.

## What is "good" partnership?

### EQUAL



Partnership treats all partners equally. The patient or service user partner has access to the same information as other partners so there is a level playing field when it comes to knowledge. The partner has equal voting rights and their input is given equal consideration alongside other expert voices. Partnerships reflect the diversity of individuals using our health and social care services, and removes any barriers to participation.

Partnership is a meaningful and positive experience for both the patient or service users partner and the health service. The partner is involved from the earliest stages, in identifying the problem and in defining the parameters of the future partnership. The partner is involved in developing the principles or values of the partnership; in co-creating the direction of travel and the preferred destination; and in setting and evaluating measures of progress and outcomes.

### MEANINGFUL



### TRANSPARENT



Partnerships are transparent and it is clear why partnerships have been built, with whom, and how. The patient or service user partner has the opportunity to express their interest in joining a partnership and they are able to speak about their involvement in a partnership with their broader community. In this way, partnerships are representative, democratic, and inclusive.

Partnerships are able to be sustained over months and years by both partners. The patient or service user partner is supported in their role to grow as a partner and to participate without being financially out-of-pocket or emotionally overburdened. Mentorship and remuneration policies are co-developed with (and co-monitored by) partners. Partners have access to training and personal supports, and their accessibility requirements are met.

### SUSTAINABLE



## Who are the partners?

### The DAILY or FREQUENT patient or service user

Many partners are individuals who manage a chronic or rare condition and regularly use or rely daily on our health and social care services.

They have extensive 'lived experience' of interacting with various services, and they have ideas around how these services (policies and governance) could be improved.

### The OCCASIONAL patient or service user

Some partners are individuals who interact with our health service during an isolated or short-term health episode.

### The FAMILY, CARER OR SUPPORTER

Partners can also be individuals who are entrusted by the patient or service user to represent their will and preferences.

### The patient or service user ORGANISATION

Partners can also be organisations who represent, support or advocate for a community of individuals with daily, frequent, or occasional experience of interacting with our health service.

Many organisations focus on a particular condition, and they have a strong understanding of the challenges individuals face when accessing and relying on care. They have recommendations for improving services, policy, and governance.



**PATIENTS & SERVICE USERS ARE  
PEOPLE**



**PEOPLE ARE  
PARTNERS**

# Why do we need partnership?

## QUALITY



Partnerships stretch us beyond our 'comfort zone'. They require us to 'lean in' and to 'think outside the box'. This helps us to be creative, to be brave, to push for better. Patients and service users can be partners in identifying and implementing service improvements - strengthening the quality of care provided.

Partnerships force a range of issues to the surface. They require us to create a 'safe space' for 'constructive criticism'. This helps us to acknowledge our shortcomings, to review standards and practice, and to change our processes. Patients and service users can be partners in identifying and implementing safety solutions.

## SAFETY



## OWNERSHIP



Partnerships give people a stake in decision-making. They require us to 'take ownership' of an outcome. This helps us to engage in self-management and to become advocates for ourselves and for others. Patients and service users can be partners in improving their own care and in improving the health system which delivers their care.

Partnerships generate higher levels of trust and confidence. They require us to 'see the other side' and to empathise with others. This helps us to understand what is achievable within the short, medium and longer-term. Patients and service users can be partners in assessing and communicating public needs, preferences, and expectations.

## CONFIDENCE



## When do we need partnerships?



**Partnerships for  
individual care**



**Partnerships for  
service management**



**Partnerships for  
policy development**



**Partnerships for  
organisational change**



# Where do we start?

**Lead  
CULTURE  
CHANGE**

**Develop  
PARTNERSHIP  
POLICY**

**Establish  
GOVERNANCE  
ROLES**

**Identify  
GOOD  
PRACTICE**

**Offer  
EDUCATION  
& TRAINING**

**Launch  
PUBLIC  
CAMPAIGN**

**Measure  
PROGRESS  
& IMPACT**

**Invest in  
STAFF  
& BUDGETS**



# Partnerships in 2024+

1

## **Draft a Patient & Service User Partnership Strategy**

Co-create with patient and service users the key objectives and targets needed to embed partnership within the culture of the organisation over the next five years. Agree timelines and identify the resources needed to make progress towards this vision.

## **Develop internal policies to support partnership in action**

Develop internal policies to give life to the Partnership Strategy, including guidance on when partners are included and how partners are identified, selected, and supported. Co-create approaches with partners, and focus on participation from a diversity of patient and service users. Updated the HSE Expenses Policy to offer a 'partner involvement fee'.

2

3

## **Invest in partnership programmes and activities**

Increase the budget available to implement the Partnership Strategy, funding the organisation of a calendar of partnership events, the delivery of a schedule of partnership training days and resources, and the creation of digital tools and content to keep partners engaged. A 'partnership involvement fund' should be established to manage the timely administration of partner involvement fee payments.

## **Recruit staff with expertise in partnership approaches**

Allocate new staff to the National Patient and Service User Engagement Office to standardise the approach to partnership across the HSE, nationally and regionally. Experts in partnership will coordinate the work of the Patient and Service User Engagement Leads in the hospitals, and support the implementation of the HSE Patient Engagement Roadmap,

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## **Establish Regional Patient & Service User Offices**

Build a Patient and Service User Partnership Office in each Health Region. Create a reporting line from these offices to the National Patient and Service User Office, Identify common responsibilities and standardised approaches to partnership.

## **Establish a Board Sub-Committee on Partnership**

6

Establish a Sub-Committee of the Board to focus solely on partnership. Identify sub-committee members from the full spectrum of the patient and service user community (individual patient advocates, patient organisation representatives, and community and voluntary sector representatives). Make partnership should be a standing item on the HSE Board agenda.

## **Design a Patient & Service User Partnership Scorecard**

Co-create partnership performance measurement tools to measure progress towards partnership objectives and targets, including scorecards with KPIs and surveys to measure the experience of partnership. Appoint partners to all mechanisms monitoring and evaluating performance.

7

## **Involve Patient & Service Users in Budget Planning**

8

Invite patient and service users to sit on strategic and operational working groups, including the development of Corporate Plans, Service Plans, Budget Estimates, and forecasting. Provide specialist training for partners to ensure that they can meaningfully contribute. Allow partners to consult with the wider patient and service user community when preparing their input.

## **Commit to Patient & Service User Partnership Dialogue**

Co-organise an annual HSE Patient and Service User Partnership Conference to ensure the partnership agenda receives the public attention it deserves. Support complementary activities to encourage regular, collective reflection on progress made towards agreed goals.

9

## **Provide Staff Training on Partnership**

10

Require all staff to complete a basic online training on partnership, and offer a series of in-person lectures and workshops for those interested in learning more. Build a library of resources on HSEland. Engage patients and service users as co-educators and co-mentors in the process of upskilling others. Co-develop special training tools for HSE Board Members, senior management, national directors, and health region chief executives.

# 11

## **Appoint a Patient & Service User Partnership Advisor**

Create a new role of Patient and Service User Partnership Advisor within the National Patient and Service User Engagement Office. Working alongside the Assistant National Director, the Advisor assesses the quality of HSE partnership initiatives and makes recommendations to advance the partnership agenda. The Advisor should be a patient or service user.

## **Offer Training to Patient & Service User Partners**

Develop education and training tools to onboard new patient and service user partners, and to allow existing partners to periodically refresh their knowledge and skills. Create an introductory course 'Your HSE' to explain how the organisation works. Provide partners with access to relevant parts of HSEland via a new Partner Portal.

# 12

# 13

## **Create a Patient & Service User Partner Portal**

Launch a new Partner Portal to advertise partner opportunities and to sign up new partners. Provide a description of active partnership opportunities, and share the names and contact details of partners contributing to various projects and programmes to facilitate communication and transparency. Share links to training material and share the details of upcoming events.

## **Launch a Public Partnerships Campaign**

Develop a National Public Campaign to publicise the HSE's new approach to partnership with patients and service users. Co-create messages to share the value of partnership. Provide information on the partnership mechanisms and opportunities available across the HSE, and invite expressions of interest. Focus on growing a diverse pool of partners, as well as on building public trust and confidence.

# 14

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**#OURHSE**



**PARTNERSHIPS**

require **PEOPLE**

with a **PASSION**

and a **PURPOSE**

and a **PLACE** to meet

and a **PAYMENT** for their involvement.



Learn more about the work of the HSE National Patient and Service User Forum at

<https://www.hse.ie/eng/about/who/national-services/partnering-with-patients/national-patient-forum/>

If you would like to join the Forum, please contact: Nicola Williams, HSE Patient & Service User Engagement Office, [nicolaj.williams@hse.ie](mailto:nicolaj.williams@hse.ie) or Laura Kavanagh, the current co-Chair of the Forum, [lkavanagh@ipposi.ie](mailto:lkavanagh@ipposi.ie)

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**#OURHSE**

## **Before we go.....please remember**

There will be language, interpretations, and suggestions in this document which not all of us involved in the health sector agree upon.

The purpose of this document is never to offend and we hope only to provide some 'food for thought' to keep the conversation around partnership alive and to make proposals for how we might strengthen our combined efforts in the future.

We welcome all and any input around this topic, and we look forward to make revisions and additions to our vision as we learn together, and put our ideas into practice.

We take this opportunity to thank the many individuals in the health service who work tirelessly to provide care to patients and service users.