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

Based on the Proposal Document Finalised on 14 February

We developed this proposal after we received submissions from patient and service user partner groups. We also used a co-design workshop process to get feedback from patient and service user partners and staff from the HSE and the Department of Health.

'Our HSE Tree' was used at the first Patient and Public Partnership Conference in October 2023. People who went to the conference added a leaf to the tree, so the tree grew on the day. The tree shows that every person who uses or works in our health services is important and we are 'better together'.

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Plain English
Approved by NALA

To note: The document you are reading was edited using plain English guidelines up to and including section 3.5 on page 41. We also used some of these guidelines for all appendices apart from the original submissions from our patient and service user partners. These were left as provided.

This plain English version was completed in July 2024.

Glossary

The following glossary explains some specialist terms in this proposal document. If you see a word or words in blue font in this glossary, then we have explained the word or words elsewhere in the glossary. For example, if you want to find out what 'co-design' means, you can read about it in row 4 below. In explaining it, we mention Health Regions like this in blue. This means we have explained 'Health Regions' later in the glossary.

Terms	What they mean in this proposal
Accountability	Seeing who or what structure is responsible for what.
Acutes (acute hospitals)	Public acute hospital services are HSE hospitals and public voluntary hospitals. Some hospitals are specialist, for example, maternity, such as the National Maternity Hospital, Holles Street, Dublin or orthopaedic hospitals, such as Croom Orthopaedic Hospital. Examples of general hospitals are University Hospital Kerry and St James's Hospital Dublin.
Co-design	This is an approach to designing solutions in which patients and service users are equal collaborators in the design process. In this proposal, we are mainly talking about designing patient partnership within the Health Regions.
Community Health Network (CHN)	These are networks delivering primary healthcare to about 50,000 people in different geographical areas. There are 96 of these. There are about 4-6 primary healthcare teams in each of these with GPs involved in delivering services. See https://www.hse.ie/eng/services/list/2/primarycare/community-healthcare-networks/
Concept proposition	Two or more ideas (concepts) connected by words or phrases to form a statement that is meaningful. Example: Patients are 'listened to and equal'. 'Listened to' and 'equal' are the ideas.
Design Thinking	A way of coming up with answers to difficult questions. [We describe the design thinking process we used in section 2.1.]
Electronic Heath Record	This is comprehensive medical record in electronic form that captures care encounters for an individual across different healthcare providers.
Health Regions[1]	These are the six new structures that represent a change to how we organise health care. They will help provide care in a more joined up

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[1] See details at https://about.hse.ie/our-work/hse-health-regions/

	way through GPs (family doctors), community services, nursing support, social care services and acute hospitals.
Health Regions Implementation Plan 2023	This plan sets out the actions to put the Health Regions in place. It provides information and identifies who is responsible for its actions and timelines – Link to this plan: https://www.gov.ie/en/press-release/2e705-government-approves-hse-health-regions-implementation-plan/
Health Regions Implementation Planning Group	A group in place from September 2023 to January 2024. The group oversaw the development of organisational restructuring at regional and other levels. It also monitored progress.
Health Regions Programme Team	A group that leads, plans and co-ordinates and supports the effective planning and delivery of the necessary reforms to enable the implementation of the Health Regions.
Health and Social Care Services	A wide range of the services provided by the HSE and its funded partners that you can find across community and hospital settings. It includes services delivered across settings such as: Acute hospitals, Social Care settings, Mental health settings, Primary Healthcare and Health and Wellbeing Services, and the National Ambulance Service.
Integrated Health Areas (IHAs)	These are proposed areas to support the workload of Health Regions. There will be 20 of these areas. (See below.) Each of these areas will serve the health needs of up to 300,000 people. They will help people access: • the right care • at the right time • in the right place • with the right team They will serve a wide range of people in different locations and with different needs. They will also work closely with local services. These areas are part of the Health Region sub structure.

Multi-disciplinary team (MDT)	This is a team made up of different health and medical specialists. These specialists often include: • Medical Doctors • Nurses • Social Workers • Counsellors • Consultant Psychiatrists • Clinical Psychology • Project and Other Workers • Social Care workers • Allied Health Professionals, such as physiotherapists and speech therapists, dieticians, and so on • Others
Patient Partnering	The active collaboration between patients and providers to design, manage and achieve positive health results.
Primary healthcare	All of the health or social care services that you find in your community outside of hospital. It includes: • GPs (family doctors) • Public Health Nurses • a range of other services. These services provide a single point of contact to the health system.
Regional Patient and Service User Partnership Implementation Plan	This is a plan in which each Health Region will be required to set out how it will provide patient and service user partnership in line with the National Strategy (See Strategy in next entry).
'The Strategy' –the National Patient and Service User Partnership Strategy (currently being developed)	This is a document that will set out **the direction of Patient and Service user partnership approach**. It will be developed by the National Patient Service User Experience (PSUE) Office. (See reference to this office on Figure 2 on page 30). This high-level document will be closely informed by the proposal you are now reading.

Abbreviations

The following list of abbreviations will help you as you read.

CEO	Chief Executive Officer
CHN	Community Healthcare Network [Defined in the glossary above]
DoH	Department of Health
EHR	Electronic Health Record [Defined in glossary]
EMT	Executive Management Team (Health Regions)
HSE	Health Service Executive
IHAs	Integrated Health Areas
ISD	Integrated Service Delivery
IT	Information Technology
KPIs	Key Performance Indicators (KPIs)
NDOPI	National Director for Operational Performance and Integration (HSE)
PfPSI	Patients for Patient Safety Ireland
PIP	Patient Involvement Partner
PPI	Patient Partnership Involvement
PPPGs	Policies, Procedures, Protocols and Guidelines
PSUE	Patient Service User Experience [Office]
REO	Regional Executive Officer
RHA	Regional Health Area (referenced in submissions from patient partners and ideation themes captured at the workshops only and was the term used previously when referring to Health Regions)
SLT	Senior Leadership Team
WHO	World Health Organization

Footnotes

We also include some footnotes. They often give you links to further information.

Executive summary

We are the Health Regions Programme Team and we have written this proposal document to:

- make sure patients and service users are central to the work of the Health Regions Programme.

We also wanted to:

- set out and co-design the future of patient and service user partnership within the six new Health Regions in the Health Service Executive (HSE).

We, the HSE Health Regions Programme Team, developed this proposal jointly with patient and service users. Our team leads, co-ordinates and supports the Health Regions as they are put in place. We work closely with the Department of Health.

Our proposal is informed by four submissions from patients and service users and patient partners. We received these submissions through the Patient Service User Experience (PSUE) Office in April 2023.

The proposal is also based on later patient and service user partnership workshops in 2023.

This proposal has three main priority areas:

➢ Patient and service user representation

➢ Improving the patient and service user experience

➢ Improving governance and accountability

(We explain more about these priority areas and their recommendations in 1.5 of this executive summary. You can find full details of our proposal in section 3.)

1.1 Objective

When creating this proposal document, we worked with patient and service user groups to design how we could work together more effectively throughout the Health Regions. We have captured the main themes and also the steps we need to put in place to help us formally involve patient and service user partners. The aim is for these groups to work with the structures within these six Health Regions.

We want to make sure that the patient and service user voice is built into the ongoing design of the Health Regions Programme and within the Health Regions in 2024 and beyond.

1.2 Key findings

We must recognise patient and service user groups in a formal way and include them as part of how we organise the structures within each of the Health Regions. You can read the main findings from the written submissions and workshops below.

Key findings from submissions and workshops

1.3 Submissions

Their key themes were:

- the need to improve collaborative working
- access to health services needs to be fairer
- the need to improve and change how health and social care services are managed and organised (governed)
- the challenges in our health service.

Patient and service user partnership is vital

Patient and service user partnerships are essential to a well-functioning health system. They make sure that all voices across all health conditions are democratically represented across health services.

Need for standardised model of involvement

All Health Regions should have a consistent model for patient and service user partnership. This should start with patient and service user representatives being on the appropriate governance structures.

Patient and service users should be involved at an early planning stage

At the earliest stage, we need to put in place the building blocks for diverse, meaningful, and sustained patient and service user partnerships. We need to do this when deciding about:

- care
- service design
- research
- governance (how an organisation like the HSE is managed and run).

This would result in a clear organisation regional structure with a clear line of communication. It would mean information could be shared within and between the six Health Regions.

What each Health Region needs

One of the key elements that was highlighted as being needed in each Health Region was a National Patient and Service User Partnership Strategy.

This is currently being developed by the National Patient Service User Experience Office – or PSUE Office.

Other key elements highlighted as being needed were:

- a regional framework in line with the National Strategy just mentioned
- a regional Patient and Service User Partnership Office
- a regional Patient and Service User Partnership Budget.

You can read all four submissions in Appendices 4.1, 4.2, 4.3 and 4.4.

1.4 Workshops

At the first workshop on the 10 May 2023, those taking part used a process called '*Design Thinking.*'

'Design thinking' is a way of coming up with answers to difficult questions. The workshop used design thinking to:

- understand patients' and service users' views and needs
- challenge assumptions
- redefine problems
- create innovative solutions to try and test

The May workshop explored many important themes. We then agreed priorities with patient and service user partners.

The Design Thinking process identified priorities, and these are called 'concept propositions'.[2] Simply put, concept propositions have two or more concepts connected by linking words or phrases. They form a meaningful statement like: 'listened to and equal'.

The findings from the three workshops showed there were three core concepts ('concept prepositions') or ideas. We will focus on these so that we can embed the patient and service user voice in Health Regions structures. Let's look at each of these in turn.

The three core ideas ('concept propositions') from the workshops were:

There needs to be formal patient and service user representation in Health Region structures through appropriate forums
This can be achieved in many ways, for example, through:

- patient and service user councils
- council member representation on relevant committees

This would give patients and service users a platform where they could use their voice, be heard and be equal. Think of this idea as:

> **'Communications equals a voice that is listened to and equal'.**
> (Concept proposition 1)

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[2] More information on design thinking is available at the following website: https://www.interaction-design.org/literature/topics/design-thinking#what_is_design_thinking?-0

Patients and Service Users should be able to navigate health services

It should be possible for the patient and service users to effectively navigate health and social services.

Think of this idea as:

'The Compass – right service, right place, right time'.

(Concept proposition 2) One of the attendees described this as: 'The compass-navigation of the health regions – a symphony of efficiency'.)

Key principles, and patient and service user partnership

The workshops emphasised the importance of:

- respect
- behaviours
- culture
- strengthening accountability at HSE level. (Accountability is about seeing who or which structure is responsible for what).

These principles were linked with the HSE Performance and Accountability Framework[3] (2023). Think of this idea as:

'Key Principles, Why partnership?'

(Concept proposition 3)

You can read more about the workshops in Appendix 4.6 and 4.7.

We have reviewed the submissions and feedback from the co-design workshops. They inform our key proposals.

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[3] https://www.hse.ie/eng/services/publications/performance-and-accountability-framework-2023.pdf

1.5   Key proposals

A key focus of our team, the Health Regions Programme team, is making sure the patient and service user voice is at the centre of:

- the ongoing design of structures in 2024 within the Health Regions Programme
- other relevant developments in the Health Regions.

Main proposal - Along with the patient and service user partners, we are making recommendations to embed patient and service user partnering in the design of the governance structures of Health Regions. Our recommendations are based on agreed priority areas (see 1.4 above). The recommendations relate to: Patient and service user representation, Improving the patient and service user experience, and improving governance and accountability. **The full details of the proposal are in section 3.**

Let's look briefly at each of these **three priority areas.**

➢ **Patient and service user representation**
The workshop participants made recommendations in relation to:

- patient and service user partnership
- patient and service user council
- strategy and planning

The workshop participants also recommended that a Patient and Service User Partnership Office be created that will support all needs in relation to patients and service user partnering.

➢ **Improving the patient and service user experience**
The workshop participants made recommendations on how to improve:

- communication
- culture
- access to, and integration of, services
- data and information
- training, education and research

➢ **Improving governance and accountability**
The workshop participants made recommendations on how to improve:

- governance (how well the HSE is managed and run)
- standards and measurement

Introduction and background

The Sláintecare[4] Report (2017) included a commitment to HSE regionalisation. This means organising national and social care health services in a way that is aligned at regional level. This commitment was reaffirmed by Government in July 2019 when six new HSE Health Regions were approved.

In April 2022, the Government approved a document outlining:

- next steps
- programme of work
- timelines for putting the six Health Regions in place

In July 2023, the Department of Health published the 'HSE Health Regions Implementation Plan'[5] and the Government approved it.

The core vision behind setting up and putting in place the HSE Health Regions is the continued improvement of patient and service user care. This will be done through a health and social care system that is more integrated in terms of both its approach to service planning and how services are provided.

The changes in how healthcare is being managed and organised are designed to:

- make our services easier for people to navigate
- facilitate more integrated care (right care, right time, right place, right team)
- strengthen how our healthcare services are managed
- make our healthcare services more accountable (answerable)
- increase transparency across the health sector.

The new structures will:

Help with more local decision-making

The new structures will empower the six new Health Regions to make more decisions at a local level. These decisions will be on areas such as integrated working and planning. They will also integrate acute and community care in line with:

- government policy
- Sláintecare's overall objectives.

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[4] https://assets.gov.ie/22609/e68786c13e1b4d7daca89b495c506bb8.pdf
[5] https://www.gov.ie/en/publication/4eda4-slaintecare-regional-health-areas-rhas/#hse-health-regions-implementation-plan

Support a 'population-based' service planning and delivery

The new structures will also help with service planning and delivery which will be based on 'population-based' information. Population-based information means that we aim to distribute available healthcare resources according to population need.

The HSE Chief Executive Officer, Bernard Gloster, was appointed in March 2023. His vision for the HSE is a health and social care service where the: "Patient and service user is central to everything we do."

Purpose

The purpose of this proposal document is to:

- make sure the patient and service user are central to the work of the Health Regions Programme
- set out and co-design the future of patient and service user partnership within the HSE Health Regions.

How do I read this proposal document?

This document has two main parts: the proposal document and appendices. You can read this document as you wish, or you may prefer to go straight to the detail of its proposals in section 3.

Irrespective of how you read it, you may need to refer to:
- the glossary and its plain English explanations
- the list of abbreviations

You will also find the figures (visuals) in this document useful.

In the next section, 2.1, we tell you briefly how we developed this proposal document.

Section 3.1 lists our three proposal priorities and related recommendations.

Section 4 represents the second half of this document. It contains the appendices and includes the full text of the written submissions we received along with detail on the co-designed workshops. These workshops greatly helped us develop this proposal document.

2.1 Scope and methodology

The HSE Health Regions Implementation Plan (Department of Health, 2023) sets out a high-level approach in relation to the design of the six Health Regions. However, it was accepted that more work would be needed with patient and service users in order to co-design the partnership approach.

At the end of this section, you can see a visual timeline of the Health Regions and our work to date in co-designing the partnership approach. You can see that the journey started in 2022 and has been ongoing. We share below key highlights for each year.

2022

In 2022, the Government approved the plan to create six new Health Regions. The HSE Health Regions Programme Team was also set up in this year.

2023

In 2023, members of the Health Regions Programme Team presented at a workshop on 24 January. The workshop was led by the National Director for Operational Performance and Integration (NDOPI). Some patient and service user partners attended.

The Team asked those taking part the following three questions.

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?**
   After the Team's presentation, we received four written submissions from:

- the Chair and Vice Chair of the HSE National Patient and Service User Forum[6] – Appendix 4.1
- a member of the National Representative Service Panel – Appendix 4.2
- Sage Advocacy[7] (this was a standalone submission from Sage which is part of the National Patient and Service User Forum) – Appendix 4.3
- Patients for Patient Safety Ireland[8] (PFPSI) – Appendix 4.4

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[6] The Forum is the first point of reference for HSE divisions and clinical care programmes when seeking an input from patients and service users in the planning, design and delivery of services. It acts as a sounding board for implementation of new and existing national programmes.

[7] 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.

[8] Patients for Patient Safety (PFPS) is a World Health Organization initiative aimed at improving patient safety in health care.

We considered these submissions and reflected on the best methods to identify priorities from them. On advice from the National Director for Operational Performance and Integration (NDOPI) and with the agreement of the Chair and Vice Chair of the HSE National Patient and Service User Forum, we selected the 'Design Thinking' methodology.

We used a co-design workshop process put together specifically for Health Regions. We ran three workshops for patient and service user partners. Some staff from the HSE and the Department of Health also attended. See Appendix 4.6 for a breakdown of attendees.

Our objective when using the *Design Thinking* process was to describe the priorities as identified by the patient and service user partners. The Health Regions Programme Team (we) did this while working with:

- Our patient and service user partners
- HSE and Department of Health colleagues.

In section 4, we provide detailed outputs (results) from submissions and the three workshops with patient and service users. They underpin this proposal for patient and service user partnership within HSE Health Regions.

In October 2023, we provided a draft of this proposal document to all workshop attendees. We gave them the draft so they could comment and give feedback. We received 18 responses. These responses had 176 feedback points.

The HSE Health Regions Programme Team considered all of this feedback when completing the draft proposal document.

2024

In 2024, we brought the core proposal to the Health Regions governance groups. Our proposal document has now been approved. We edited the proposal document with assistance from the National Adult Literacy Agency (NALA) using plain English guidelines up to the proposal conclusion (section 3.5). This proposal document will also help develop the National Patient and Service User Partnership Strategy.
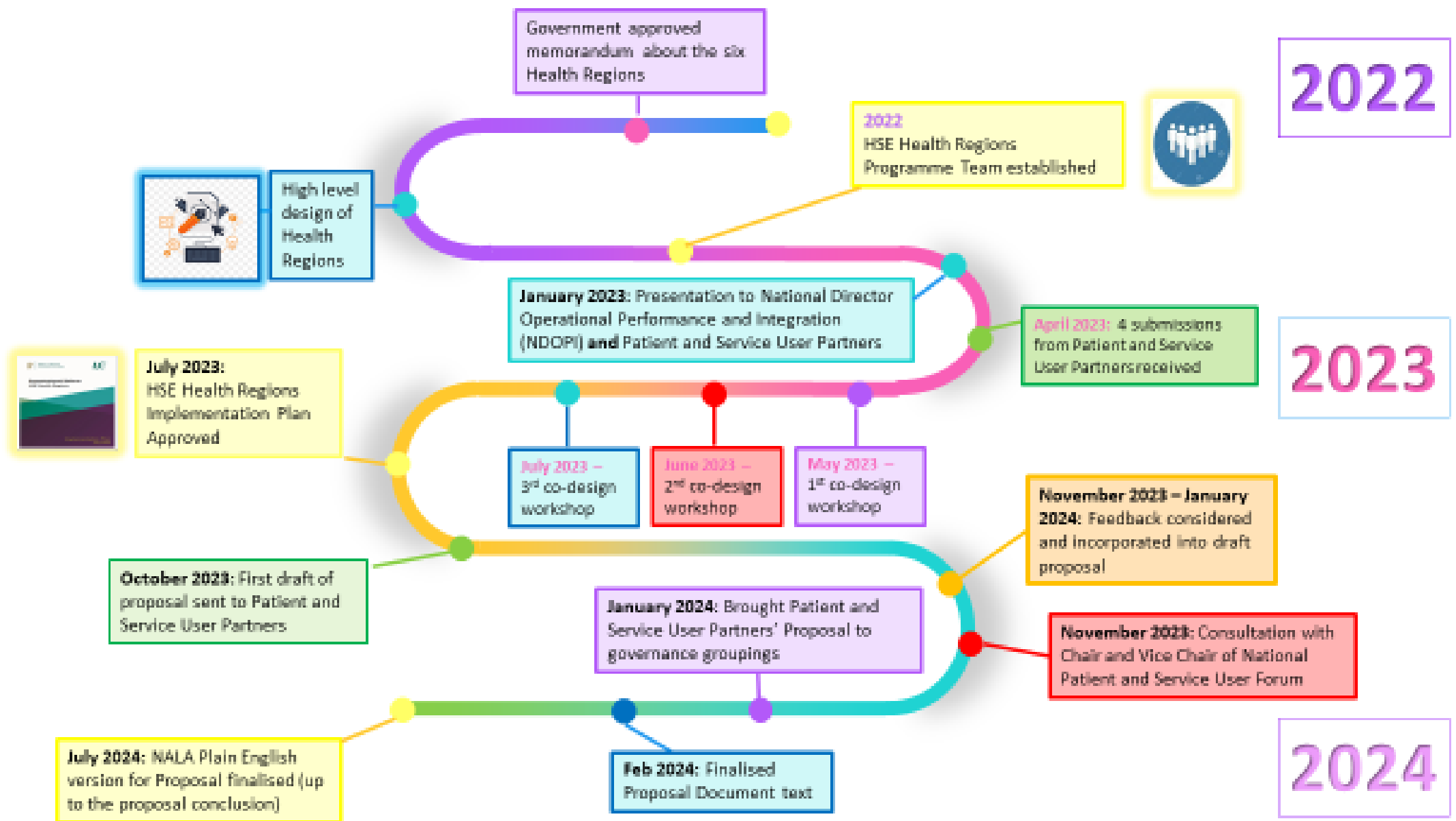
Figure 1: Timelines of methods to date to co-design the partnership approach

Government approved memorandum about the six Health Regions

2022
HSE Health Regions Programme Team established

High level design of Health Regions

January 2023: Presentation to National Director Operational Performance and Integration (NDOPI) **and** Patient and Service User Partners

April 2023: 4 submissions from Patient and Service User Partners received

July 2023: HSE Health Regions Implementation Plan Approved

July 2023 – 3rd co-design workshop

June 2023 – 2nd co-design workshop

May 2023 – 1st co-design workshop

November 2023 – January 2024: Feedback considered and incorporated into draft proposal

October 2023: First draft of proposal sent to Patient and Service User Partners

January 2024: Brought Patient and Service User Partners' Proposal to governance groupings

November 2023: Consultation with Chair and Vice Chair of National Patient and Service User Forum

July 2024: NALA Plain English version for Proposal finalised (up to the proposal conclusion)

Feb 2024: Finalised Proposal Document text

2022

2023

2024

Proposal

3.1 Patient and service user partnership proposal introduction

The following proposal represents the joint vision and priorities from the submissions and co-designed patient and service user partner workshops. The proposal was jointly developed to embed patient and service user partnership into how Health Regions are designed and operated. It used the agreed priority areas (based on the three 'concept propositions' identified in section 1.4) as follows:

- patient and service user representation (see 3.2.)
- improving the patient and service user experience (see 3.3)
- improving governance (how an organisation is managed) and accountability (see 3.4)

We look at each priority area in turn on the following pages.

The Health Regions Programme team proposes recommendations under each of these priorities.

3.2 Patient and service user representation

Patient and service user representation

The main points under this priority relate to:
- patient and service user partnership (recommendation 1)
- patient and service user council (recommendation 2)
- strategy and planning (recommendation 3)
- patient and service user partnership office (recommendation 4)

Patient and service user partnership (Recommendation 1)

A key part of this proposal is active patient and service user participation as true partners in the health services.

As the HSE Health Regions are put in place, there is an opportunity to provide a health system that works in partnership with the communities and populations that we aim to serve.

Partners in decision making

As we build a better health system, we must put in place the building blocks for diverse, meaningful, and sustained patient and service user partnerships. Patients and service users need to be seen as partners in decisions about:

- care
- service design
- research
- governance (how the HSE is run or managed).

Ensuring structures that meet patients' and services users' needs

The agreed patient and service user partnership structures should, where possible, meet patient and service users:

- preferences
- needs
- expectations
- values

The partnership structures should also foster an appropriate culture.

The structures should support and use best practice to put in place practical approaches in relation to patient and service user:

- partnership
- standards
- future developments

However, patients and service users are not solely responsible for partnership activities. Each team within the new Health Regions structures will be responsible for partnership activities.

Patient and service user partnership is an essential part of a well-functioning health system.

The Health Regions Programme Team proposes:

- a standardised model for this partnership nationally (underpinned by a National Patient Service User Partnership Strategy currently being developed)
- core standards for patient and service user partnership – these standards will be developed and embedded in Health Regions

The 'Better Together: The Health Services Patient Engagement Roadmap'[9] (2022) will be useful in this work.

While each patient and service user may not be an experienced advocate, they each have valuable experience to share that will help shape positive outcomes.

Patient and Service User Council (Recommendation 2)

It is proposed that there should be a Patient and Service User Council in each of the six Health Regions.

Regional Patient and Service User Partnership Council
This is the main way patient and service users communicate at a **regional** level. There is one Council per Health Region.

We consider the Council under the following headings:

- Its advisory role

- Its role in discussion, partnership and representation

- Its terms of reference (written description of its work)

- Its critical elements

Advisory role

It is proposed that the Patient and Service User Partnership Council would advise the Regional Executive Officer (REO) and the Executive Management Team (EMT). This advice would help them provide an improved service to patients and service users.

The council would also provide advice and guidance to the region in areas relevant to patients and service users. The objective of the council is to improve the patient and service user experience.

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[9]:Available at https://www.hse.ie/eng/about/who/national-services/partnering-with-patients/resourcesqid/hse-better-together-patient-engagement-roadmap-book.pdf

Allow for discussion, partnership and representation

The councils in each Health Region would be the main way in which patients, service users and organisations come together to discuss issues across Health Regions.

Some of the council members will also serve on other key committees and groups. They will work across all layers of the Health Region as follows:
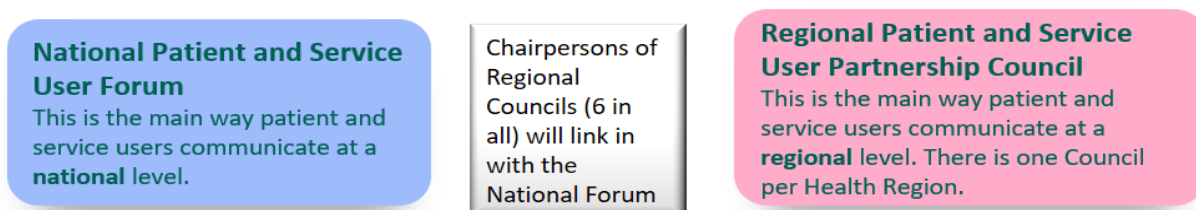
- Integrated Health Areas (IHAs): will be the substructures within each Health Region

- Community Health Networks (CHNs): there will be 96 of these providing primary healthcare such as that provided by doctors and Public Health Nurses and Acute Hospitals

- Health and Social Care Services (examples include mental health services).

(You can find more complete descriptions of the above three points in the glossary at the start of this document.)

This partnership approach should filter down across all services within the Health Region as they transition into Integrated Health Areas.

These councils should bring in representatives from existing regional partnerships within specific parts of the health service, for example, mental health and disability services.

The six chairpersons of the regional partnership councils will be linked in with the National Patient and Service User Forum. This forum will be the main way in which patient and service user organisations come together at a national level.

National Patient and Service User Forum
This is the main way patient and service users communicate at a **national** level.

Chairpersons of Regional Councils (6 in all) will link in with the National Forum

Regional Patient and Service User Partnership Council
This is the main way patient and service users communicate at a **regional** level. There is one Council per Health Region.

How the National Patient and Service User Forum and the Regional Council link together

The next phase of the partnership will identify:
- the different committees and working groups that patients and service users will be taking part in
- the mandate (authority) for the Council

Regional Patient and Service User Councils (6 in all) and designated patient and service user representatives must have an input into decision making in key areas of health care. Their input will represent the wider patient and service user body within each Health Region. These Council members will have representation at different levels.

Work in line with terms of reference

Terms of reference for these councils should be co-developed nationally. They will provide clear written guidance to the councils on their:

- role
- remit (scope of responsibility)
- structure
- reporting arrangements

The terms of reference can be changed to reflect the local or regional context. This can be done without affecting the core design of councils.

Critical elements – an overview

The critical element of this proposal will be making sure patient and service users on the Patient and Service User Council in each Health Region have the following:

A clear mandate (authority to take and act on decisions) – this mandate must be consistent across all Health Regions.

Broad representation – the Health Regions must have a broad representation in relation to:

- location
- ethnicity
- health
- age
- gender
- sexuality

Clear outcomes – to make sure the Health Regions are consistent, patient and service users on the council must have a clear set of achievable outcomes (results) which can be nationally:

- collated (gathered together)
- measured
- analysed

Positions supported by the Health Region Patient and Service User Partnership Office – it is proposed that there must be patient and service user positions at Health Region level and on key committees and groups. These positions must be supported by a Health Region Patient and Service User Partnership Office.

This office is needed to make sure patient and service user experience is taken on board by the Health Regions. (See page 27 for more details of this office.)

It is proposed that the Patient and Service User Partnership Office in the Health Region should report directly to the Regional Executive Officer (REO) or delegated authority.

Reporting relationship between the CEO and the Office of the REO

This will make sure that partnership is embedded across the Health Regions and that a change in culture is led from the top. This approach will ensure that key resources are available to those working at hospital and community level. (This approach aligns with the HSE Centre Design).

Membership of designated committees – patient and service users must have a role in putting forward members for specific patient and service user partner positions on key committees and groups within each Health Region. Those put forward (nominated) should also get peer support when on committees and groups.

Involvement in multidisciplinary groups – when the Patient and Service User Partnership Councils are being set up in each Health Region, they must include plans to enable patients and service users to be actively involved in multidisciplinary working groups. These are groups whose members have different specialities. (See glossary for more details on multidisciplinary groups.)

Active recruitment to fill patient and service user partner positions – it is proposed that Health Regions will recruit a diverse, inclusive and interested group of patient and service user partners with appropriate skills for each of the committees and groups within each Health Region. This should mean that patient and service user experience is enhanced and that they are empowered while using services. This would happen mainly by patient and service user partners taking part and influencing decisions within Health Regions.

We suggest the following:

- that opportunities for patients and service users should be advertised to the public

- that there be set recruitment criteria and a selection process
- people in these positions should rotate to allow for new people to be appointed after a fixed period of time

The plans to include patients and service users on councils must be set out in actions in the Regional Implementation Plan[10]. This plan can be completed once the National Patient Service User Partnership Strategy is ready.

Partnerships must be impartial and share best practice

Patient and service user partnerships should be impartial and independent. They should help:

- develop a new model of patient and service user advocacy that brings organisations together and allows the results of research on best practice in partnership to be shared quickly
- promote patient and service user-led change through partnerships with groups such as industry and academia (colleges and education bodies).

Strategy and planning (Recommendation 3)

Strategy development

In the area of patient and service user partnership, the National Patient Service User Engagement (PSUE) Office is responsible for developing:

- the National Patient and Service User Partnership Strategy
- policy
- standards

The National Patient and Service User Office is attached to the Chief Executive Officer of the HSE.

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[10] This refers to the Implementation Plan for patient and 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 being developed.

HSE Chief Executive Officer (CEO)

PSUE Office reports through the HSE National Director to the CEO

Reporting relationship between the Patient and Service User Office and the CEO

Patient and Service User Engagement (PSUE) Office
This office develops strategy, policy and standards and provides guidance.

Regional partnership offices work with National PSUE office

It is proposed that there will be Regional Patient and Service User Partnership Offices – one in each of the six Health Regions under the Office of the REO. These offices will co-ordinate with the Office of the relevant Regional Executive Officer. They will also co-ordinate with the PSUE Office to make sure policy and standards are consistent.

Patient and Service User Engagement (PSUE) Office
This office develops strategy, policy and standards and provides guidance.

These two offices will co-ordinate to make sure policy and standards are consistent

Office of the Regional Executive Officer (REO)
This includes the Patient and Service User Partnership Office. There is one partnership office per Health Region.

Reporting relationship between the Patient and Service User Office and the Office of the REO

These regional partnership offices should focus on identifying the priorities and activities of greatest importance in their regions.

It is also proposed that the Patient and Service User Partnership Office within each region should coordinate, implement and monitor a **Regional Implementation Plan**. This office should design this plan in partnership between the Patient and Service User Council and the Health Regions management. The implementation plan must be aligned to the National Patient Service User Partnership Strategy (when finalised). The implementation plan should have clear:

- objectives and targets
- actions
- timelines

It should say how these can be measured and how their progress can be assessed on a national level.

It must have the resources and budget needed to successfully put the implementation plan in place.

The Patient and Service User Partnership Office for each Health Region (Recommendation 4)

A Patient and Service User Partnership Office should be set up for each Health Region to help the Patient and Service User Partnership Council achieve its objectives. The role of the office will be to:

- recruit for a permanent administrative office or department (called the secretariat)
- recruit for the councils
- develop and make sure a Regional Implementation Plan is put in place
- co-ordinate the activities of the patient and service user partnership within the Health Regions

The Health Regions Programme team propose that the Patient and Service User Partnership Office has appropriate resources and clear reporting and coordinating arrangements.

Resources for the role of Patient and Service User Lead

We propose that the Patient and Service User Lead (HSE Staff Member) in the Health Region(s) will be responsible for patient and service user engagement as part of the office of the Regional Executive Officer. This lead person will have relevant expertise.

The office will play a lead role in:

- outreach (providing services) to the local community
- education and training for staff
- putting in place partnership projects.

Resources for other dedicated staffing

Each Health Region Patient and Service User Partnership Office should have dedicated staffing to:

- provide a meaningful partnership programme
- facilitate the delivery of the Regional Implementation Plan

Office budget resources

It is proposed that the budgets for these offices would provide for reasonable remuneration (pay) and involvement payments to patients and service users. These payments would be for those who give their time to support:

- co-design projects
- working groups and key committees
- advisory boards in line with the National Patient and Service User Partnership Strategy.

Budgets associated with this office should be 'ring-fenced' (put aside) to make sure the Health Regions Implementation Plans can be put in place and its actions achieved.

When these offices are established, we expect National and Regional HSE internal communications will help to raise public awareness about them. This would enhance public confidence in the health services.
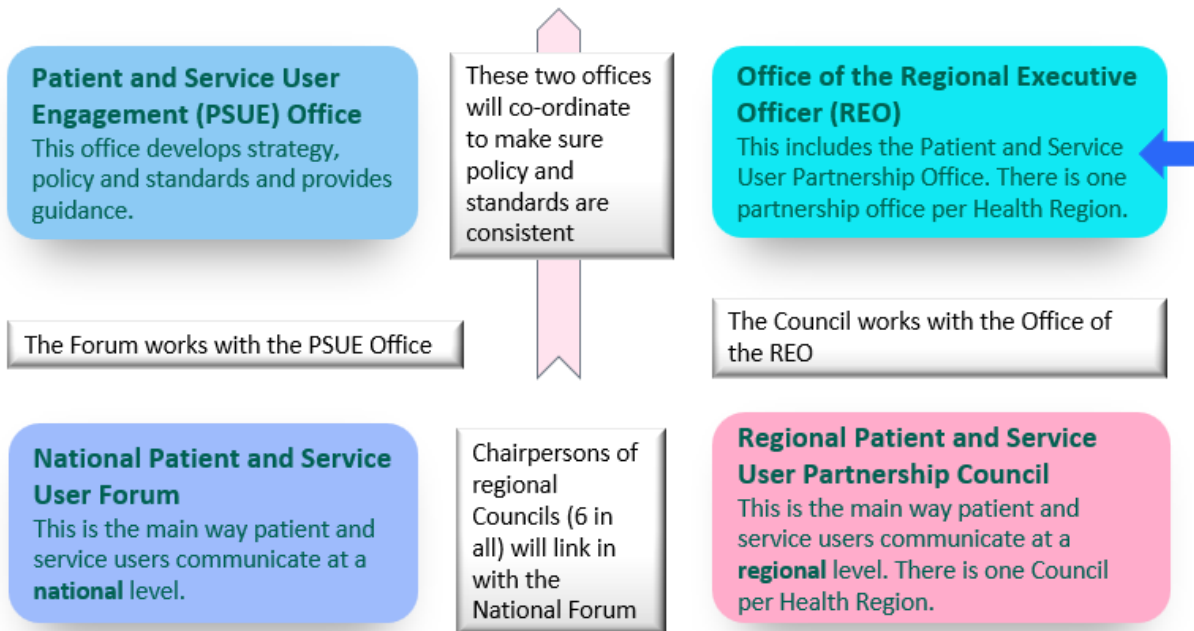
Value of allocating appropriate resources

The introduction of the Health Regions is an opportunity for Regional Executive Officers (REOs) to allocate appropriate resources. This will make sure that the partnership agenda will achieve both national and regional objectives and that each region:

- builds internal capacity
- grows a new culture of working
- builds public trust in our health services.

Reporting and co-ordinating

We propose that the Regional Patient and Service User Partnership Offices report into the Office of the REO while also coordinating with the National Patient Service User Engagement (PSUE) office.

Patient and Service User Engagement (PSUE) Office
This office develops strategy, policy and standards and provides guidance.

These two offices will co-ordinate to make sure policy and standards are consistent

Office of the Regional Executive Officer (REO)
This includes the Patient and Service User Partnership Office. There is one partnership office per Health Region.

The Forum works with the PSUE Office

The Council works with the Office of the REO

National Patient and Service User Forum
This is the main way patient and service users communicate at a **national** level.

Chairpersons of regional Councils (6 in all) will link in with the National Forum

Regional Patient and Service User Partnership Council
This is the main way patient and service users communicate at a **regional** level. There is one Council per Health Region.

Reporting and Co-ordinating Relationships for Patient Partners

The PSUE office will develop and oversee how the National Patient Service User Partnership Strategy (once finalised) is being put in place. This office will also provide guidance and policy on:

- preferred partnership approaches
- tools
- performance measures – signs of progress, also called key performance indicators.

The Patient and Service User Partnership offices will provide the leadership to follow the recommendations in this proposal document. This office will also facilitate involvement in other areas, for example, testing systems such as:

- those used to access patient and service user healthcare records
- Appointment Applications also known as 'Apps' for the public (Note: an application usually on your smart phone is a software program that is designed to perform a specific function directly for the user).
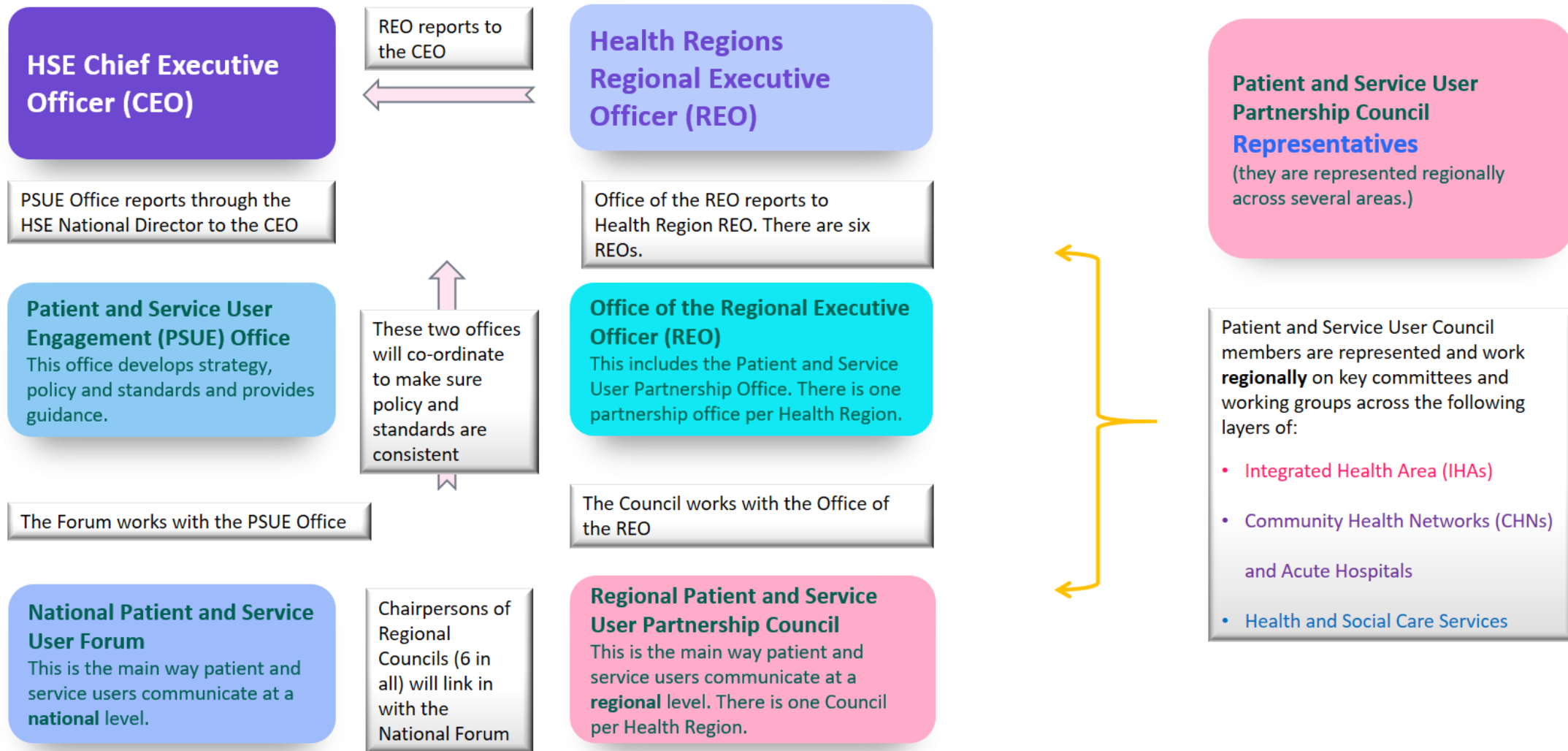
HSE Chief Executive Officer (CEO)

REO reports to the CEO

Health Regions Regional Executive Officer (REO)

Patient and Service User Partnership Council Representatives
(they are represented regionally across several areas.)

PSUE Office reports through the HSE National Director to the CEO

Office of the REO reports to Health Region REO. There are six REOs.

Patient and Service User Engagement (PSUE) Office
This office develops strategy, policy and standards and provides guidance.

These two offices will co-ordinate to make sure policy and standards are consistent

Office of the Regional Executive Officer (REO)
This includes the Patient and Service User Partnership Office. There is one partnership office per Health Region.

Patient and Service User Council members are represented and work **regionally** on key committees and working groups across the following layers of:

- Integrated Health Area (IHAs)

- Community Health Networks (CHNs) and Acute Hospitals

- Health and Social Care Services

The Forum works with the PSUE Office

The Council works with the Office of the REO

National Patient and Service User Forum
This is the main way patient and service users communicate at a **national** level.

Chairpersons of Regional Councils (6 in all) will link in with the National Forum

Regional Patient and Service User Partnership Council
This is the main way patient and service users communicate at a **regional** level. There is one Council per Health Region.

Figure 2: Proposed Regional Patient and Service User Partnership Structures

Description of areas patient and service user council representatives contribute regionally:

Integrated Health Areas (IHAs)

These are proposed areas to support the workload of Health Regions. There will be 20 of these areas. Each of these areas will serve the health needs of up to 300,000 people. They will serve a wide range of people in different locations and with different needs. They will also work closely with local services. Integrated Health Areas (IHAs) will be the substructures within each Health Region.

Community Health Networks (CHNs)

These are networks delivering primary healthcare to about 50,000 people in different geographical areas. There are 96 of these. Primary healthcare is the health or social care service you find in your community outside of hospital such as your GPs (family doctors), Public Health Nurses and a range of other services. These services provide a single point of contact to our health system.

Acute Hospitals

Public acute hospital services are HSE hospitals and public voluntary hospitals. Some hospitals are specialist, for example, maternity, such as the National Maternity Hospital, Holles Street, Dublin or orthopaedic hospitals, such as Croom Orthopaedic Hospital. Examples of general hospitals are University Hospital Kerry and St James's Hospital Dublin.

Health and Social Care Services

This is a broad term used to describe the wide range of the services provided by the HSE and its funded partners that you can find across community and hospital settings. It includes services delivered across settings such as acute hospitals, social care settings, mental health services, and others.

3.3. Improving the patient and service user experience

The main points under this priority relate to:

- Communication (Recommendation 1)
- Culture (Recommendation 2)
- Access to, and integration of, services (Recommendation 3)
- Data and information (Recommendation 4)
- Training, education and research (Recommendation 5)

This priority emphasises supporting 'staff, patient and service users and carers to navigate the health and social care system within their new Health Regions'. We look below at each of the five priority recommendation areas in turn.

The Health Regions Programme team proposes the following recommendations.

Communication (Recommendation 1)

We propose that Patient and Service User Councils and Partnership Offices (described in recommendation 4 in section 3.2) will have the authority to:

- establish small research groups (focus groups) aimed at improving patient and service user communication
- make the Patient and Service User Council visible within the Health Regions
- make the council's structures attractive to help recruit more patient and service user partners

Communication training

The Patient and Service User Councils and Partnership Offices will also have the authority to help with communications training. The objective will be to improve partnership between professionals and patient and service users. Both groups will actively listen to and learn from each other's perspectives.

Terminology

The Patient and Service User Councils and Partnership Offices will support the Health Regions as they adopt the use of consistent terminology. This terminology will be known and understood by patients, service users and staff.

Have everyone's voice heard

The Patient and Service User Councils and Partnership Offices will work on communicating and ensuring everyone's voice is heard when putting the National Patient Service User Partnership Strategy in place.

Surveys and schemes

The Councils will help to follow up on:

- surveys and schemes like the National Inpatient Experience Survey[11]
- any recommendations from these surveys and schemes. The councils will emphasise supporting patients and service users, carers, and staff so they can navigate the health and social care system within their new Health Region.

The Patient and Service User Councils and Partnership Offices will also help with staff surveys and raise awareness about the needs of patient and service user partnership.

Learning from excellence

It is proposed that the Patient and Service User Councils and Partnership Offices will learn from excellence in other Health Regions. This will be supported by the national co-ordinating role of the Patient Service User Engagement (PSUE) office.

Plain language

The Patient and Service User Councils and Partnership Offices will work with policy makers on the use of clear, plain[12] language and accessible formats in any literature or communications.

They will help to review communication websites and other platforms from the user's point of view through user testing.

Other work to promote clear communication

They will also work with the Communications Departments and other parts of the Health Regions to improve communication so that it is more open. They will do this by making the systems more user friendly.

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[11] https://www.hiqa.ie/areas-we-work/health-information/data-collections/national-inpatient-experience-survey

[12] Guidelines for Communicating Clearly using Plain English with our Patients and Service Users. Available at https://www.hse.ie/eng/about/who/communications/communicatingclearly/guidelines-for-communicating-clearly-using-plain-english.pdf

They will work with the regions on patient and service user feedback using existing models like 'Your Service Your Say' (YSYS).[13]

They will play a lead role in creating planned communications (described as 'deliberate dialogue' by one of the patient and service user partners) with members of the Health Region Executive Management Team. This will help to build and maintain good working relationships.

Culture (Recommendation 2)

We propose that Patient and Service User Councils and Partnership Offices will have the authority (mandate) to support the Health Regions so they can develop a patient and service user-friendly culture. This is a culture where the patient and service user are seen in a wider context and not just in the context of their condition or illness.

They will work with the Health Regions Executive Management Teams to foster partnership arrangements through training and education on patient and service user partnership.

Patient and Service User Councils and Partnership Offices will work with the Health Region Executive Management teams to develop the required user-friendly culture.

Access and integration (Recommendation 3)

Technical solutions

It is proposed that Patient and Service User Councils and Partnership offices will support the Health Regions to develop technical solutions that will improve access to, and integration of services and supports. They will do this by giving the Health Regions the end users' perspectives on what solutions would work best.

Practical suggestions include:

- Apps for patients and service users
- an accessible easy-to-recall direct phone number
- published directory of services
- an accessible website.

Waiting list information

It is proposed that Patient and Service User Councils and Partnership offices will work with Health Regions to publish information on waiting lists. This would mean service users would know how long they have to wait for an appointment or other service.

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[13] https://www2.hse.ie/complaints-feedback/

This would ensure patient and service user partners are involved in providing guidance on the users' view of how connected services are inside and outside the Health Region. An example of these projects would be an App showing how to access health services.

Patient and service user feedback

It is proposed that Patient and Service User Councils and partnership offices will help to review healthcare systems from the patients' and service user's perspective. This will improve services and make it easier for users to navigate through the system.

Assist on projects

It is also proposed that they assist on projects providing guidance on the public's perspective around connectivity between services inside and outside the Health Region.

Improve access

As part of service improvement initiatives, Patient and Service User Councils and Partnership offices will guide the Health Region in the reform of existing services. This will improve access for patients and service users where appropriate.

Systems that will last and work well

Patient and Service User Councils and Partnership offices will help the Health Region to make sure that integrated structures and ways of working last and improve over time. They will help them to develop longer-term systems.

Patient and service user partners need to be involved in the design of such systems (like the Electronic Health Record (EHR)[14]) to make sure their views are considered. This is especially important for patients and service users who access services.

Any systems that are introduced need to work at a local, regional, national and European level.

The digitisation of patient and service user records should include a patient and service user portal (a type of website). On this portal, patients, service users and their families could upload or access their own:

- information
- knowledge
- experiences

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[14]An EHR is a digital version of a patient and service users 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.

This portal should also give patients and service users the ability to see their own data and be active partners in their own care. Where appropriate, their families may also be able to upload and access information.

'Maps and a compass'

It is proposed that Patient and Service User Councils and Partnering Offices will work with the Health Regions to help develop 'maps and a compass' for services. These structures would help in locating and finding specific services for individual patients and service users.

Data and information (Recommendation 4)

Access to patient and service user information is a key part of current and future needs. Digital transformation will have a large impact on patients and service users and the type of service they receive. We propose that patient and service user partners be involved in creating and developing data and information systems. This will improve access to information (where appropriate).

Training, education and research (Recommendation 5)

Training and education should be integral to the patient and service user partnership process. Training and education requirements should be identified. These requirements should then be:

- set out in the National Patient Service User Partnership Strategy
- incorporated into the Regional Implementation Plan.

Training and education will be key to making sure we develop a patient and service user community who feel empowered and equipped with appropriate tools to negotiate and fully take part in the partnership process.

Training and education plan

It is proposed that the Councils and Patient and Service User Partnership offices should develop a training and education plan for Patient and Service User Council members.

This will help patients and service user's gain the skills and knowledge needed to engage with the Health Region at all levels. The training would cover:

- general information
- awareness of health structures and terminology

A training and education programme should be developed. It should focus on subjects relevant to council or member roles such as:

- patient and service user partnership governance.

The Councils and Patient and Service User Partnership offices should also support learning and continuous improvement in other areas. There should be a joint and integrated approach to training and education within Health Regions in relation to patient and service user partnership. This includes supporting education programmes for both patients and service users and staff around core components of patient and service user partnership.

Academic partners

The councils and offices should develop strong links with academic partners (third-level institutions). This will build on patient and service user partner representation in research, training and education.

Research and evaluation

The councils and offices should be involved in research so they can help to evaluate key areas of Health Regions that relate to patients and service users. An example of this would be evaluating the impact of an effective patient and service user partnership structure within one Health Region as compared to another Health Region.

Health literacy

Patient and Service User Councils and Patient and Service User Partnering Offices should empower and engage patients and service users through health literacy. The World Health Organization defines health literacy as the ability of individuals to "gain access to, understand and use information in ways which promote and maintain good health" for themselves, their families and their communities.[15]

3.4 Improving governance and accountability

The main points under this priority relate to improving:

- Governance (Recommendation 1)

- Standards and measurement (Recommendation 2)

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[15] Health Promotion (who.int) The definition originally came from Nutbeam, Don. 1998.

Governance is about how the HSE is run and managed. While developing this proposal, patient and service users emphasised the importance to patients and service users of:

- respect
- behaviours
- culture
- strengthening accountability (this is about seeing who or which structure is responsible for what).

The following recommendations are proposed by the Health Regions Programme team.

Governance (Recommendation 1)

Measure improvements

Patient and service user councils and partnering offices should support the improvement of patient and service user experience within the Health Regions structure through the development of relevant measurements in the HSE Accountability Framework.

Meetings and planning

Councils and offices should meet with the Executive Management Team (EMT) at Health Region level to make sure patients' and service users' views are communicated and adopted.

There should be a joint planning meeting twice a year between the Health Region EMT and the Regional Patient and Service Users Council. This meeting should consider:

- progress on the Regional Implementation Plan over the previous six months
- the plan for the year ahead.

Partnership representation

The Patient and Service User Partner Lead (HSE staff member) will work on behalf of the Regional Executive Officer (REO) with members of the EMT on partnership issues. This will allow the partnership community to be confident that their voice will be regularly, adequately and meaningfully represented.

Work with senior staff

Patient and service user councils and partnership offices should help senior staff teams, such as the EMT within the Health Regions, reach out to patient and service users. This could be done by:

- including patient and service user partnership as a standing item on agendas
- having a schedule of engagements between the councils and the EMT.

Accountability

Having feedback from patient and service user councils and partnership offices should strengthen accountability within Health Regions. This will make it easier to see who or which structure is responsible for what.

Add a new part to the Accountability Framework

Some participants suggested that the above themes should be considered along with the other domains in the national HSE Performance and Accountability Framework.

The Accountability Framework is made up of four parts:

- Finance
- Human Resources (HR)
- Access
- Quality[16]

The Health Regions Programme Team propose that the HSE consider formally acknowledging the increased involvement of a patient and service user partnership. The HSE could do this by adding a fifth domain or section: Patient and Service User Partnership to the Accountability Framework.

Like the existing four sections, the new section would use agreed standards and measurements and be managed and monitored under the HSE Performance and Accountability Framework.

This should result in patient and service users having:

- consistency and continuity of integrated care
- improved access to services
- improved access to information.

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[16] https://www.hse.ie/eng/services/publications/performance-and-accountability-framework-2023.pdf

Standards and measurement (Recommendation 2)

We need to measure what we are doing against expected standards of patient and service user partnership. This will show us where we are doing well and where we need to do better. It is proposed that Patient and Service User Councils and partnership offices will have the authority to co-design the:

- Key Performance Indicators (KPIs) – or measures of progress that need to be set up and monitored
- national standards

KPIs should focus on patient and service user outcomes (results) and include Quality of Life Measures. These include patients' and service users' views on the impact of their health and healthcare interventions on their lives.

Local audit (check)

It is proposed Patient and Service User Councils and partnership offices will support with the audit of how well relevant HSE policies, procedures, protocols and guidelines (PPPGs) are being put in place at a local level.

In this way, councils and partnership offices can support audits to make sure the services in relation to Patient and Service User Partnership we provide are consistent throughout the country.

Improvements

It is proposed that Patient and Service User Councils and partnership offices will be able to set up a Model of Improvement (a way to inspire and support continuous improvements). This model will put in place outcomes from service initiatives such as patient focus groups.

They will consider using the HSE's 'Your Voice Matters'[17] to evaluate patient and service user partnership experiences. Its focus is on what matters most to patients and service users, and it allows the opportunity to capture both positive and negative feedback.

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[17] https://www.hse.ie/eng/about/who/cspd/patient-narrative/your-voice-matters/

3.5 Proposal conclusion

This is a joint document between the HSE and patient and service user partners. The proposal is the outcome of a co-designed approach to patient and service user partnership that will feed into the design of the Health Regions.

Patient and service user at core

The proposal includes the patient and service user as core to the regional structures and sub-structures (such as Integrated Health Areas, Community Health Networks and acute hospitals). Having patient and service user representation in council and executive level posts will result in patient and service users being represented at every level in the six Health Regions.

Reporting and the Patient and Service User Partnership Lead

In this proposal, the Patient and Service User Partnership Lead (HSE appointed staff member) will report to the Regional Executive Office (REO).

Patient partners highlighted the need for a patient partnership representative at the Executive Management Team level, which is not included in this proposal. This reporting relationship is an evolving area and requires further consideration from the HSE Health Regions Programme Governance group. The proposed reporting relationship of the Patient and Service User Partnership Lead to the Office of the REO will help keep pace with the changing nature of the newly formed Regional Patient and Service User partnership structure. This structure will also be informed by the National Patient and Service User Strategy when developed.

Our overall proposal document

The Health Regions Programme Team sought approval of this proposal document from the HSE Health Regions Programme Oversight Group.

We acknowledge the significant opportunity that we have been given to embed patient and service user partnership in the design, delivery and improvement of services. We remain fully committed to this process and will work closely with the National Patient Service User Experience Office in aligning their work to the National Patient and Service User Strategy.

On this basis we recommended that the HSE Health Regions Programme Governance Group consider this co-designed proposal and approve it as part of Health Regions.

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 1 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 (RHAs[18]), 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.

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[18] The term RHA (Regional Health Area) has been replaced by Health Regions. This term was left in the text of the submissions received as the term RHA was still in use when we get submissions.

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.

4.2 Appendix 2 – Submission from a member of the National Representative Service Panel

Slide	Comment
	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. 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
2	**Stakeholder Engagement – did that include any PIPs?**
3	The abyss between acute and community services has long been evident, I've been thrown into it many times! 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. 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. What are the CHO populations and what are the RHA populations based on current figures?
4	Dublin centric labelling – Dublin is A. RHA F seems a larger geographic area than others. How are the issues of area planned for: population density, demographic a) health b) disability c) age, what are current healthcare resources Is the new model Dublin centric for expertise re paediatric services, specialist services? Are there plans to ensure that: a) Other than for very specialist services, all RHAs have access to equivalent resources, services within them? b) Patient/service users have equitable travel distances and also effective public transport to access them.

	c) 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
5.1	Sensible. Need to define the terminology used, person-centred Change Guide Page 196 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. Community first – good move. What are the needs of the population? How will this be assessed, considered, what data will be used? 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. 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. Building the new on a very unstable base re community services is a challenge which needs a different process to identify: 1. 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. 2. 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. 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	Then add in effective governance practice

	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.
	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.
	Then national audit is a secondary, rigorous, governance check feeding into the National Scorecard.
	How will equity between RHAs be assessed?
	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?
	E.g. YSYS Case Book. Does the learning shared result in measurable change elsewhere and how is that measured.
	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.
5.3	See 5.1 How are the needs to be assessed.
	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'.
	See Better Together Framework Page 46 & 47 and consider the:
	a) Change Guide Standards on engagement, Page 241 applies to those working in or relying on services
	b) NSS Patient/Service User and Public Partnership Strategy 2019 -2023 Page 11 Arnstein's Ladder of Citizen Participation
	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.
	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.
5.4	See above. Important that the standards are known of by ALL employees and service users. 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'. 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. 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. 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! 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. One caution re-funding: 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. 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. 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.
6	See above. 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'?

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.

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?

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.

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.

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.

Improve the health and well-being.

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.
	How will the GP problem be addressed?
	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?
7	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.
	Clarity and continuity of care – the vision is sound.
	Question: what changes are needed in current practice to address the following issues?

	- 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 - how will any possible perceived threat be addressed - to enable a framework of standards known, understood and strived for across all services - clear accessible information about all services to ensure that the principles in the National Consent Policy 2022 are supported in practice - gaps in services filled

What would success look like?

- I would have all my PA hours, seven days a week, not 2/7 alone the rest of the time.

- I would have confidence in what was happening, I would know what 'should' be happening

- Relationships with employees would be sufficiently strong to support flexibility when 'life happens'

- There would be trust, openness

- I would know my needs were met

- I would trust acute services to meet my needs

- I would never again fear being thrown into the abyss between acute and community care

- 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

- 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?

- 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.

- I would see true partnership, the highest levels of engagement not tokenistic involvement

- Staff would understand how effective patient/service user involvement serves all of us

- I would understand how out health services work, the national and local structure

- 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
- 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
- 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
- - my care would be equivalent to that of a person with an 'acceptable' and known illness

What is important to you? See above

- 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 3 – Submission from Sage Advocacy

'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 immerging 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 and 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 specialised 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 4 – Submission from Patients for Patient Safety Ireland

'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 retails 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 5 – Design Thinking Methodology

On advice from the National Director for Operational Performance and Integration (NDOPI) and with the agreement of the Chair and Vice Chair of the HSE National Patient and Service User Partnership Forum, we selected the 'Design Thinking' methodology. This was a co-design workshop process specifically for Health Regions.

The objective of the Design Thinking process was two-fold:

1) to define the priorities as identified by the patient and service user partners working with HSE and Department of Health colleagues

2) to feed into the design and transition planning for the Health Regions.

Design thinking is a human-centred process. It is a way of coming up with answers to difficult questions. Teams use this process to:

- understand users
- challenge assumptions
- redefine problems
- create innovative solutions to prototype and test

Based on five principles

Design thinking involves five principles:

- Empathize (with patients and service users which can help to figure out issues)
- Define (the problem)
- Ideate (generating ideas to consider)
- Prototype (show how idea can be tested)
- Test (test your new solution find new problems and make changes, and so on, before settling on a final design)

The Design thinking tool is evidenced based. It is particularly useful for tackling 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 (Patients for Patient Safety Ireland)
- the HSE National Patient Representative Panel

A number of HSE and DoH staff also participated (See Appendix 4.6)

Participants followed 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 through to evaluation.

Outcomes (ideas – also called ideations in design thinking)

Workshop 1: ideas and themes identified

At the first workshop on the 10 May 2023, participants proposed ideas (ideations) and ideation themes (Appendix 4.7). These will be incorporated into a patient and service user partnership blueprint for Health Region Executive Management Teams. This will 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.

Workshops 2 and 3 (June and July 2023): Three Concept Propositions discussed

At these workshops, participants were asked to focus on concept propositions. Concept propositions have two or more concepts connected by linking words or phrases. They form a meaningful statement like: 'listened to and equal'.

The three concept propositions that were prioritised were as follows:

1: Patient and service user representation in the Health Regions

2: The Compass – the right care, right place, right time

3: Key principles: Why partnership?

Let's look at each of these in more detail below.

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:

Problem: No participation or 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 [regularly].

The proposal participants put forward emphasised the importance of the following to address the above problem:

Patient and user representation and councils

- Patient and service user representation, **particularly** within governance structures, including committees, on each of the Health Regions (**top recommendation**)
- Two patient and service user representatives at a national level
- Two patient and service user representatives at each Health Region.

Strong links with academic partners

- Strong links with Academic Partners to build on patient and service user partner representation.

National standards and clear measures of success

- The importance of having key performance indicators (KPIs – a measure of progress) and national standards to measure, support and grow this concept was emphasised to improve patient and service user representation.

Regional Councils (as well as a National council)

- There should be a Patient and Service User Partnership Council in each Health Region. This council should have its own office and a budget.

Active recruitment

Active recruitment of patient and service user partners with appropriate skills match with each of the respective committees should start. This would make sure that a diverse and inclusive group is found.

Active partnership should then translate to an enhanced experience for patients and service users as well as a sense of being supported while using the services. This would mainly result 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.

Structure to support patients and service users within Health Regions structure

Patients and service users proposed an organisation structure identifying how patient and service users will fit into the Health Regions. This structure proposes that each Health Region has a:

- Patient and Service User Partnership Office
- a council

This proposed patient and partnering structure would have membership and 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
- input into decision making in key areas of health care functions on behalf of the Patient and Service User Council.

Critical elements of patient and service user representation in the Health Region (concept 1)

Workshop participants suggested that the critical elements of the concept are ensuring patient and service users have:

- A clear mandate (authority to take part in a certain way) which is standardised nationally
- A clear set of achievable outcomes
- Broad representation across geographic, ethnic, health, age and gender
- Clear outcomes which are measurable, collected and analysed nationally to ensure consistency.

From a Health Regions Programme perspective, establishing patient and service user positions will ensure that the patient and service user experience is embedded in the governance structures of each Health Region. These positions would need to be supported by a Patient and Service User Council and a Patient and Service User Partnership Office at Health Region level.

2: The Compass – the right care, right place, right time

This concept of 'the Compass' was described as 'The right care, right place, right time'. It made reference to 'Issues with timely access to services'. An example of a suggested improvement was: '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 proposal participants put forward emphasised the importance of:

Trust

- Trust, reassurance, confidence, and transparency
- The use of clear, plain language in any literature or communications

Meeting needs

- Relationship building, needs assessment, information sharing and dissemination between Health Regions and the local area
- Addressing service users and staff needs in regard to best practices for partnering with patient and service users.

Sharing and clarifying what works well and what could be done differently

- Health Regions communicating with each other and learning from excellence in other Health Regions (that is what 'works well', and what could be 'done differently') and how we can access the learnings, such as through an online resources portal.
- Clarifying that accessibility includes services outside of the health system. For example, co-ordinated care, bus and other transport services, and 'joined up thinking' across public services ensuring equitable access to services.

Culture change

- 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 or illness'.

Understanding

- 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 in the future.

Participants **also** referred to the importance of:

- The appointment of the Regional Executive Officer(s) (REOs)
- their team
- establishing a **Patient and Service User Partnership Office** so that the patient or service user would know about local Health Regions and their services.

Seamless access to information based on Electronic Health Record

The emphasis was on integrated working with information flowing seamlessly through an **Electronic Health Record (EHR).** (See glossary at the start of this document.)

Using EHR, information would flow between the following:

- General Practitioner (GP) – local family doctors who treat common medical conditions. They refer people to hospitals and medical services for other urgent or specialist treatment
- Community health professionals and services
- Public and or private hospitals
- Acute care such as that provided in many of our hospitals
- All other health and social care settings.

Participants suggested 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 'seamless access', and this ideal was described as a 'symphony of efficiency' by workshop participants.

Advertising using television, radio, and other social media (depending on the age group being targeted) were put forward as examples of how patients and service users could learn about the Health Regions.

Workshop participants also suggested ways to target certain groups of people so we could communicate our information on services and further engage patient and service users. Methods suggested included:

- Sharing information at places of worship

- Providing an App

- Providing a designated accessible 'easy to recall' phone number

- Publishing a directory of services[19] along with an accessible website

- Clear and accessible information on waiting lists, particularly so that service users would be aware of the '*now and the next'* in terms of wait times. (Much of this will be covered in the HSE's plan for the HSE Digital Health Strategic Implementation Roadmap 2024-2030[20]).

Clinical Pathways

The importance of Clinical Pathways[21] and the suggestion that they be accompanied by 'maps and a compass' for the services were also highlighted.

A Care Co-ordinator role discussed

It was suggested that a Care Co-ordinator role could be assigned for people with multiple health issues and that it could be a HSE staff member or a family member.

There was also discussion about how the above structures would help to facilitate seamless access to the service and information as regards waiting lists, and so on.

All stakeholders known and visible

There were repeated references as to how important it is that all stakeholders are known and visible in the new Health Regions, including all those with multiple complex needs, chronic illnesses and rare diseases. Concerns were expressed that not all patient and service user groups were represented at the appropriate forums presently.

Open communication, user friendly systems, training and education for both staff and service users

Many participants emphasised the value of maintaining the relationship with patients and service user partnership(s). An example given was of webinars (online seminars). In addition, they noted that the following methods were also valuable:

- sending text messages (Short Message Service (SMS)) to remind people of health appointment prompts

- information to tell them where they are on waiting lists for health services

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[19] Similar to the current 'Services' website available at https://www2.hse.ie/services/
[20] https://www.ehealthireland.ie/technology-and-transformation-functions/chief-technology-transformation-office-ctto/ctto-overview/hse-digital-health-strategic-implementation-roadmap-2024-2030/
[21] 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/

As you can see, Information technology (IT) was seen as being able to assist in the development of a patient and service user roadmap for information and services. Participants suggested this would provide accessible health services (an '*even playing field*'). This improved access should be easy to show using reliable measures that are tracked and regularly reported on.

It was also suggested that the patient and service user should experience a culture represented by the 'Make Every Contact Count' [22] approach as the norm. 'Making Every Contact Count' is an initiative where health professionals encourage patients and services user to make healthier lifestyle choices during routine contacts. This helps to prevent and manage chronic diseases.

Critical elements of this concept
Workshop participants suggested that the critical elements of the concept of right care, right place, right time are: - A clear focus on trust, reassurance, confidence and transparency   - Adaptability and culture change in the Health Regions   - Information technology to support seamless access to up-to-date information about the Health Services   - Integrated service and roadmaps to access health information and health services.

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[22] Read more about Making Every Contact Count at https://www.hse.ie/eng/about/who/healthwellbeing/making-every-contact-count/

Concept Proposition 3: Key Principles: Why partnership?

This concept was presented as a visual (see below figure 3). Governance, standards and principles were outlined in terms of the Health Regions Implementation Plan (2023) along with a partnership approach. In this approach members of the public and patient and service user partners are involved in applying the relevant requirements in the Health Regions Implementation Plan (2023) within each Health Region.

The participants also highlighted the importance of respect, behaviours, culture and the strengthening of accountability. A patient partner suggested that these should be closely linked with the national HSE Performance and Accountability Framework. Adding a *5th* (Patient and Service User Partnership) **domain** alongside the existing four domains was also suggested. The four domains at present are:

- Finance
- Human Resources
- Access
- Quality[23]

This was in the context of developing and co-creating standards and measurement (KPIs) for patient and service user partnership with national oversight under the Performance and Accountability Framework.

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

- Consistency and continuity of integrated care
- Accessibility and a clear pathway, that is 'a door for everyone' in terms of accessing services
- Access to information.

Participants suggested solutions to improve the patient and service user experience within the Health Regions structure by including relevant metrics in the Performance and Accountability Framework.

It was suggested that senior health teams should consider patient and service users' views as an important part of their agendas. Senior HSE teams are:

- the Executive Management Team (EMT) at Health Region level
- the Strategic Leadership Team (SLT) at National level

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

- the HSE Board[24]
- the Department of Health (DoH)
- the Department of Children, Equality, Disability Integration and Youth[25]

This was described in terms of these senior groupings 'reaching out' to patient and service users, as regards, for example, having 'partnering with patient and service users' as a standing item on their agendas. This would support dialogue to ensure the partnership is not tokenistic.
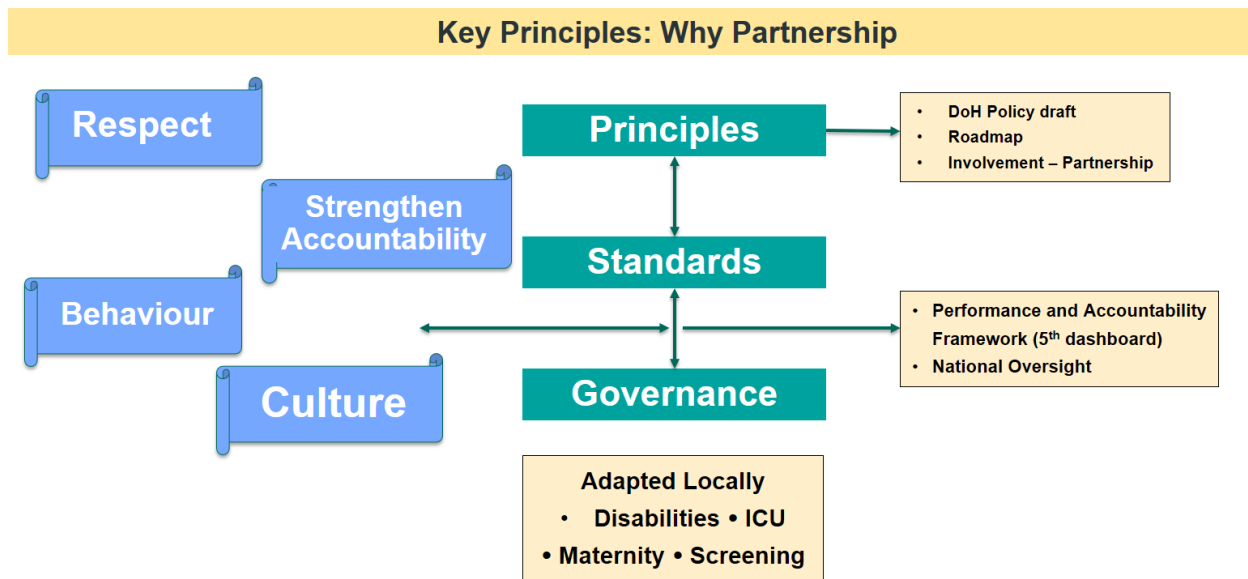
Key Principles: Why Partnership

Respect

Strengthen Accountability

Behaviour

Culture

Principles

Standards

Governance

- DoH Policy draft
- Roadmap
- Involvement – Partnership

- Performance and Accountability Framework (5th dashboard)
- National Oversight

Adapted Locally
- Disabilities • ICU
• Maternity • Screening

Figure 3: Visual of concept proposition number 3

(ICU – stands for Intensive Care Unit)

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 two areas:

- their understanding of partnership
- recognition of the 'gaps' that occur when patient and service users are attempting to access services

It was suggested that the Regional EMT 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.

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[24] Information available at https://www.hse.ie/eng/about/who/board-members/board-members

[25] Further Information available at :https://www.gov.ie/en/organisation/department-of-children-equality-disability-integration-and-youth/

Critical elements of this concept

- Greater trust through partnership
- Principles of partnership, trust and inclusivity
- Standards in relation to patient and service user partnership
- Governance for quality and safety where all can see who has responsibility for what (on an organisation map)
- a true partnership that is inclusive, meaning patient and service users are 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 Performance and Accountability Framework with a focus on standards, measurement and performance.

This should translate to patient and service users being heard and acknowledged and the experience 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 6 – Consultation engagements and submissions

24 January 2023

The following organisations and individuals took part in the January 2023 meeting of "*Designing the patient and service user experience Model Together*" (which was a series of three workshops):

- Patient and service user partners (x 6)
- Representatives of patient and service user advocacy and liaison service network
- Patient and service user engagement officers
- Patient and service user partnership staff.

The Health Regions Programme team presented at this meeting. After this, we received four written submissions.

Submissions received from:

- The Chair and Vice Chair of the HSE National Patient and Service User Forum
- A member of the National Representative Service Panel
- Sage Advocacy
- Patients for Patient Safety Ireland (PfPSI)

Co-designed workshops – participants at each of the core consultation engagements:

Table 1 - Attendees at the co-design workshop process for Patient and Service User Partnership in Health Regions

Dates in 2023	Patient and service user Partnership Forum attendees	Dept. of Health (DoH) attendees	HSE attendees
10 May	24	3	8
7 June	13	2	7
7 July	7	2	5
Totals:	**44**	**7**	**20**

September 2023

We emailed the Patient Service User Engagement Office (PSUE) Office to ask that they distribute the draft proposal to patient and service user partners for their feedback. We also provided a draft to colleagues from the DoH and the HSE who had attended the workshops.

This draft gave all participants the opportunity to review the content and comment and provide feedback. We got 18 responses and 176 feedback points. The Health Regions Programme Team considered these responses and the feedback points raised.

4.7 Appendix 7 – Workshop themes and ideas (May 2023 workshop)

The following themes and ideas were captured at the first co-design workshop on 10 May 2023.

Ideation Themes (Main themes)	Ideas ('ideations')
• **Culture** • **Human rights based** • **Takes into account its weakness**	- Golden rule – 'treat others as you wish to be treated' - Create an equal partnership – patient included in setting the agenda - Change should revolve around patient satisfaction - Regional Health Area level – build trust - Opportunity to assess public value
• **Communication** • **Ability to share data collected**	- Better informed staff and patients and service users - Do we need roadshows, e-surveys or e-polls? (e stands for electronic) - Data visible to key stakeholders
• **Access**	- Patients/service users have access to their information
• **Design and implementation** • **Processes**	- Patient Partnership Office in each Regional Health Area (RHA) - Participation at all levels, groups and committees - Opportunity to decide what to 'leave behind' - Create a budget for patient partnering in each RHA
• **Consider the barriers**	- New thinking around service delivery
• **Upskilling and training of staff**	- Staff awareness of patient engagement - More training of staff to change the culture
• **Integrate the logistic parts**	- Look closely at transport for access to health and social care
• **Real-time feedback**	- Real-time feedback to be acted upon, - Accessible anywhere (real time)
• **Outcome measures** • **Performance management** • **Monitoring of services** • **Accountability** • **Transparency**	- Importance of outcomes and measures
• **Patient and Partner Involvement (PPI) Policy** • **PPI at Dept. of Health Level**	- Agree a PPI structure at Regional Health Area level - Need a national PPI policy - Make PPI the norm - Resource and allocate staff and budget for Patient Partnership Involvement
• **Learning from others' experiences** • **Advice capturing**	- Start with the end user. Value our experience - Storytelling – personal experiences
• **Technology**	- Electronic Health Record (EHR) [Defined in glossary]
• **Possibility of integration [of services]**	- New thinking around service delivery
• **Partnership**	- Involve Patient Partners in oversight to transition to Regional Health Areas (Oversight means 'overseeing')
• **Input at point of patient**	- Involve Patient Partners in identifying local needs at the earliest stage
• **Language**	- Health Literacy for all in the community

4.8 Appendix 8: Document versions (document control)

Document control of this proposal document

Drafts were issued to:

- all stakeholders in September 2023
- the Health Regions Implementation Planning Group 11 January 2024
- all stakeholders on 12 January 2024
- Health Regions Oversight Group 19 January 2024
- The Regional Executive Officer (REO) Induction Pack 1 February 2024

This proposal document was finalised on 14 February 2024.

The document you are now reading was edited using plain English guidelines up to and including section 3.5. We also used some of these guidelines for all appendices apart from the original submissions from our patient and service user partners. These were left as provided.