OUR VISION FOR PARTNERSHIP ACROSS "OUR HSE"

HSE National Patients' Forum

June 2023

NATIONAL PATIENTS' FORUM

What do we do?

The forum comprises of individual patient advocates, family members, carers and supporters, as well as representatives of patient organisations, disability organisations, advocacy groups, and other special interest groups.

Members of the forum meet every 4-6weeks, frequently online but occasionally in person, to discuss issues which are of collective importance to the patient and service user community.

The forum can request updates from HSE teams; provide a patient and service user perspective on specific programmes, processes and policies; as well as suggest opportunities for where the HSE might partner with patients and service users.

Issues addressed by the forum include plans for patient and service user engagement, integrated care, digital health, and health regions. Members of the forum participate in co-design working groups, project oversight panels, programme advisory committees, and board sub-committees.

The forum welcomes new members. For more information, please contact Nicola Williams, the HSE Patient and Service User Engagement Office, nicolaj.williams@hse.ie.

Who are the forum members?

Anne Lawlor,

Chair, 22q11

Laura Kavanagh,

Co-Chair, IPPOSI

The following organisations formed the NPF in 2015:

- Disability Federation of Ireland
- Patients for Patient Safety Ireland
- 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

The forum also includes many individual advocates, family members, carers and supporters from across the patient and service user community. Each of whom contributes their significant lived experience and knowledge of the health service to the work of the forum.

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 a responsive, resilient, and respected health service.

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 managers and health and social care professionals across the HSE, nationally and regionally.

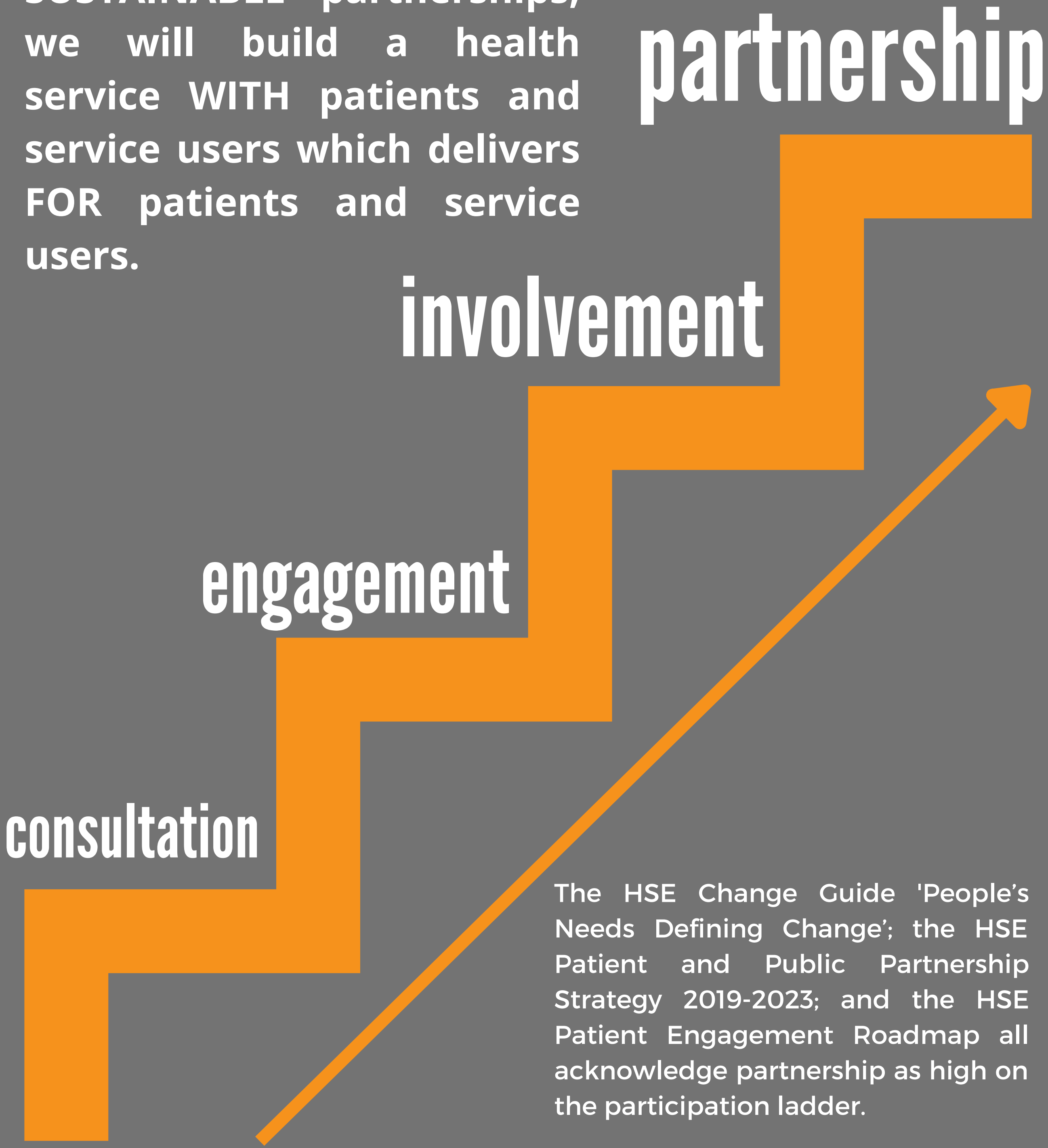
We want to see patient and service user perspectives inform how we design and improve care, how we develop and implement policy, and how we govern and assess performance across our health service.

> “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.



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 service, and removes any barriers to participation.

MEANINGFUL

Partnership is a meaningful and positive experience for both the patient and the health service. The patient or service user 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.

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 more representative, more democratic, and more inclusive.

SUSTAINABLE

Partnerships are able to be sustained over months and years by both partners. The patient or service user partner is supported in their role so that they can grow as a partner and so that they can participate without being financially out-of-pocket or emotionally over-burdened. Mentorship and remuneration policies are in place, and these policies are co-developed with and co-monitored by patients. Partners have access to training and to personal supports

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 service.

They have extensive 'lived experience' of interacting with various services, and ideas around how these services (and policy, research 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/support) CARER

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

The patient or service user ORGANISATION

Partners can also be organisations who represent a community of individuals with daily, frequent, or occasional experience of interacting with our health service. While many organisations focus on a particular condition, their experience results in a strong understanding of the challenges individuals face when accessing and relying on care. They have clear recommendations for improving services, policy, research and governance.

PATIENTS & SERVICE USERS ARE

PEOPLE

PATIENTS & SERVICE USERS 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 quality improvement solutions.

Safety

Parternships 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 good practice, and to change our processes. Patients and service users can be partners in identifying and implementing safety solutions.

Autonomy

Partnerships give people a stake in decision-making. They requires 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.

Satisfaction

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 public needs and expectations.

When do we need partnerships?

Partnerships for individual care

Partnerships for service management

Partnerships for policy development

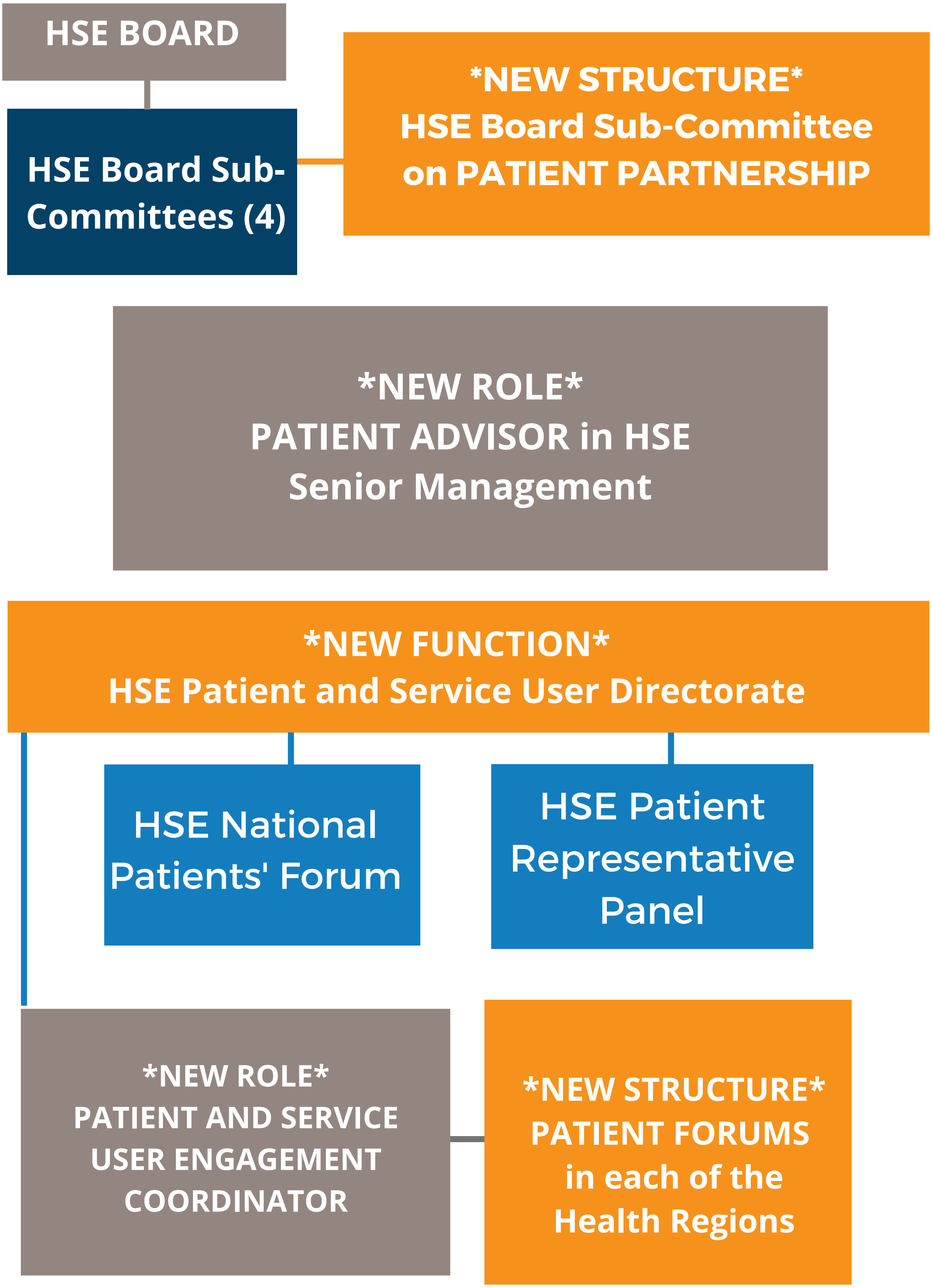
Partnerships for organisational change

Who should create partnerships?

Anyone can invite patients and service users (or the public) to partner with them.

Across the health sector in Ireland, we seek invitations to partner from the Department of Health, the HSE Senior Management, the HSE National Programmes, the HSE Hospital Groups, the Community Health Areas (and in time, the Regional Health Areas), the GPs, and the research and innovation community.

What mechanisms do we need for partnership?



HSE BOARD

HSE Board Sub-Committees (4)

NEW STRUCTURE
HSE Board Sub-Committee on PATIENT PARTNERSHIP

NEW ROLE
PATIENT ADVISOR in HSE Senior Management

NEW FUNCTION
HSE Patient and Service User Directorate

HSE National Patients' Forum

HSE Patient Representative Panel

NEW ROLE
PATIENT AND SERVICE USER ENGAGEMENT COORDINATOR

NEW STRUCTURE
PATIENT FORUMS in each of the Health Regions

Where do we start with partnerships?

Lead a
CHANGE IN
CULTURE

Develop a
PARTNERSHIP
POLICY

Establish
GOVERNANCE
ROLES

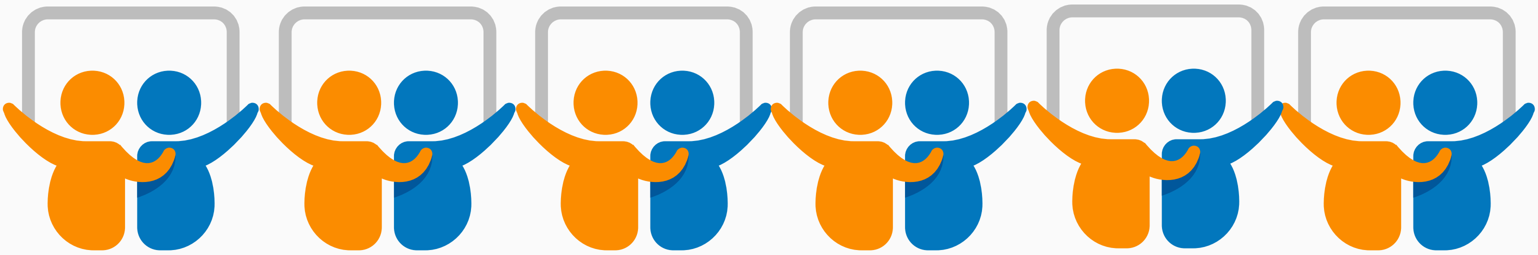
Identify
GOOD
PRACTICE

Offer
EDUCATION
& TRAINING

Develop a
PUBLIC
CAMPAIGN

Measure
PROGRESS
& IMPACT

Invest
STAFF
& BUDGET



Partnerships in 2024+

1

Appoint a Patient & Service User Partnership Advisor

A new role for a Patient and Service User Partnership Advisor should be created within the National Patient and Service User Engagement Office, working closely alongside the Assistant National Director, advising on the quality of HSE partnership initiatives and recommending actions to advance the partnership agenda. The Advisor should be a patient or service user.

2

Staff the National Patient & Service User Office

Additional staff should be added to the National Patient and Service User Office to implement a standardised approach to partnership across the HSE, including the implementation of the HSE Patient Engagement Roadmap and the organisation of the annual HSE Patient and Service User Partnership Conference.

3

Resource the National Patient & Service User Office

Additional budget should be allocated to the National Patient and Service User Office to procure the services needed to manage partnership events, to develop partnership training resources, and to create the digital tools and communication campaigns needed to keep a pool of partners mobilised. A 'partner involvement' fund should be established to remunerate partners.

4

Draft a Patient & Service User Partership Strategy

A first draft of a HSE Patient Partnership Strategy should be initiated to detail the HSE’s cross-organisational commitment to embed patient partnership, to set some key objectives and targets, and to identify the timelines and the resources needed to make progress towards this vision.

5

Develop a Patient Partnership Policy

A new HSE Patient Partner Policy should give life to the HSE Patient Partnership Strategy, detailing where the HSE will include patient partners (mandating co-design in certain areas), and how these patient partners will be identified, selected, and supported to ensure a diversity of patient partners. An updated HSE Expenses Policy should include a new ‘partnership fee’.

6

Commit to Patient & Service User Partnership Dialogue

A commitment to fund an annual HSE Patient and Service User Partnership Conference should be part of the HSE Partnership Strategy to ensure the partnership agenda receives the public attention it deserves, but also to allow for regular, collective reflection on the progress made towards agreed partnership goals.

7

Involve Patient & Service Users in Budget Planning

Patient and service users should be invited to sit on strategic and operational working groups within the HSE. They should contribute to the development of Corporate Plans, Service Plans, Budget Estimates, and forecasting. Partners involved in this work should be given specialist training to ensure that they can contribute on an equal footing. They should also be permitted to consult with the wider patient and service user community in providing their input.

8

Provide Staff Training on Partnership

All staff should be required to complete an online training on partnership. For those wishing to delve deeper, a series of in-person lectures and workshops should be offered. A library of resources on partnership should be added to HSEland. Patient and service user engagement staff (PSUE) at the hospital and community level should be engaged in the process of upskilling other colleagues. Special training tools should be developed for the HSE Board Members, co-designed with and co-delivered by patients and service users.

9

Offer Patient & Service User Partner Training

A suite of education and training tools should be developed to onboard new patient and service user partners, and to allow existing partners to periodically refresh their knowledge and skills. An introductory course 'Your HSE' should explain how the organisation works. Partners should have access to relevant parts of HSEland via the Partner Portal.

10

Create a Patient & Service User Partner Portal

A new Partner Portal should be created to sign up new partners and to advertise partner opportunities. In the interests of transparency and to facilitate communication between partners, this portal should also provide the names and contact details of partners actively contributing to various projects and programmes.

11

Establish Board Sub-Committee on Partnership

A Sub-Committee of the HSE Board should be established to govern the partnership agenda and to measure progress. The Sub-Committee members should be from the patient and service user community (individual patient advocates, patient organisation representatives, and community and voluntary sector representatives). Partnership should be a standing item on the HSE Board agenda.

12

Design a Patient & Service User Partnership Scorecard

A suite of HSE Partnership Measurement Tools should be co-created with patient and service user partners to measure the progress of the HSE towards partnership objectives and targets - including scorecards with KPIs and surveys to measure the partnership experience. Partners need to be appointed to the committees that evaluate progress against these tools.

13

Establish Regional Patient & Service User Offices

A Patient and Service User Partnership office (with the appropriate staff and budgets) should be established in each Health Region. These offices should develop close links with the National Patient and Service User Office. Coordination from the centre should establish common responsibilities and standardised approaches to partnership. Regional Patient and Service User Forums should be created with local patient and service user communities.

14

Launch a Public Partnerships Campaign

A HSE Public Partnerships Campaign should announce the HSE's new approach to engaging with patients and service user. A strong message for sharing the value of partnership should be co-created with patietns and service users. The campaign should publicise the partnership mechanisms and opportunities across the HSE. The campaign should focus on growing a diverse pool of patient partners, and building public trust and confidence.

#PARTNERSINVOLVED **#OURHSE**

PATIENT, PUBLIC, PROFESSIONAL PARNERSHIPS

The many Ps of partnership PATIENT, PUBLIC, and
PROFESSIONAL PARTNERSHIPS requires
PEOPLE with a PASSION and a PURPOSE
a PLACE to meet and
a PAYMENT for their involvement.

It requires a willingness to pursue POLICY and PROGRAMME CHANGE with PERSEVERANCE and PERSISTENCE while mindful of the need for PRACTICAL APPLICATION and PARTNERSHIP APPROACHES.