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**Health Regions Programme Team  
Proposal on Patient and Service User  
Partnership in Health Regions Design**

**DATE: 14 FEBRUARY 2024**

**Developed following the receipt of submissions from Patient and Service User Partner Groups and a co-design workshop process including Patient and Service User Partners and staff from the HSE and the Department of Health.**

**Proposal developed by:** Health Regions Programme Team, Health Services Executive (HSE)

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# Glossary

<b>Term/ Acronym/ Abbreviation</b>	<b>Definition</b>
<b>Acutes</b>	Acute Hospitals/Services
<b>CHN</b>	Community HealthCare Network <sup>1</sup> :
<b>DoH</b>	Department of Health
<b>EHR</b>	Electronic Health Record
<b>EMT</b>	Executive Management Team (Health Regions)
<b>Health Regions Implementation Plan</b>	Health Regions Implementation Plan published by the Department of Health (2023)
<b>HSE</b>	Health Service Executive
<b>ISD</b>	Integrated Service Delivery
<b>IT</b>	Information technology
<b>KPIs</b>	Key Performance Indicators (KPIs)
<b>NDOPI</b>	National Director for Operational Performance and Integration (HSE)
<b>PFPSI</b>	Patients for Patient Safety Ireland
<b>PPI</b>	Patient Partnership Involvement / Public Patient Involvement
<b>PPPGs</b>	Policies, Procedures, Protocols and Guidelines
<b>Implementation Plan</b>	Regional Patient /Service User Partnership Implementation Plan
<b>REO</b>	Regional Executive Officer
<b>RHA</b>	Regional Health Area (referenced in submissions from patient partners only)
<b>SLT</b>	Senior Leadership Team
<b>SMS</b>	Short Message Service
<b>Strategy</b>	The National Patient and Service User Partnership Strategy (currently under development nationally)

<sup>1</sup>CHNs: Geographically-based community healthcare networks delivering primary healthcare to an average population of 50,000 people. Generally 4-6 multi-disciplinary primary care teams per CHN. See <https://www.hse.ie/eng/services/list/2/primarycare/community-healthcare-networks/>

## 1. Executive Summary

This document sets out a proposal for the approach to patient and service user partnership within Health Regions. It has been jointly developed by patient and service users and the Health Regions Programme Team. The proposal is informed by four submissions received from patients and service users and patient partners via the Patient Service User Experience (PSUE) Office in April 2023. It is also based on subsequent patient and service user partnership co-designed workshops which were used to generate ideas and outputs. These were held on 10<sup>th</sup> May, 7<sup>th</sup> June and 7<sup>th</sup> July 2023.

### 1.1 Objective

The objective of the Health Regions Programme was to set out through co-design a future approach for patient and service user partnership within Health Regions. This document captures the main themes and recommendations for formalised involvement of patient and service user partners in the Health Regions structures. A key focus for the Health Regions programme is ensuring that the patient and service user voice is integral to ongoing design work within the programme, and within the Health Regions as they are stood up in 2024.

### 1.2 Key Findings

It is crucial for patient and service users to be recognised in a formal capacity within the governance structures of each Health Region. The findings from the four submissions and the three workshop are detailed in the appendices section of this proposal paper and key findings are summarised for both the submissions and the workshops as follows:

### 1.3 Submissions

The key themes that emerged were:

- Improving collaborative working
- Equity and Access
- Governance
- Challenges

With an emphasis on ensuring:

- Patient and service user partnership is an essential element of a functioning health system, democratically facilitating and representing all voices across all disease areas from community and acute hospitals
- A standardised model for patient and service user partnership is embedded in the national approach to Health Regions starting with patient and service user representatives on the Health Regions Implementation Planning Group and Health Regions Oversight Group
- The building blocks are put in place for diverse, meaningful, and sustained patient and service user partnerships, at the earliest stage, in decisions about care, service design and research and governance. This would translate to a clear organisational framework with a clear line of communication, and an information sharing process both within and between the regions.

Key elements that were highlighted as being required in each Health Region include:

- A National Patient and Service User Partnership Strategy (This is currently being developed by the National PSUE Office)
- A regional framework in line with the National Strategy
- A regional Patient and Service User Partnership Office
- A regional Patient and Service User Partnership Budget

## 1.4 Workshops

At the first workshop on the 10<sup>th</sup> May 2023, in line with 'Design Thinking'<sup>2</sup> methodology, ideations<sup>3</sup> and ideation themes were identified. While it is accepted that each of these ideations is important, the agreed priorities are explored in further detail in the proposal section. Many of the themes that were identified in the initial workshop have emerged during the design thinking process and are captured under the concept propositions<sup>4</sup> detailed in the document. These concept propositions are captured under three themes as follows:

- 1. Formal patient and service user representation in Health Region structures through appropriate forums**, e.g. Patient and service user Councils and member representation on relevant committees. This is captured under the concept proposition: '*Communications= A voice that is listened to and equal*'.
- 2. Service users and patient and service user partners being able to effectively navigate health and social services**. This was captured under the concept proposition: '*The Compass- Navigation of the Health Regions-A Symphony of Efficiency*'.
- 3. Key Principles and patient and service user partnership**. The importance of respect, behaviours, culture and the strengthening of accountability (at HSE level) was emphasised. These were linked with the Performance and Accountability Framework<sup>5</sup> (2023) and national oversight. This is captured under the concept proposition: '*Key Principles, Why partnership?*'

## 1.5 Key Proposals

A key focus for the Health Regions programme is ensuring the patient and service user voice is at the centre both for the design work that is ongoing within the programme, and within the Health Regions as they are stood up in 2024. Having reviewed the submissions, and the outputs of the co-design workshops, the Health Regions Programme Team in conjunction with patient and service user partners are making recommendations to embed patient and service user partnering in Health Regions design and governance using the agreed priority areas (the three concept propositions) as follows:

- Patient and service user representation:- with recommendations in the areas of:
  - Patient and Service User Councils
  - Patient and Service Users Partnering Office
  - Patient and Service User Lead
  - Strategy and Planning
- Improving the patient and service user experience:- with recommendations in the areas of:
  - Communication
  - Culture
  - Access and integration;
  - Data, information
  - Training, Education and Research
- Improving governance and accountability. This concept proposition makes recommendations in the areas of:
  - Governance
  - Standards and measurement

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<sup>2</sup> [https://www.interaction-design.org/literature/topics/design-thinking#what\\_is\\_design\\_thinking?0](https://www.interaction-design.org/literature/topics/design-thinking#what_is_design_thinking?0)

<sup>3</sup> Ideation: the activity of forming ideas in the mind: Source: <https://dictionary.cambridge.org/dictionary/english/ideation>

<sup>4</sup> Concept Propositions are statements about some object or event in the universe (a concept), either naturally occurring or constructed. Propositions contain two or more concepts connected using linking words or phrases to form a meaningful statement.

<sup>5</sup> <https://www.hse.ie/eng/services/publications/performance-and-accountability-framework-2023.pdf>

## 2. Introduction / Background

The Sláintecare<sup>6</sup> Report (2017) included a commitment to HSE regionalisation namely the organisation of national health and social care services in a manner that is fully coherent and aligned at regional level. This commitment was reaffirmed by Government in July 2019 when the geographies of six new HSE Health Regions were approved. A Memorandum on next steps, programme of work, and timelines for Health Region implementation was approved by Government in April 2022 and a *HSE Health Regions Implementation Plan*<sup>7</sup> was approved and published in July 2023 (DoH, 2023).

The core vision driving establishment and implementation of the HSE Health Regions is the continued improvement of patient and service user care through a more joined-up integrated health and social care system with an integrated approach to service planning and delivery.

The changes in healthcare governance arrangements are being designed to:

- Make our services easier to navigate for people
- Facilitate more integrated care
- Strengthen governance and accountability practice
- Increase transparency across the health sector.

The new structures will:

- Empower local decision-making
- Support population-based service planning and delivery
- Integrate community and acute care in line with government policy and Sláintecare's overall objectives.

On his appointment in March 2023, the Chief Executive Officer Bernard Gloster outlined his vision for the HSE as a health and social care service where the "*Patient and service user is central to everything we do*" (7<sup>th</sup> March 2023). The purpose of this document is to ensure the patient and service user is central to the work of the Health Regions Programme, and to set out and co-design the future of patient and service user partnership within the Health Regions.

### 2.1 Scope and Methodology

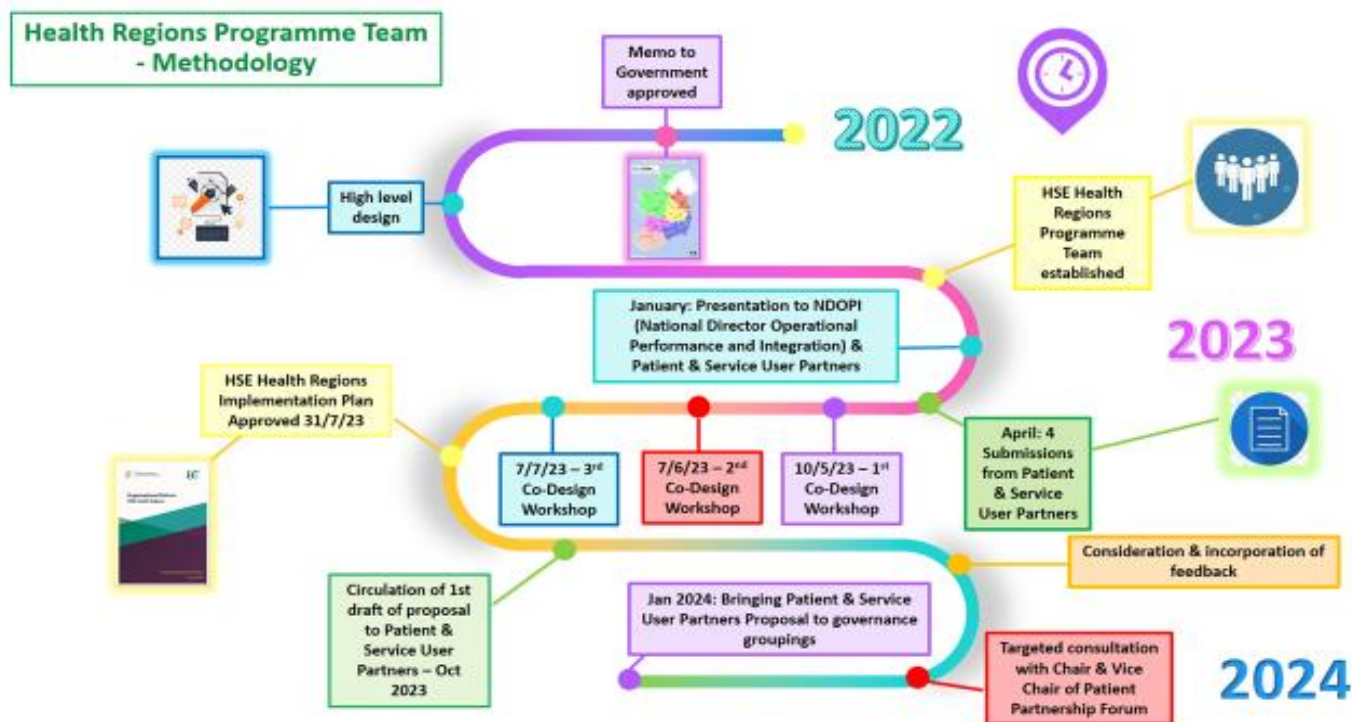
While the HSE Health Regions Implementation Plan (DoH, 2023) sets out a high-level approach in relation to design, it was accepted that further work would be required with patient and service users to co-design the partnership approach. Outputs from submissions and a series of three workshops with patient and service users are detailed in the appendices section of this document and underpin this proposal for patient and service user partnership within Health Regions.

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<sup>6</sup> <https://assets.gov.ie/22609/e68786c13e1b4d7daca89b495c506bb8.pdf>

<sup>7</sup> <https://www.gov.ie/en/publication/4eda4-slaintecare-regional-health-areas-rhas/#hse-health-regions-implementation-plan>

**Figure 1: Timeline representing the methodology process to date in the co-design of the partnership approach**



On the 24<sup>th</sup> January 2023, the Health Regions Programme team attended one of a series of workshops led by the National Director for Operational Performance and Integration (NDOPI), for patient and service user partners and staff on “*Designing the Patient and Service User Experience Model Together*”. At this forum the participants were asked the following three questions by the Health Regions Programme Team:

1. What would success look like from a patient and service user perspective?
2. What is important to you that we need to factor into the detailed design?
3. How do we best ensure the patient and service user voice in this design process?

Following the presentation at this forum, four submissions were received from:

- The Chair and Vice Chair of the HSE National Patient and Service User Forum<sup>8</sup> ( Appendix I)
- A member of the National Representative Service Panel (Appendix II)
- Sage Advocacy<sup>9</sup> (This was a standalone submission from Sage who are part of the National Patient and service user Forum)(Appendix III)
- Patients for Patient Safety Ireland<sup>10</sup> (PFPSI) (Appendix IV).

Following consideration of these submissions, advice from the NDOPI and agreement with Chair and Vice Chair of the HSE National Patients and Service User Forum, it was decided to proceed with the ‘*Design Thinking*’ methodology through a co-design workshop process specifically for Health Regions. The objective of the Design Thinking process was to define the priorities as identified by the patient and service user partners working with HSE and DoH colleagues, and to feed into the design and transition planning for Health Regions.

A draft of this proposal document was provided to patient and service user partners and to colleagues from the DoH and the HSE (who had attended the workshops) in October 2023. This was to facilitate comment on the content and to provide feedback on the document. There were 18 responses received with 176 feedback points for consideration by the Health Regions Programme team.

<sup>8</sup> The Forum is the first point of reference for HSE divisions and clinical care programmes when seeking an input from patient/service user in the planning, design and delivery of services and acts as a sounding board for implementation of new and existing national programmes

<sup>9</sup> Sage Advocacy is the national advocacy service for older people. It also supports vulnerable adults and healthcare patients in certain situations where no other service is able to assist

<sup>10</sup> Patients for Patient Safety (PFPS) is a World Health Organisation initiative aimed at improving patient/service user safety in health care.

## 3. Proposal

### 3.1 Patient and service user Partnership Proposal

This proposal represents the joint vision and priorities following consideration of the submissions received and the outputs from the co-design patient and service user partner workshops. It has been jointly developed to embed patient and service user partnering in Health Regions design and governance using the agreed priority areas (the three concept propositions) as follows:

- Patient and service user representation
- Improving the patient and service user experience
- Improving governance and accountability

### 3.2 Patient and service user Representation

#### Patient and service user Partnership

Active patient and service user participation and the patient and service user as a ‘true partner’ is the key component of this proposal. The restructuring of the health system regionally, and the proposed implementation of Health Regions offers an important opportunity to deliver a health system which works in partnership with the communities and populations that it aims to serve. The continued focus on building a better health system must put in place the building blocks for diverse, meaningful, and sustained patient and service user partnerships recognising them as true partners in decisions about care, service design, research, and governance.

The agreed patient and service user partnership structures should deliver on patient and service user’s preferences, needs, expectations and values, while also cultivating an appropriate culture. The structures should support and input into best practice and practical approaches in relation to patient and service user partnership, standards and future developments. However, patients and service users are not solely responsible for partnership activities, as this will be the responsibility of each and every team within the new structures.

Patient and service user partnership is an essential element of a functioning health system and the Health Regions Programme proposes a standardised model for this partnership nationally. This will be underpinned by a National Patient Service User Partnership Strategy (currently in development) and core standards developed at the centre and embedded in Health Regions from design stage. The ‘*Better Together: The Health Services Patient Engagement Roadmap*’<sup>11</sup> (2022) will be used to assist in this regard. It is acknowledged that not every patient and service user is an experienced advocate, however every patient and service user has a valuable experience to share that can help shape positive outcomes.

#### Patient and Service User Council

There should be a **Patient and service user Council** in each Health Region. This is an advisory council that has a mandate to assist the Regional Executive Officer (REO) and Executive Management Team (EMT) to deliver an improved service to patients/service users and to ensure their needs are met. The council will provide advice and guidance to the region in areas relevant to patient and service users with the objective of improving the patient and service user experience. These councils will be the primary mechanism for patients and service users and organisations to come together and discuss cross-organisational, strategic issues. This council would have membership/roles on various different committees and working groups across all layers of the Health Region. This partnership approach should filter down across all services within the Health Region as they transition into Integrated Health Areas<sup>12</sup>.

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<sup>11</sup>: Available at <https://www.hse.ie/eng/about/who/national-services/partnering-with-patients/resourcesqid/hse-better-together-patient-engagement-roadmap-book.pdf>

<sup>12</sup> As the six Health Regions will serve large populations in their own right, it is recognised that a sub-structure within each region will be required and must be designed from the ground up. It is proposed that these sub-structures will be called Integrated Health Areas (IHAs). They will serve a population of up to 300,000, will take account of varying geographies, population size, local needs, and services.



These councils should bring in representatives from existing regional partnership mechanisms within specific parts of the health service e.g. mental health, disability services etc. The regional partnership council chairs will be linked in with the national patient and service user forum which is the primary mechanism for patient and service user organisations to come together at the national level.

Identifying these various different committees and working groups that patients and service users will be participating in and the mandate, will be part of the next phase of the patient and service user partnership design. Patient and Service User Councils and designated patient and service user representatives must have an input into the decision making in key areas of health care on behalf of the wider patient and service user body within each Health Region. Terms of reference (TOR) for these councils should be co-developed nationally, with clear guidance provided around their structure, reporting line and remit. The ToR can subsequently be tailored to reflect the local/regional context, without impacting upon the core design.

The critical elements of this proposal will be ensuring patient and service users on the council have the following:

- A clear mandate which is standardised nationally
- Broad representation across geographic, ethnic, health, age, gender and sexuality
- A clear set of achievable outcomes which are measurable, collated and analysed nationally to ensure consistency
- Patient and service user positions at Health Region and other committees and groups supported by a **Health Region Patient and service user Partnering Office** to ensure that the experience is embedded in the various layers of the governance structures of each Health Region. Training and education supports should be provided to council members to assist in the successful delivery of the council objectives.
- The Office should report directly to the REO (or delegated authority) as this ensures partnership is embedded across the health regions and a change in culture is led from the top. This is aligned with the HSE centre design.
- A role in the nomination of members to specific patient and service user partnering positions on designated committees within each Health Region. This includes the provision of peer support to nominees of committees. In the setting up of the Patient and service user Partnership Councils in each Health Region, deliberate thought must be given to the development of patients being actively involved in multidisciplinary working groups across specialities. This would be driven by actions in the Regional Implementation Plan<sup>13</sup> resulting from a National Patient Service User Partnership Strategy (when completed).
- These patient and service user partnerships should have a responsibility to be impartial and independent at a high level. They should contribute to developing a new model of patient and service user advocacy to bring organisations together to accelerate research, share results and promote patient and service user led change through partnerships with academia, industry etc.

Active recruitment of patient and service user partners with appropriate skills match with each of the respective committees should commence to ensure a diverse and inclusive cohort of interested representatives are available within each Health Region. This should translate to an enhanced patient and service user experience of being empowered while using services. This would occur primarily from patient and service user partners actively participating and influencing decisions within Health Regions. The following is suggested:

- That the opportunities available to patients and service users are advertised to the public
- That there be dedicated recruitment criteria and a selection process
- That a plan to renew and rotate personnel in these positions following a designated time period be articulated.

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<sup>13</sup> This refers to the Implementation Plan for patient/service user partnership. Each region must have their own implementation Plan. Each Plan is specifically designed to implement the vision and objectives from the National Strategy for Patient and Service User Partnership. This strategy is currently under development.

## Strategy & Planning

The National PSUE office attached to the CEO's office is responsible for the development of strategy, policy and standards in the area of patient and service user partnership.

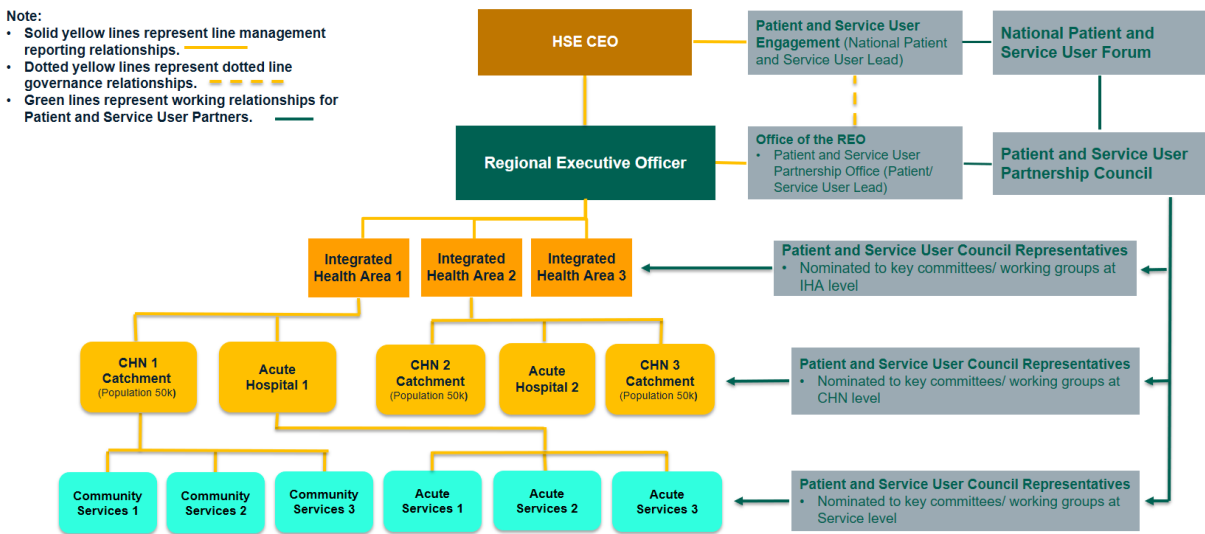
The six regional Patient and Service User Partnership Offices will have a dotted line governance relationship to the National PSUE Office to ensure consistency of policy and standards. The focus of the regional partnership offices should be on identifying the partnership priorities and activities of greatest importance in their regions.

Patient and service user partnership design at regional level will need to be aligned to the National Patient Service User Partnership Strategy (when finalised), through a Regional Implementation Plan. The plan for this design should be set out nationally, and each Health Region will be required to set out how it will deliver patient and service user partnership in line with the National Strategy.

The plan/design should have clear objectives and targets with timelines and measurable indicators of progress set nationally. It must be adequately resourced and have an appropriate budget identified for successful implementation. The co-design of this plan should be a partnership approach between the Patient and service user Council and the Health Regions management structure. The plan should be coordinated, implemented and monitored by the Patient and service user Partnership Office within each region.

**Figure 2 - Proposed Regional Patient and service user Partnership Structures**

### Proposed Regional Patient and Service User Partnership Structures



*This is one of a number of management structure options being considered. This is being used for illustration purposes to identify the Patient and Service User Partnership Council and its interactions in the National and Regional structure. It does not represent all interactions with partnership/ governance forums etc.*

### Patient and service user Partnership Office

A Patient and service user Partnership Office should be established for each Health Region. This is the executive function of the patient and service user partnership whose mandate is to assist the council achieve its objectives. Significant functions of the office will include the:

- recruitment to the secretariat<sup>14</sup> and to the councils,
- development and delivery of an Implementation Plan

<sup>14</sup> A permanent administrative office or department

- co-ordination of the activities associated with the patient and service user partnership resource within the Health Regions.

It is proposed that:

- the patient and service user engagement leads in community and acute hospital settings will be part of this office
- the office will play a lead role in out-reach to the local community, education and training for staff, and implementation of partnership projects. Health Region Patient and service user Partnership offices will have a designated **Patient and service user Partnership Lead** with relevant expertise relating to this role.
- Each Health Region Patient and service user Partnership Office should have dedicated staffing to provide a meaningful partnership programme and to facilitate the delivery of the Regional Implementation Plan. These office budgets would provide for reasonable remuneration/involvement payments to patients/service users who give their time to support co-design projects, working groups, or advisory boards' in line with the National Strategy. Budgets associated with this office should be ring-fenced to ensure the successful implementation of the Health Regions Implementation Plan. It is envisaged that national and regional HSE internal communications will assist in raising public awareness of these offices once established, and this would enhance public confidence in the health services.

The introduction of the Health Regions provides an opportunity for REOs to allocate/align appropriate resources to ensure that the partnership agenda is core and will deliver on objectives (both National and Regional). This will ensure each region builds internal capacity, grows a new culture of working, and builds on public trust in our health services.

It is proposed that the Regional Patient and Service Use Partnership Offices will report directly to the office of the REO, however, they must also ensure coordination with the National PSUE office. The National office will set and oversee the implementation of the National Patient Service User Partnership Strategy (once finalised) and issue guidance and policy on preferred partnership approaches, tools and performance metrics.

The mandate applied to the Patient and Service User Councils and Partnering offices will allow the organisation to embrace the recommendations highlighted in the three Concept Propositions. This will also allow the partnering structures to be flexible enough to facilitate creative involvement in other areas such as user testing of public facing systems (e.g. appointment Apps<sup>15</sup> and repositories for accessing patient and service user healthcare records). These improvement areas should be identified in the Health Regions Implementation Plan initially and delivered through service improvement plans under the governance of the Patient and Service User Partnering office and ultimately the REO.

### 3.3 Improving the Patient and service user Experience

Patient and service user partners have identified the importance of improving the patient and service user experience as part of the Health Regions design. They recognise the need to invest their time in contributing to the areas of communications, education, training, systems, and culture. This concept proposition placed emphasis on supporting '*staff, patient and service users and carers to navigate the health and social care system within their new Health Regions*'.

#### **Communication**

It is proposed that Patient and Service User Councils and Partnering Offices will be mandated to:

- Establish focus groups aimed at improving patient and service user communication
- Make the Patient and Service User Council visible within the Health Region(s)

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<sup>15</sup> An App is an abbreviated form of the word "application." An application is a software program that is designed to perform a specific function directly for the user or, in some cases, for another application program.

- Make the structures and visibility of the council attractive for further recruitment of patient and service user partners
- Assist with communications training with the objective of improving partnership between professionals and patient and service users, both actively listening to and learning from each other's perspectives
- Support the Health Regions in adopting the use of consistent terminology that is known/defined for patient and service users and staff
- Work within the Health Region on communication and implementation of the National Patient Service User Partnership Strategy (currently in development) to ensure that those who have not historically been heard have their voice heard
- Assist with the implementation and follow up of surveys/schemes such as the National Inpatient Experience Survey<sup>16</sup> with an emphasis on supporting patients and service users, carers, and staff to navigate the health and social care system within their new Health Region
- Assist with staff surveys/awareness of patient and service user partnership/needs
- Participate in the learning from excellence in other Health Regions which will be supported by the national co-ordinating function of the PSUE office
- Work with policy makers on the use of clear, plain<sup>17</sup> language and accessible formats on any literature or communications
- Assist with a review of communication platforms in the context of the user's perspective and assist in the improvement of public facing systems and information platforms in the context of user testing
- Work with the organisational Communications Departments and other elements of Health Regions to improve communication so that it is more open, through user friendly systems
- Work with the regions on patient and service user feedback through existing models such as Your Service Your Say (YSYS)<sup>18</sup>.
- Play a lead role in creating a '*deliberate dialogue*' with members of the Health Region Executive Management Team (EMT) in building and maintaining those working relationships.

## **Culture**

It is proposed that Patient and Service User Councils and Partnering Offices will be mandated to:

- Support the Health Regions to develop a patient and service user-friendly culture
- Work with the Health Regions Executive Management Teams on furthering partnership arrangements through training and education on patient and service user partnership
- Work with the Health Regions Executive Management teams to develop a culture where the patient and service user is seen holistically and not just in the context of their condition/illness.

## **Access / Integration**

It is proposed that Patient and service user Councils and Partnering offices will be mandated to:

- Support the Health Regions in the development of technical solutions to improve access and integration by providing the end users perspective on how the solutions would work best. Practical suggestions such as patient and service user facing App development, a designated accessible 'easy to recall' phone number and a published directory of services in conjunction with an accessible website were provided as examples in the concept propositions
- Work with Health Regions to publish information on waiting lists so that service users would be aware of wait times
- Assist on integration projects with patient and service user partners providing guidance on the end users perspective around connectivity between services (internal and external to the Health Region)
- Assist in a review of healthcare systems from the patient and service user's perspective to improve services and navigate through the system
- As part of service improvement initiatives, assist the Health Region by providing guidance in the reform of existing services to improve access for patients and service users where appropriate
- Support the Health Region to future proof the integrated structures and ways of working with longer term systems development. There is a need for patient and service user partners to be involved in the design

<sup>16</sup> <https://www.hiqa.ie/areas-we-work/health-information/data-collections/national-inpatient-experience-survey>

<sup>17</sup> Guidelines for Communicating Clearly using Plain English with our patient/service user. Available at <https://www.hse.ie/eng/about/who/communications/communicatingclearly/guidelines-for-communicating-clearly-using-plain-english.pdf>

<sup>18</sup> <https://www2.hse.ie/complaints-feedback/>

of such systems (e.g. Electronic Health Record [EHR<sup>19</sup>]) to ensure their perspective is considered especially as patient and service user facing access will be a key part of the design. Any systems that are introduced need to be interoperable at a local, regional, national but also a European level. This would ensure that Ireland's participation in the European Reference Networks<sup>20</sup> would not be hampered and impeded by the barriers currently faced in data sharing and patient and service user records. The digitisation of patient and service user records should also include a 'patient and service user portal' whereby patients and service users/families (where appropriate) could upload and or access their own information, knowledge, and experiences. This should also include patients and service users having the capacity to interpret their own data so that they can be active partners in their own care

- Work with the Health Regions on the ongoing development of '*maps and a compass*' for services. These structures would assist in facilitating seamless access to the service and information as regards waiting lists etc.

## **Data / Information**

Access to patient and service user information is considered a key component of current and future needs. Much of what happens in terms of digital transformation will have a large impact on patients and service users and the type of service they receive. It is proposed that patient and service user partners be involved in the co-creation/ development of data/information systems to improve access to information (where appropriate).

## **Training, Education and Research**

Training and education should be integral to the patient and service user partnership process. It should be identified in the National Patient Service User Partnership Strategy and incorporated into the Implementation Plan. It will be key to ensuring the development of a patient and service user community who feel empowered and equipped with appropriate tools to negotiate and participate fully in the process. It is proposed that Patient and Service User Councils and patient and service user partnering offices will be mandated to:

- Develop strong links with Academic Partners to build on patient and service user partner representation.
- Be involved in research to assist with evaluating key areas of Health Regions which relate to patient and service users. An example of this would be the evaluation and assessment of the impact of an effective patient and service user partnership structure within a Health Region as compared to other Health Regions or the satisfaction rating of patient and service users within that Health Region.
- Develop a training and education plan for patients and service users to educate them so that they have the skills, and also the knowledge of the organisation to facilitate optimal engagement at all levels
- Develop a training and education programme for patient and service user council members.
- Support a joint/integrated approach to training and education within Health Regions in relation to patient and service user partnership where appropriate. This includes supporting education programmes for both patients and service users and staff in expectations and core components of patient and service user partnership. This should be reflected in the training and education plan.
- Empower and engage and patients and service users via health literacy through Health Regions. This should also be reflected in the training and education plan.

### **3.4 Improving Governance and Accountability**

The importance of respect, behaviours, culture and the strengthening of accountability to patients and service users was emphasised throughout the process while developing this proposal. These were linked with the Performance and Accountability Framework. It is proposed that, in order to give a formal acknowledgement to the increased involvement of a patient and service user partnership, consideration should be given to the addition of a 5<sup>th</sup> domain of patient and service user partnership. This should be

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<sup>19</sup>An EHR is a digital version of a patient's medical record that is designed to be shared between different healthcare organisations, such as hospitals, clinics, and pharmacies. EHRs are designed to improve patient care coordination and communication between healthcare providers.

<sup>20</sup> [https://health.ec.europa.eu/european-reference-networks\\_en](https://health.ec.europa.eu/european-reference-networks_en)

considered alongside the existing four domains of Finance, HR, Access and Quality<sup>21</sup> with agreed standards and measurements (Key Performance Indicators [KPIs]) for patient and service user partnership with national oversight under the Accountability Framework.

This should result in patient and service users being valued with:

- Consistency and continuity of integrated care
- Improved accessibility to services
- Improved access to information

## **Governance**

It is proposed that patient and service user councils and partnering offices will be mandated to:

- Support with the improvement of patient and service user experience within the Health Regions structure through the development of relevant metrics in the Accountability Framework
- Meet with the EMT at Health Region level, in terms of ensuring that the patient and service user's view is communicated and adopted. A twice yearly joint planning meeting between the Health Region EMT and the regional patient and service users council should take place to consider progress on the Implementation Plan from the previous six months and to plan for the year ahead
- The Patient and Service User Partner Lead will work on behalf of the REO to engage with members of the EMT on partnership issues so that the partnership community can have confidence that their voice will be regularly, adequately and meaningfully represented
- Support senior staff teams within the Health Regions to reach out to patient and service users. This could be done by having patient and service user partnership as a standing item on agendas and facilitate 'deliberate' dialogue
- Strengthen accountability within Health Regions through partnership and patient and service user feedback

## **Standards / Measurement**

It is proposed that patient and service user councils and partnering offices will be mandated to:

- Co-design the development of KPIs and national standards in relation to patient and service user partnership. KPIs should focus on a number of patient and service user focussed outcomes including Quality of Life Measures<sup>22</sup>
- Support local audit to ensure that there is effective implementation and governance of relevant PPPGs
- Support the use of audit to ensure consistency nationally and support learning and continuous improvement
- Support the development of policy and performance
- Establish a Model of Improvement to implement outcomes from service initiatives e.g. focus groups
- Consider the use of the 'Your Voice Matters'<sup>23</sup> to evaluate patient and service user partnership experiences.

### **3.5 Proposal Conclusion**

This is a joint document and it represents the outcome of a co-designed approach to patient and service user partnership that will feed into the design of the Health Regions. The proposal includes the patient and service user as core to the regional and sub structures. The combined council and executive level posts will result in patient and service users being represented throughout the regional structure.

It should also be noted that in this proposal the Patient and Service User Partnership Lead will report into the office of the REO, however it is proposed at this time that they will not sit on the EMT as a member or advisor. It is acknowledged that this area is evolving and developing and that patient partners have also highlighted the need for a patient partnership representative at EMT level. This is being proposed to keep

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<sup>21</sup> <https://www.hse.ie/eng/services/publications/performance-and-accountability-framework-2023.pdf>

<sup>22</sup> Quality of life measures are designed to include the perspectives of patient/service user regarding the impact their health and healthcare interventions have on their lives and includes aspects of clinical decision-making and research.

<sup>23</sup> <https://www.hse.ie/eng/about/who/cspd/patient-narrative/your-voice-matters/>

pace with the evolving nature of this function, including the development of the National Patient and Service User Strategy. This requires further consideration from programme governance.

The Health Regions Programme team will be seeking approval for this proposal from Programme Governance and acknowledge the significant opportunity that has been afforded to them to embed patient and service user partnership in the design, delivery and improvement of services. The team remains fully committed to this process and will work closely with the Assistant National Director, PSUE Lead and their team in aligning this work to the National Patient and Service User Strategy, which is currently in development.

On this basis the Health Regions Programme Team are recommending that the co-designed proposal as has been described should be considered for approval as part of Health Regions design.

**Acknowledgements:** *The Health Regions Programme Team wish to acknowledge the co-operation and goodwill afforded to them by the Patient and Service User partners and all stakeholders during this process.*

## 4. Appendices

### 4.1 Appendix I - Full Text of the Submission from the Chair and Joint Chair of the HSE National Patient & Service User Forum

The restructuring of the health system regionally, and the proposed implementation of Regional Health Areas (RHA<sup>24</sup>s), offers an important opportunity to deliver a health system which works in partnership with the communities and populations it aims to serve.

In parallel to clinical and operational engagement, the continued focus on building a better health system must put in place the building blocks for diverse, meaningful, and sustained patient/service user partnerships with patient/service users and service users, to involve them in decisions about care, service design, research, and governance.

In many cases, the structures for these sustainable partnerships are not yet in place – nationally or regionally. We want to see patient/service user partnership viewed as an essential element of a functioning health system. We propose a standardised model for patient/service user partnership embedded in the national approach to RHAs from the start, which would send an important message publicly that the re-structuring to the regional level is more than ‘shuffling the cards’.

Specifically, we want to see three patient/service user partnership elements in place in each RHA:

- **A Patient/Service User Partnership Strategy:** Each RHA should develop a strategy for how it will deliver patient/service user partnership. This strategy should be co-designed with patient/service user representatives (both patient/service user organisations and individual advocates) from the RHA. It should have clear objectives and measurable indicators of progress. Ideally, RHA strategies for patient/service user partnerships would be guided by a broader HSE strategy for patient/service user partnerships.
- **A Patient/Service User Partnership Office:** Each RHA should establish an office for implementing its patient/service user partnership strategy and associated programme of activities. This office should be adequately staffed with experienced patient/service user partnership practitioners. The patient/service user engagement leads in community and acute hospital settings should be part of this office. The office should lead on outreach to the local community, education and training for local staff, and implementation of partnership projects. Ideally, RHA offices for patient/service user partnerships would be led by a patient/service user director – an individual with lived experience of the health system.
- **A Patient/Service User Partnership Budget:** Each RHA should be allocated a budget to support the implementation of its patient/service user partnership strategy and to staff and resource its patient/service user partnership office. This budget should be co-managed with patient/service user representatives from the RHA. Ideally, RHA budgets for patient/service user partnerships would, among other things, provide for ‘involvement payments’ to patient/service users who give their time to support co-design projects, working groups, or advisory boards.

To ensure that these patient/service user partnership elements are prioritised in the RHA implementation work plan we believe that **two patient/service user representatives should immediately be added to the RHA implementation working group**, rectifying the lack of formal patient/service user involvement to date.

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<sup>24</sup> The term RHA (Regional Health Area) has been replaced by Health Regions and is now used in place of RHAs. This term was left in the text of the submissions received as the term RHA was still in use when the submissions were received.



## 4.2 Appendix II - Submission from a member of the National Representative Service Panel

Slide	Comment
	<p>It would have been useful to see the slides in advance so that questions could be asked in person and a discussion generated as that would trigger ideas and thoughts, a conversation and would likely result in this exercise providing a more comprehensive output.</p> <p>Slides don't print out on the page. It is important to remember that in terms of accessibility some people need hard copies to work from</p>
2	Stakeholder Engagement – did that include any PIPs?
3	<p>The abyss between acute and community services has long been evident, I've been thrown into it many times!</p> <p>In part caused by budget held by acute or by community, service protects own budgets, no monies assigned to support transition from one to the other, nor effective policy re transition as Integrated Discharge seems not to be evident in practice.</p> <p>New system has to address this and create an accountable pathway, both financially and operationally to facilitate effective community to acute to community transitions which have patient/service user Safety as the defining quality measure.</p> <p>What are the CHO populations and what are the RHA populations based on current figures?</p>
4	<p>Dublin centric labelling – Dublin is A. RHA F seems a larger geographic area than others.</p> <p>How are the issues of area planned for: population density, demographic a) health b) disability c) age, what are current healthcare resources</p> <p>Is the new model Dublin centric for expertise re paediatric services, specialist services?</p> <p>Are there plans to ensure that:</p> <ol style="list-style-type: none"> <li>Other than for very specialist services, all RHAs have access to equivalent resources, services within them?</li> <li>Patient/service users have equitable travel distances and also effective public transport to access them.</li> <li>In the absence of effective public transport or for those who cannot use it, are arrangements made to ensure parking cost concessions as otherwise there would be an associated cost to access health services in one RHA which are not equitable with another due to lack of infrastructure/transport links</li> </ol>
5.1	<p>Sensible.</p> <p>Need to define the terminology used, person-centred Change Guide Page 196</p> <p>Our HSE desperately needs a consistent terminology which everyone uses, where the conceptual understanding of each term is consistent across all involved with our HSE, employees and users.</p> <p>Community first – good move.</p> <p>What are the needs of the population?</p> <p>How will this be assessed, considered, what data will be used?</p> <p>Historical data which would root 'the new' in the old or is a 'modern' more wide ranging 'needs' assessment being used which involves ALL stakeholders' groups, PIPs as equal partners in mapping where the current strengths and weaknesses of an area currently are.</p> <p>Make sure strategies are created to reach those who have not historically been able to make their voice heard as they are housebound or otherwise invisible.</p> <p>Building the new on a very unstable base re community services is a challenge which needs a different process to identify:</p> <ol style="list-style-type: none"> <li>Where current systems do not exist, are not working, do not support staff or patient/service users/service users/SU. Staff need connectivity and support of their team in pressured situations, yet geography means those teams are often poorly connected and I question if there is chance for staff to tap into a formalised support network. Such a network would provide the opportunity for 'together' discussion of new policy, changing practice, local and national developments etc. providing a connectivity which is currently, from my observations, lacking.</li> <li>Funding – basing funding on an existing data profile is not advised unless there is a high probability that that data profile does capture the RHA 'character', needs, population, current resources and those that are not equitable with other areas.</li> </ol>

	Add in effective practice implementation of all PPPGs and operational practice to ensure consistency of standards across ALL RHAs and audit implementation practice!
5.2	<p>Then add in effective governance practice</p> <p>My caution is that without rigorous local audit, with practice consistent across all RHAs. Consider a model where those responsible for local audit have access to those from other RHAs competing the same process, this ensures a team for support and the 'standards' are more likely to be met when others are aiming for the same standard of process.</p> <p>Whilst there may be a need for some local variation without consistency in the audit tool RHAs cannot be compared as to equity of provision, an ongoing problem in CHOs and hospital groups where geographic inequality is evident.</p> <p>Then national audit is a secondary, rigorous, governance check feeding into the National Scorecard.</p> <p>How will equity between RHAs be assessed?</p> <p>Devolved decision making is a sound proposition but needs to be balanced with effective networking with others across the country so that learning is transferred in an effective manner between RHAs. Whilst there are current mechanisms which 'should' facilitate this, is their effectiveness measured?</p> <p>E.g. YSYS Case Book. Does the learning shared result in measurable change elsewhere and how is that measured.</p> <p>There needs to be care taken to avoid having 6 mini HSE's with no strong network between them. Strong effective network strategies need to be considered throughout the planning process.</p>
5.3	<p>See 5.1 How are the needs to be assessed.</p> <p>The most robust practice re patient/service user involvement in this process is needed, Focus groups are a very basic level of engagement, active participation is needed, involve the population in creating 'Our RHA'.</p> <p>See Better Together Framework Page 46 &amp; 47 and consider the:</p> <ol style="list-style-type: none"> <li>Change Guide Standards on engagement, Page 241 applies to those working in or relying on services</li> <li>NSS Patient/Service User and Public Partnership Strategy 2019 -2023 Page 11 Arnstein's Ladder of Citizen Participation</li> </ol> <p>Think of music being made up of notes and silences. If we base funding only on the notes (current data or easy access vies/quantitative responses) we miss the opportunity for a true assessment of need which shines the light on areas where need has never been acknowledged never mind measured.</p> <p>The reasons why need has not been acknowledged needs to be considered – too big a problem, an unsolvable problem, not sufficiently in the public eye, a less attractive demographic, geographically too scattered a problem so hard to provide a budget contained solution etc. Whatever assessment tool is used it needs to comprehensively capture all the notes AND the silences so that the music of an RHA is actually heard, not just the noise of it.</p>
5.4	<p>See above.</p> <p>Important that the standards are known of by ALL employees and service users.</p> <p>Day to day governance, soft governance arises when any person relying on an organisation (for employment or service) can say to another 'what about ... I thought x was supposed to happen next'.</p> <p>Creating a cultural shift where it is 'ok' for one person to open a conversation with another about what 'should' be happening is a sign of a healthy organisation and seeds organic growth.</p> <p>It is one reason why PIP is essential as are all aspects of patient/service user engagement, the patient/service user as a true partner in our HSE and our RHAs.</p> <p>Suggest a requirement for EVERY new piece of documentation has a 'one pager' to summarise it as an introduction. More accessible for staff and SU, it offers a 'starter' option before trying to digest the (sometimes overwhelming) main course!</p> <p>That one pager can also be revised to ensure all accessibility needs are met and can be the core information provided when using more modern methods (young people communication methods!!) who must be actively attracted as they are the future of all our health services, we need to connect with them and include them now.</p> <p>One caution re-funding:</p>

	<p>I have seen in another country new budget allocation process being introduced. In the years prior to the new funding formula being applied one area had been fiscally responsible another had not.</p> <p>The needs of the non-responsible one were assessed as being higher as they had run out of money! In the years that followed the one area with lower funding, yet arguably higher needs, was always struggling where the other had the 'additional %' in their budget to indulge in innovation.</p> <p>The difference in staff morale when there is room for innovation for personal passion to flow is evident, those trying to make ends meet closes the door on vision and passion.</p>
6	<p>See above.</p> <p>Question: How do we solve the existing problem of lack of PA/Carer support which is an existing national problem? Is it worse in some areas than others? Is Government intervention needed if HSE management cannot? I'm sure there are other areas where similar questions could be asked. If we cannot manage the current PA/care in the community, no solutions have come to light, is there a robust national data set on those:     Under 18 b) 18 – 65 c) 65 and over To help us understand where the problem is and why it is happening? a) How on earth do we change that in the 'new model'?</p> <p>Is the current model of provision appropriate, acceptable and does it meet the threshold of effective governance and equality of provision given so much of this work is 'farmed out' to Section 39's or to for profits who are not Section 38s or 39s. Whilst I understand the for profits are subject to an SLA, how do they sit within the Health Act 2004 which seems only to refer to Section 38 and 39s.</p> <p>Does the current model where health budgets are being poured into for profit businesses do we need now to check that those patient/service users and people relying on these services which CHOs are currently funding, are providing the quality of service, consistency and equality of approach and principles as would be expected of a Section 38 or 39? If not why are those relying on a 'for profit' not 'equal' to those reliant on those with Section 39 designation?</p> <p>A similar consideration is the cost of 'agency' staff and how they impact on quality and safety standards and if the high cost translates to acceptable standards and quality of patient/service user care which evidence HSE standards.</p> <p>High turnover of agency staff does not support the patient/service user or network opportunities as the 'permanent team' is smaller than it needs to be for effective support.</p> <p>Also buy in to HSE standards and principles is not facilitated nor is there buy in from agency staff as there is no long-term commitment. N.B. this is no reflection on the quality of staff rather on the model which does not include them as partners who have 'bought into' improvement opportunities because it is 'their' team, 'their' work area and they are invested in longer term improvements.</p> <p><b>Improve the health and well-being.</b> There is an assumption that all health issues can be improved. This not the case. The language could be interpreted as implying a 'you are not included/blamed if you don't improve'. Given the lack of services for those with chronic illness, both acute and community and the lack of staff who can attend a home where the person cannot get out, has no PA support to leave their home, no support network, access to an OT, physio, dental services, chiropody etc. remains a part of the unlevel playing field in a health service which requires a person 'to attend' a service. Please build into the assessment that there are those who cannot reasonably leave their homes or can only do so with effective supports which, if those are not available, there is an immediate inequality in service provision – if you are insufficiently able there is no health service for you – you have to attend. Many Service Providers of 'home care' services will not travel a Client and many CHOs do not assess/provide hours to leave a home, the need is not acknowledged or considered.</p> <p><b>How will the GP problem be addressed?</b></p>

	<p>GPs are the gatekeeper to acute services through referral. If a person cannot register with a GP or cannot get to them how is a referral to another service possible?</p>
7	<p>How are 'better' outcomes to be measured? See page 172/173 of the Change Guide. At the end of page 173 it says 'improved' and 'better' are not specific enough. QI requires: a) measuring the starting point, the current situation b) measuring end point Assessing the difference, qualitative and quantitative between the two. As the RHAs will be new, how will their 'starting point' be assessed? This is where the assessments which support the profiling process can have a dual role, if strategically planned so that Public Value (Change Guide Page 298) can be assessed and measured to assess improvements and to signal the next cycle of change. Public Value is THE measure and that requires innovative methods as we move to a culturally different organisation which considers the patient/service user/SU voice as integral to design, planning, implementation, assessment and governance. <b>Clarity and continuity of care</b> – the vision is sound. Question: what changes are needed in current practice to address the following issues?  <ul style="list-style-type: none"> <li>- an energy source is going to be provided for stressed and drained staff and patient/service users/service users/SU to feel they can be 'excited' or raise an interest about what's ahead</li> <li>- how will any possible perceived threat be addressed</li> <li>- to enable a framework of standards known, understood and strived for across all services</li> <li>- clear accessible information about all services to ensure that the principles in the National Consent Policy 2022 are supported in practice</li> <li>- gaps in services filled</li> </ul> </p>
	<p><b>What would success look like?</b></p> <ul style="list-style-type: none"> <li>- I would have all my PA hours, seven days a week, not 2/7 alone the rest of the time.</li> <li>- I would have confidence in what was happening, I would know what 'should' be happening</li> <li>- Relationships with employees would be sufficiently strong to support flexibility when 'life happens'</li> <li>- There would be trust, openness</li> <li>- I would know my needs were met</li> <li>- I would trust acute services to meet my needs</li> <li>- I would never again fear being thrown into the abyss between acute and community care</li> <li>- The hidden, invisible, unseen people would be sought out, invited to speak, to be heard and their voices valued and change would arise from their stories</li> <li>- The complaint system would be effective, a straightforward, quality process to capture experiences, understand them and to identify where the experience fell below commonly known standards so that recommendations would be focussed on, this standard was not met what does this RHA/service need to do to mitigate against the chance of this happening again?</li> <li>- I would see the same standards shining out of all staff and being reflected back by patient/service users/service users/SU and there would be a commitment to a culture where saying to someone 'that is ok/not ok' is accepted as constructive feedback.</li> <li>- I would see true partnership, the highest levels of engagement not tokenistic involvement</li> <li>- Staff would understand how effective patient/service user involvement serves all of us</li> <li>- I would understand how out health services work, the national and local structure</li> <li>- I would have access to easy to use, attractive information for me (different people find different things attractive) which is the information I want and need not that which 'someone' decided they were willing to give me</li> <li>- I would see a happy and confident workforce who were not fearful of a complaint, of being blamed when the failure lies in poor policy/processes and inadequate government practice – the senior line managers are responsible for ensuring their staff have the supports they need to do the job they want to do</li> <li>- I would meet staff who know about the illness I live with in acute and community care, I would not be the person responsible for teaching staff</li> <li>- my care would be equivalent to that of a person with an 'acceptable' and known illness</li> </ul>
	<p><b>What is important to you?</b> See above</p>

**How do we best ensure the patient/service user voice in this design process?**

- National
- Local
- Understand the rich resource which is available to be tapped into.
- Use facilitators who do understand effective engagement to support a Chair of a group who is adhering to older practice of tokenistic/lower levels of participation as they have too much on to manage changing their practice whilst the same time getting the job done
- Do not let the Government draft policy of patient/service user Voice Partners limit access to the rich patient/service user resource available

### 4.3 Appendix III - Sage Advocacy Submission

This submission commenced with a number of comments and questions as follows:

'It is important to ask the question, whether or not patient/service user representatives and Representative bodies were involved in the initial discussions and planning of the changes that have been proposed to take place within the Health care system i.e. the move from CHO's to RHA's.

Careful consideration needs to be given to the messaging that is being given by the Department of Health and HSE regarding the importance and value of the patient/service user's voice (i.e. Patient/Service User Voice Participation PVP). Through this current process, where patient/service user representatives are being asked to give feedback on a very complex and challenging system transitional process, it appears that patient/service user/ patient/service user representatives are being asked for their input at a very late stage in overall process and have not been included as a valued decision maker from onset'.

Answers to the questions that had be posed by the Health Regions Team in January 2023 were then provided:

#### Question 1

#### What would success look like from a patient/service user perspective?

##### Structure

- One-tier system replacing the current Public and Private system (as outlined in a document created by Sage Advocacy "New Deal")
- The newly emerging community networks are top-heavy, with little focus on outcomes – there will be a period of trial & error for a while until the cultural shift required will happen
- Patient/service user representative groups have been raising issues experienced while navigating the healthcare system such as the lack of services, inadequate care pathways, gaps, etc. – these considerations would have to be addressed with the immersing of new RHAs
- A healthcare system that is fit for purpose and will meet the needs of the patient/service user across all care settings, hospital, respite, nursing home care, and home care
- Complete shift from current culture of "in best interest" to "will and preference", and use of "next of kin" to "Emergency contact person"
- Connectivity between hospitals and community services (including Mental Health and Disability services)
- The new RHAs should directly impact positively the quality of CARE and services received by the public
- A common purpose that crosses all disciplines of professionals, A common Vision by all for a better healthcare system that is inclusive of service providers and service users - Shared values, integrity, kindness, humility, empathy, compassion, and respect – a collective vision for change
- Partnership between professionals and patient/service users/service users, both actively listening and learning from other's perspectives
- Consistency across the RHAs – no more postcode lottery. The care of older people is a priority as services are so inequitable across the country and many are denied basic statutory entitlements, due to the lack of resources distributed from the top-down
- Good clinical governance needed – clarity re same should trickle down through the system
- Key workers/Advocates being appointed to a patient/service user in a timely manner where complex multidisciplinary teamwork is required to ensure adequate feedback to the patient/service user at all times (advocacy not just offered for complaints process)
- Regular Reviews of system/services/departments and reset after success and failure
- Delegation - Consultants need to agree on devolving some of their responsibilities to ANPs for example – this will enable patient/service users to be seen quicker and consultants should intervene when necessary
- Holistic view of patient/service user care to be adopted by all levels of acute and community services
- Current appointment system gives a number of patient/service users the same appointment time which is challenging for patient/service users to have to wait very long periods in waiting rooms (especially if a person is older/vulnerable)
- Healthcare system needs to be easier to navigate for everyone. Current system is complex and difficult to navigate - Needs to be made easier, especially for our most vulnerable and aging population– proper assistance to be given throughout the patient/service user's journey, e.g. admission to hospital- regular check-in and clear plain English communication with patient/service users/service users
- Clearly laid out care pathways for specific conditions, as well as for complex patient/service user issues where multidisciplinary teams are made available

- Patient/service users should no longer feel that they “fall through the system’s cracks” and that there is no care pathway for them.

*Accessibility and availability to appropriate services in a timely manner, such as:*

- GP in the community at present is difficult, this is resulting in patient/service users having no other option but to arrive at Emergency Departments or further deterioration which results in an increase in care needs and longer medical attention. Consideration of having telephone consultations when and where appropriate, with support in the community to cut down on time and unnecessary travel for frail/ vulnerable people.
- A need for improvement on the relationship/partnership between HSE, Disability Services, and Mental Health services – lack of engagement of one or both of these services often results in patient/service users having delayed discharges from much-needed acute beds or having multiple re-admissions to hospital. Also, lack of funding for vulnerable adults from Disability service/Mental Health service resulting in funding coming from Older person services instead
- Careful consideration when Budgeting for services and recourses - to meet the needs of the RHA, need to consider the increase in population AND aging population (especially beds in acute settings) along with the impact of Covid 19 on people’s mental and physical health
- Critical need for community services to include home help as opposed to just Home Care (for personal care only)– Currently Older people are presenting to acute settings due to Social issues with no medical care need, resulting in patient/service users taking up much-needed hospital beds. This is often due to community services refusing to enter people’s homes due to the condition of the home and not providing some level of care OR Gardaí/Neighbours/family raising concerns that an older person/vulnerable adult is no longer able to manage at home – this needs to be addressed in the community by community services
- Quicker response times for accessing Consultant / Consultant Reports – currently delays result in patient/service users/service users’ condition deteriorating and often having to be admitted to ED, taking up much-needed hospital beds and delaying discharges

### **Transparency & Accountability**

- Transparency of service provision i.e. costing of services, wait lists etc. (Service users would have the opportunity to understand barriers to care if there was a quarterly published report in each RHA and likewise there would be accountability for each RHA and the service they are delivering)
- Patient/service users want/need to be treated fairly, and equally without prejudice as to their age/condition/presentation, this includes being included in any discussion or decision-making that is taking place, “Nothing about you, without you”. If a clinical error takes place, owning it and giving a timely genuine apology works better than withholding the information for a long time.
- Where outsourcing of service to private providers exists, proper oversight and accountability need to be in place - Older people have experienced private home care providers withdrawing service of care, leaving them vulnerable without any consultation or alternatives explored in good time.

### **Training, Education, Communication**

- Proper Communication skills are essential, and a need for an easy-to-follow, plain English language to be used throughout all levels of service
- Professionals (Public and Private sectors) sharing the information between them appropriately, so that the patient/service users don’t have to give the same account over and over again – especially where patient/service users may not be in a position to give this information due to communication difficulty or impaired cognition
- Focus on Training, development, and knowledge within staff and teams
- Mandatory Training needed for all staff who work within private/public healthcare systems re ADMA, Consent, Patient/service user-centered care, etc. – everyone needs to be working under the same guiding principles to ensure success
- Public awareness is needed regarding existing services & referral pathways, basic human rights (ADMCA), Consent policy, “Next of Kin” limitation, including in Media
- Adequate training for professionals to work across boundaries outside of their own scope of practice i.e. patient/service users with more than one care need (person with a disability along with Dementia).

### **Question 2**

## What is important to you that we need to factor into the detailed design?

- Cultural shift is required.
- Trust is restored to us all in our healthcare system – service users as well as a service providers – this can only be done by ensuring patient/service user/patient/service user representative involvement at every level of the process
- All issues raised by patient/service users/service users/patient/service user representatives and other bodies to date will be addressed and careful consideration will be taken regarding the same when designing new RHA's.
- Direct action is taken to improve the quality of care and experience for our most vulnerable people.
- Healthcare system is service user/patient/service user-friendly, the complexity of the current healthcare system is removed.
- interRAI rollout nationally is needed.
- Patient/service user healthcare record issue needs to be addressed – having a unique healthcare identifier can improve greatly patient/service user's care & experience – e.g. PPSN
- Patient/service user transport – availability, awareness, affordability & accessibility – patient/service users not being able to get transport from the community or Nursing homes to hospital appointments often resulting in deterioration of patient/service users resulting in hospital admission
- Access to Community Therapies (Physio, Occupational, Speech and Language) – availability, awareness, affordability & accessibility – Currently in various CHOs, patient/service users not being able to access appropriate therapies or equipment due to a shortage of resources/funding in the community- patient/service users often informed that these therapies are not available if the patient/service user is in a Private nursing home
- Home Care Package – current extremely narrow focus on personal care only. Other elements of support are needed in order to keep people at home
- New Deal - If Long Term Care and Home Help are funded from the same source, then there may not be such a bias toward Nursing Home care.
- People in all parts of the country need to have the same entitlements and access e.g. variations on the limit of Home help hours around the country.
- Availability of Services such as Social prescribing, Day care centres around the country along with Home Help hours to allow people to live at home longer
- Good infrastructure of professionals needed across the country (currently a shortage of many disciplines in many areas such as carers, occupational therapists, Physio Therapists etc. with access to people who need same regardless of setting. Currently, some residents, with a Medical Card, who are residing in Private Nursing homes (due to lack of beds in HSE Settings) are unable to access OT for specialized chairs because they are in a private setting due to no funding allocated for same
- Lack of alternative accommodation for people under 65s forced to be in nursing homes.
- Service Level Agreements for organisations funded under sections 38 & 39.
- All community staff need to be provided with training and information on what services are available in the community.
- Coordination on the development of services in the statutory and voluntary sector is needed- presently services are developing in a piecemeal fashion and this is costly and means that roles are overlapping with everyone trying to do everything and few achieving a good outcome for people in need; many efforts stall due to lack of statutory resources such as adequate accessible housing, transport or professionals deciding that a desired outcome for the client is not within “ their role” to supply.
- The inaccessibility of mental health services and the lack of good interprofessional structures in mental health community services need to be remedied for adults and older people and those with specialist needs.
- Regular meetings with agencies that support older / vulnerable people on a daily basis across all care settings to ensure that issues/ difficulties being raised are taken into consideration
- Accountability from the referrer and receiver of referrals throughout healthcare services (there is a sense that referrals go nowhere at times)
- Statutory basis for advocacy to support will and preference of service users
- Consideration for patient/service users with complex ever-changing care needs over time and how some of these care needs cannot be met in their own RHA but may have to move to another RHA where that need can be met, how will this be budgeted for?
- Currently, people with disabilities lose all of the services they would have had once they reach age 65, but yet, they have not lost their disability. This often results in people having no other choice but to go into Long Term Care



- Number of people with rare conditions for which there are no services available, but may belong to more than one area such as Mental Health, Disability, and possibly Older person also, often do not come to the fore until crises point, at which time the difficulty is sourcing the funding as opposed to an agreement to share the cost appropriately
- Consideration will need to be taken also to people who currently are not accounted for in the system, but yet have complex care needs with expensive costs covered privately.

### **Question 3**

#### **How do we best ensure the patient/service user's voice in this design process?**

- Patient/service users should have an equal voice at the table at every level, to ensure all perspectives are taken into consideration and to ensure the best outcome is achieved, rather than having to possibly revise the whole process at a cost
- Direct and Regular Engagement with all patient/service user representatives and Advocacy Services such as PAS, NAS & Sage Advocacy (the National Advocacy service for older people) to ensure that the voice of the patient/service user is heard, systemic issues are identified and highlighted so that they can be taken into consideration during any processes
- Reaching out to Umbrella organizations to gather as much information as possible about the numbers of people affected by certain conditions in each RHA that will need to be considered for budgeting purposes. In the case of people who have a rare condition, for which there is currently no service available, they will not present to the healthcare system until reaching a critical stage; if multidisciplinary teams and services for rare conditions would be put in place, the people affected would come forward earlier and possibly reduce extensive costs at a later stage, while also allowing for a proper collection of much more accurate data regarding various conditions'.

#### 4.4 Appendix IV – Patients for Patient Safety Ireland submission

This submission was as follows:

'Patients for Patient Safety Ireland (PFPSI) welcomes the plans for Regional Health Areas as an important step forward in integrated care and Sláintecare. As a WHO programme, we are informed by the WHO Global Patient/Service User Safety Action Plan.

Implementing RHAs provides an opportunity to innovate how healthcare is delivered. We are in general agreement with the Vision and Strategic Objectives, and would welcome the opportunity to further engage, examine and understand the plans - at a local, regional and frontline level. We would also be interested in understanding whether any patient/service user representatives were/are involved in the co-design of RHAs.

##### **What would success look like from a Patient/Service User Perspective?**

Equal access to safe, standard services where no one is disadvantaged by where they live is the minimum requirement for success - the maximum amount of care delivered as community-based services with smooth transition to and from acute services.

Primarily, PFPSI is interested in how the implementation of RHAs will develop and improve the 6 domains of healthcare as defined by the IOM:

- Increase Patient/service user Safety: Avoiding harm to patient/service users from the care that is intended to help them.
- Effectiveness: Providing services based on scientific knowledge to all who could benefit and refraining from providing services to those not likely to benefit (avoiding underuse and misuse, respectively).
- Patient/service user-centred: Providing care that is respectful of and responsive to individual patient/service user preferences, needs, and values and ensuring that patient/service user values guide all clinical decisions.
- Timely: Reducing waits and sometimes harmful delays for both those who receive and those who give care.
- Efficient: Avoiding waste, including waste of equipment, supplies, ideas, and energy.
- Inclusive and Equitable: Providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.

More specifically we would like to see the design include:

- Hospital inpatient/service user services that are for those who cannot be cared for safely anywhere else.
- Step up services from GP practices where hospitalization is not necessary and step-down services from hospitals where service users need them before returning to GP care.
- More appropriate care for elderly people with more services delivered as outreach to nursing homes thus avoiding transferring frail people to inpatient/service user hospital services unless their care path directs this is the most appropriate for their best outcome.
- Generally, more delivered to frail people in their own homes where their care is largely being well managed by their personal care network (family, carers, friends) thus avoiding the need for bed allocation, perhaps this could be done by expanding paramedics service within the ambulance service.
- Comprehensive (on site) healthcare teams to support our GP services if they are to remain the gate keepers to other services, with speedy access to patient/service user results, bloods, x-rays etc.
- More community involvement from community volunteers to foster health and wellbeing (Frome Project, Somerset, England by way of example).
- Better connection to education system to foster awareness of good health among our young people.
- Better access to mental health services, more walk-in clinics for people in crisis.
- Improved services for those with disabilities and supports for families struggling to do their best.
- Respite houses in all towns to assist families who just about cope with family members requiring enhanced services (physical, intellectual disabilities service users)

## **Important Points to Factor into the Detailed Design**

One of the many challenges facing healthcare in Ireland is how to translate the vision to strategy, then into action that improves the patient/service user experience - from national policy to management in each RHA and then through the frontline staff to the patient/service user experience. Introduce management development, based on a competency framework to create a culture of patient/service user safety, welcoming and facilitating co-design and co-production. Committed to Open Disclosure and a Just Culture.

Change always brings challenges – have a team of problem solvers to hand. Hold meetings in the towns around Ireland to activate communities to be part of this change – encourage citizens to be proactive – grow a sense of ownership – this is our health service – every voice matters – bring us your suggestions of what will make the health service in your community work for you, work with you. Reach out to rural areas via the community network – parishes, voluntary groups. Grow a new model among your staff and service users – OUR HSE (as opposed to THE HSE).

Plan for delivering multiple services in a community-based healthcare campus. Where suitable HSE estate properties are not available consider the most cost-effective alternative. There are lots of retail parks on the edges of towns that either have vacant buildings that could be repurposed or vacant land from the Celtic tiger years that are sitting as waste land. They usually have big car parks and would lend themselves to healthcare facilities. Similarly, there are many school buildings that have been replaced by new schools leaving the older schools vacant or under used in the community – repurpose them. Access by public transport (i.e., where bus services run close by or have a bus stop on site).

Patient/service user experience roles, with the relevant autonomy, reporting line and authority, must exist across RHAs to truly engage with patient/service users and patient/service user representatives on a quality basis – these roles have a clearly separate remit from those who primarily handle complaints. These roles will also ensure transparency and Open Disclosure. Finally – a rigorous audit process is important to measure progress and drive for learning and continuous development.

### **Ensure that the patient/service user voice is integral in this design process.**

Use the implementation of RHAs to embrace **true** co-design and co-production. Make it easy for people to share their experiences – the good and the bad. Invite participation. Grow civil responsibility, it's our health service, involve us. Capitalize on people sharing their ideas for improvement – what worked, what didn't. Keep complaints as a separate category - "opinions" are not necessarily complaints. Grow a listening service that takes constructive criticism and suggestions/solutions from ordinary people who use services. Forge a culture of partnership – help us to help you (Your service, your say modernized). Use the Better Together Roadmap. Grow successful initiatives, like having patient/service user advisers for all services. Expand human resources, patient/service user partnering know how and in general the communication capacity of all staff to invite and encourage patient/service user participation. We recognize that sometimes people need a little push or invitation to take part. During Covid19 we seen a lot of good community spirit – trap some of that. Community groups are good at going that extra distance – work with them and us all to make our HSE something to be proud of'.

## 4.5 Appendix V – Design Thinking Methodology

Following advice from the NDOPI and agreement with Chair and Vice Chair of the HSE National Patient and service user Partnership Forum, it was decided to proceed with the 'Design Thinking' methodology through a co-design workshop process specifically for Health Regions. The objective of the Design Thinking process was to define the priorities as identified by the patient and service user partners working with HSE and DoH colleagues, and to feed into the design and transition planning for the Health Regions.

Design thinking is a human-centred non-linear, iterative process that teams use to understand users, challenge assumptions, redefine problems and create innovative solutions to prototype and test. Involving five principles—Empathize, Define, Ideate, Prototype and Test - it is evidenced based and most useful to tackle problems that are ill defined or unknown.

Three 'Design Thinking' workshops took place which aimed to explore and understand existing challenges with Patient and Service User Partnership. These workshops were facilitated by a HSE staff member experienced in this area. Participants attending included those from the HSE National Patient and Service User Forum, PFPSI, and the HSE National Patient Representative Panel. A number of HSE and DoH staff also participated (See Appendix VI).

Participants followed the 10 Steps of the model to help understand and then develop ideas around optimising '*Patient Partnership for Our Health Service*'. Following detailed discussions about the challenges with patient and service user partnership, the workshops explored how meaningful Patient and service user Partnership can be developed to improve services from design to implementation and evaluation.

### **Overview of Outcome/Ideations**

At the first workshop on the 10<sup>th</sup> May 2023, participants proposed ideations and ideation themes (Appendix VII). These will be incorporated into a Patient and service user Partnership Blueprint for Health Region Executive Management Teams to provide a standard for how Patient and service user Partnership should be represented in the new structures.

This information will also be available to inform the Health Region teams in prioritising future plans for patient and service user partnering. The Health Regions Programme team working closely with the National PSUE Office will ensure that the outputs also inform the National Patient Service User Partnership Strategy which is currently being developed.

### **Concept Propositions**

At the second workshop, participants were asked to focus on a concept proposition. The three concept propositions that were prioritised were as follows:

#### **Concept Proposition & Proposal 1: Patient and service user Representation in the Health Regions**

This concept was developed with the following tagline:

'Patient and service user representation in the Health Regions: *Communications = A voice that is listened to and equal*'.

This described a 'problem' and a 'solution' as follows:

- 'No participation/training and support for patient and service user representatives'
- Solution 1: 'Create a structure that can be measured nationally and be effective and support them (patient and service user representatives)'
- Solution 2: 'Each Health Region needs a Director for Patient and Service User Partnership and all meet constantly'

The proposal put forward by the participants as part of this concept proposition included:

- Two patient and service user representatives at national level
- Two patient and service user representatives at each Health Region

- A Patient and Service User Partner Council in each Health Region with an office and a budget
- Strong links with Academic Partners to build on patient and service user partner representation
- Representation within appropriate governance structures/ committees
- The importance of having KPIs and national standards to measure, support and grow this concept

Participants identified that the primary focus should be on the patient and service user representation within the governance structure of the Health Regions. It was suggested that active recruitment of patient and service user partners with appropriate skills match with each of the respective committees should commence to ensure a diverse and inclusive cohort are found. Active partnership should then translate to an enhanced an experience and a sense of being supported while using the services. This would occur primarily from patient and service user partners actively participating in, and influencing decisions. It was suggested that services would benefit from the input of the patient and service user voice within the governance structures.

A suggested organisation structure identifying how patient and service users will fit into the Health Regions structures was proposed. This structure proposes a Patient and Service User Partnership Office and a council per Health Region. The proposed patient and service user partnering function would have membership/roles on various different committees across all layers of the Health Region. Their proposed mandate would be to inform the system of patient and service user partner views and input into decision making in key areas of health care functions on behalf of the Patient and service user Council.

It was suggested that the critical elements of the concept are ensuring patient and service users have:

- A clear mandate which is standardised nationally
- A clear set of achievable outcomes
- Broad representation across geographic, ethnic, health, age and gender categories
- Clear outcomes which are measurable and collected/analysed nationally to ensure consistency

From a Health Regions Programme perspective establishing patient and service user positions supported by **a Patient and Service User Council and a Patient and Service User Partnering Office at Health Region level** will ensure that the patient and service user experience is embedded in the governance structures of each Health Region.

#### Concept Proposition & Proposal 2: The Compass

This was described as ‘The *right care, right place, right time*’, and made reference to ‘*Issues with timely access to services*’ and outlined that the ‘*Population needs information and feedback loops such as - patient and service user reported outcome measures and the National Care Experience Programme*’. The concept placed emphasis on supporting, ‘*patient and service users, carers and staff to navigate the health and social care system within their new Health Region*’. The critical elements of the concept focused on the importance of:

- Trust, reassurance, confidence, and transparency
- Addressing service users and staff needs in regards to best practices for partnering with patient and service users
- Relationship building, needs assessment, information sharing and dissemination between Health Regions and the local area
- Health Regions communicating with each other and learning from excellence in other Health Regions, i.e. what ‘*works well*’, and what could be ‘*done differently*’, and how we can access the learnings, such as through an online archive of resources.
- Adaptability and culture change within the overall Health Regions and the HSE- Equal partnership which should be visible through training and education on Patient and service user Partnership
- A culture change in ‘seeing’ the person/patient and service user holistically and not just in the context of their condition/illness’
- The use of clear, plain language in any literature or communications
- Clarifying that accessibility includes services outside of the health system e.g. co-ordinated care, bus/transport services, and ‘*joined up thinking*’ across public services ensuring equitable access to services.
- Understanding the ‘*now*’ in terms of the challenges in accessing Health and Social services and understanding the ‘*next*’ in terms of how navigation and access can be improved.

- Understanding the concept of the compass '*guiding*' the path, but that it is '*important to contextualise where we are*' so that improvements can be made going forward.

Participants referred to the importance of the appointment of a Regional Executive Officer (REO) and their team and the **establishment of a Patient and Service User Partners Office** so that the patient /service user would have knowledge of local Health Regions and their services. The emphasis was on integrated working with information flowing seamlessly via an **Electronic Health Record (EHR)** between General Practitioner (GP)<sup>25</sup>/Community/Public/Private Hospitals acute care and all health and social care settings. Participants were of the opinion that (once in place) the EHR would allow comprehensive sharing of records leading to more effective, personalised care and would improve access for patient and service users. The aim is for '*seamless access*' and this ideal was described as a '*symphony of efficiency*' by participants.

Advertising through the mediums of television, radio, and other social media (depending on the age group being targeted) was put forward as a solution to the visualisation of the concept. Targeting certain cohorts at gatherings such as places of worship was also suggested for consideration for communications and informing and engaging patient and service users. Practical suggestions such as the availability of an App and a designated accessible 'easy to recall' phone number, with a published directory of services<sup>26</sup> in conjunction with an accessible website were explored. Transparent accessible information on waiting lists so that service users would be aware of the '*now and the next*' in terms of wait times were discussed (It is acknowledged that much of this will be covered in the plan for the E-Health Framework)<sup>27</sup>.

Also highlighted were the importance of Clinical Pathways<sup>28</sup>, accompanied by '*maps and a compass*' for the services. It was suggested that a **Care Co-Ordinator role** could be assigned for those with multiple health issues and that it could be a HSE staff member or a family member. It was discussed that these structures would assist in facilitating seamless access to the service and the provision of information as regards waiting lists etc. The importance of visibility for all stakeholders, including all those with multiple complex needs, chronic illnesses and rare diseases in the new Health Regions was repeatedly referenced. There was concern that not all patient and service user groups were represented at the appropriate forums.

**Open communication, user friendly systems, training and education for both staff and service users** (on best practice for patient and service user partnership) was emphasised in terms of maintaining the relationship with patient and service users. The use of webinars<sup>29</sup>, Short Message Service (SMS)<sup>30</sup> appointment prompts, access to information on waiting lists (alluded to earlier) were seen as important. In summary, information technology (IT) should be able to assist in the development of a patient and service user Roadmap, with improved access with an interactive directory and visibility for all stakeholders.

It was suggested that this should translate to a positive and meaningful patient and service user partnership within a Health Region that is accessible with an '*even playing field*', and which is demonstrated through formalised KPIs. The patient and service user should experience a culture represented by the 'Make Every Contact Count'<sup>31</sup> approach as the norm.

### **Concept Proposition & Proposal 3: Key Principles: Why partnership?**

This concept was presented as an organogram<sup>32</sup> (see figure 3) where governance, standards and principles were outlined in terms of the Health Regions Implementation Plan (2023) and using a partnership approach where members of the public and patient and service user partners are involved in the local application of the blueprint in each Health Region. The importance of respect, behaviours, culture and the strengthening of accountability was emphasised. It was suggested that these should be closely linked with the Performance and Accountability Framework. It was further suggested that consideration should be given to the addition of a 5<sup>th</sup> (Patient and service user Partnership) domain

<sup>25</sup> General practitioners (GPs) are family doctors. GPs treat common medical conditions. They refer people to hospitals and medical services for other urgent or specialist treatment. Most GPs provide services to people with medical cards, GP visit cards and other schemes.

<sup>26</sup> Similar to the current 'Services' website available at <https://www2.hse.ie/services/>

<sup>27</sup> <https://www.ehealthireland.ie/knowledge-information-plan/>

<sup>28</sup> Modernised Care Pathways have been developed by the National Clinical Programmes and are now being implemented across the country by the Strategic Programmes Office (SPO), Office of the Chief Clinical Officer. Available at <https://www.hse.ie/eng/about/who/strategic-programmes-office-overview/modernised-care-pathways/>

<sup>29</sup> A seminar conducted over the internet

<sup>30</sup> Short Message/Messaging Service, commonly abbreviated as SMS, is a text messaging service component of most telephone, Internet and mobile device systems

<sup>31</sup> By Making Every Contact Count health professionals can encourage patient/service user to make healthier lifestyle choices during routine contacts to help prevent and manage chronic diseases. Available at <https://www.hse.ie/eng/about/who/healthwellbeing/making-every-contact-count/>

<sup>32</sup> Another term for organisation chart.

alongside the existing four domains of Finance, Human Resources, Access and Quality<sup>33</sup>. This was in the context of developing/co-creating standards and measurement [KPIs] for patient and service user partnership with national oversight under the Accountability Framework.

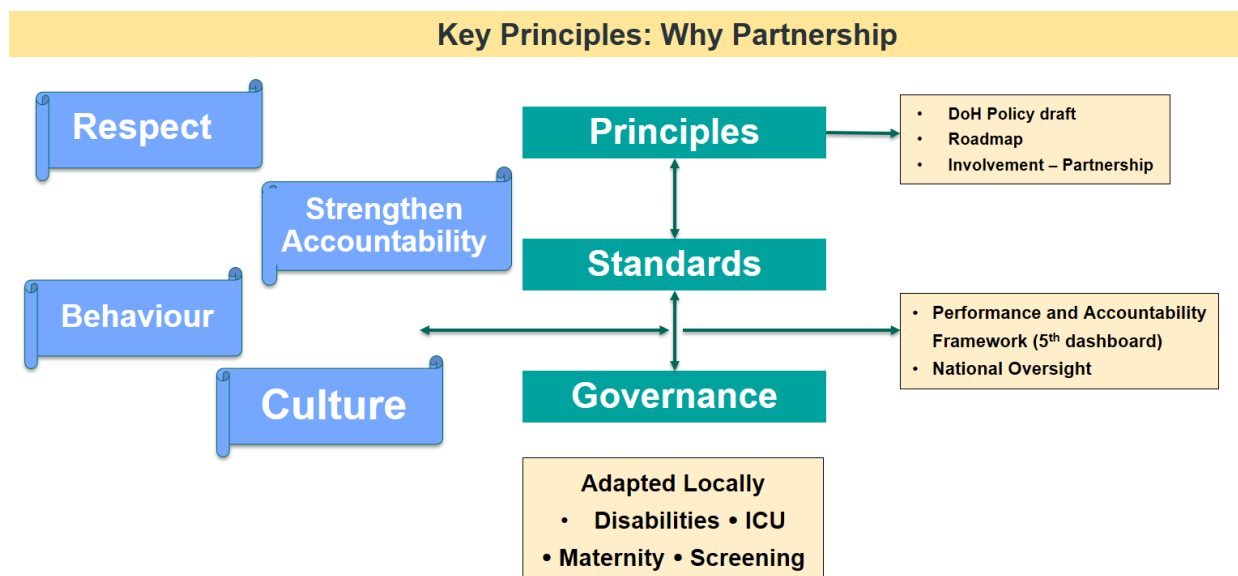
This would result in patient and service users being valued with:

- Consistency and continuity of integrated care
- Accessibility and a clear pathway, i.e., ‘a door for everyone’ in terms of accessing services
- Access to information

Participants suggested solutions for the improvement of the patient and service user experience within the Health Regions structure by the inclusion of relevant metrics in the Accountability Framework.

Consideration of the patient and service user’s view should be an important aspect of senior team agendas i.e. [the Executive Management Team (EMT) at Health Region level, the Strategic Leadership Team (SLT) at National level, the HSE Board<sup>34</sup>, the Department of Health (DoH) and Department of Children, Equality, Disability Integration and Youth<sup>35</sup>]. This was described in terms of these senior groupings ‘reaching out’ to patient and service users, e.g. as regards having ‘partnering with patient and service users’ as a standing item on their agendas. This would support dialogue to ensure the partnership is not merely tokenistic.

**Figure 3 Organogram of Concept number 3**



Policy, measurement, performance and understanding partnership were identified as being key in assisting the service users and patients ‘getting on board’. It was suggested that this should translate to a recognition on the part of the EMT, SLT, DoH and DCEDIY in terms of their understanding of partnership and recognition of the ‘gaps’ that occur when patient and service users are attempting to access services. The EMT regionally should meet regularly with the patient and service user partners and create a ‘deliberate dialogue’ in terms of building and maintaining the relationship with patient and service users.

The critical elements of this concept proposition are ensuring patient and service users have:

- Greater trust through partnership
- Principles of partnership, trust and inclusivity
- Standards in relation to patient and service user partnership
- Governance for quality and safety and an organogram for same

<sup>33</sup> See the Performance & Accountability Framework for information pertaining to the domains: <https://www.hse.ie/eng/services/publications/performance-and-accountability-framework-2023.pdf>

<sup>34</sup> Information available at <https://www.hse.ie/eng/about/who/board-members/board-members>

<sup>35</sup> Further Information available at: <https://www.gov.ie/en/organisation/department-of-children-equality-disability-integration-and-youth/>

- Inclusivity: as true partnership means being included at all times, at the earliest and at key stages as an equal voice in the process
- Strengthened accountability in terms of the Accountability Framework with a focus on standards, measurement and performance.

This should translate to patient and service users being heard and acknowledged and the experiencing of '*deliberate dialogue*'. It should also result in managers within the HSE taking on board new ideas to improve patient and service user partnership.



## 4.6 Appendix VI - Consultation Engagements and Submissions

### 24<sup>th</sup> January 2023:

Patient and service user partners (x6) and representatives of patient and service user advocacy and liaison service network, patient and service user engagement officers and patient and service user partnership staff attended the January 2023 meeting of “*Designing the patient and service user experience Model Together*” series of workshops. The Health Regions Programme team presented at this forum, and following this, a number of submissions were received as follows:

#### Submissions:

1. The Chair and Vice Chair of the HSE National Patient and service user Forum
2. A member of the National Representative Service Panel
3. Sage Advocacy
4. Patients for Patient Safety Ireland (PFPSI)

#### Co-designed Workshops:

**Table 1 - Breakdown of the attendees present at the co-design workshop process for Patient and Service User Partners**

Date	Patient and service user Partnership Forum attendees	DoH Attendees	HSE Attendees
10/05/2023	24	3	8
07/06/2023	13	2	7
07/07/2023	7	2	5

### September 2023:

A draft of this document was provided to Patient and Service User Partners (x 200) in October 2023 via the PSUE Office and to colleagues from the DoH and the HSE to comment on the content and to provide feedback on the document. There were 18 responses in total and there were 176 feedback points for consideration by the Health Regions Programme Team.

## 4.7 Appendix VII - Ideation themes and ideations captured at the co-design workshop 10th May 2023

Ideation Themes	Ideations
<ul style="list-style-type: none"> <li>• Culture</li> <li>• Human rights based</li> <li>• Takes into account its weakness</li> </ul>	<ul style="list-style-type: none"> <li>- Golden rule – ‘treat others as you wish to be treated’</li> <li>- Create an equal partnership – patient included in setting the agenda</li> <li>- Change should revolve around patient satisfaction</li> <li>- RHA level – build trust</li> <li>- Opportunity to assess public value</li> </ul>
<ul style="list-style-type: none"> <li>• Communication</li> <li>• Ability to share data collected</li> </ul>	<ul style="list-style-type: none"> <li>- Better informed staff and patients/service users</li> <li>- Do we need roadshows, e-surveys/e-polls?</li> <li>- Visible to key stakeholders</li> </ul>
<ul style="list-style-type: none"> <li>• Access</li> </ul>	<ul style="list-style-type: none"> <li>- Patients/service users have access to their information</li> </ul>
<ul style="list-style-type: none"> <li>• Design and implementation</li> <li>• Processes</li> </ul>	<ul style="list-style-type: none"> <li>- Patient Partnership Office in each RHA</li> <li>- Participation at all levels, groups and committees</li> <li>- Opportunity to decide what to ‘leave behind’</li> <li>- Create a budget for patient partnering in each RHA</li> </ul>
<ul style="list-style-type: none"> <li>• Consider the Barriers</li> </ul>	<ul style="list-style-type: none"> <li>- New thinking around service delivery</li> </ul>
<ul style="list-style-type: none"> <li>• Upskilling and training of staff</li> </ul>	<ul style="list-style-type: none"> <li>- Staff awareness of patient engagement</li> <li>- More training for/of staff to change the culture</li> </ul>
<ul style="list-style-type: none"> <li>• Integrate the logistic parts</li> </ul>	<ul style="list-style-type: none"> <li>- Look closely at transport for access to health and social care</li> </ul>
<ul style="list-style-type: none"> <li>• Real-time Feedback</li> </ul>	<ul style="list-style-type: none"> <li>- Real-time feedback to be acted upon,</li> <li>- Accessible anywhere (real time)</li> </ul>
<ul style="list-style-type: none"> <li>• Outcome Measures</li> <li>• Performance Management</li> <li>• Monitoring of Services</li> <li>• Accountability</li> <li>• Transparency</li> </ul>	<ul style="list-style-type: none"> <li>- Importance of outcomes and measures</li> </ul>
<ul style="list-style-type: none"> <li>• PPI Policy</li> <li>• PPI at DoH Level</li> </ul>	<ul style="list-style-type: none"> <li>- Agree a PPI structure at RHA level</li> <li>- Need a national PPI policy</li> <li>- Make PPI the norm</li> <li>- Resource and allocate staff and budget for Patient Partnership Involvement</li> </ul>
<ul style="list-style-type: none"> <li>• Learning from others experiences</li> <li>• Advice Capturing</li> </ul>	<ul style="list-style-type: none"> <li>- Start with the end user. Value our experience</li> <li>- Story telling – personal experiences</li> </ul>
<ul style="list-style-type: none"> <li>• Technology</li> </ul>	<ul style="list-style-type: none"> <li>- Electronic Health Record (EHR)</li> </ul>
<ul style="list-style-type: none"> <li>• Possibility of Integration</li> </ul>	<ul style="list-style-type: none"> <li>- New thinking around service delivery</li> </ul>
<ul style="list-style-type: none"> <li>• Partnership</li> </ul>	<ul style="list-style-type: none"> <li>- Involve Patient Partners in oversight to transition to Regional Health Areas</li> </ul>
<ul style="list-style-type: none"> <li>• Input at point of patient</li> </ul>	<ul style="list-style-type: none"> <li>- Involve Patient Partners in identification of local needs at the earliest stage</li> </ul>
<ul style="list-style-type: none"> <li>• Language</li> </ul>	<ul style="list-style-type: none"> <li>- Health Literacy for all in the community</li> </ul>