



Better Together

Health Services Patient Engagement Roadmap

Better Together: The Health Services Patient Engagement Roadmap

Providing the essential guidance and tools for healthcare staff to create a strong culture of meaningful Patient Engagement, where Patient Engagement is encouraged, expected and respected.

HE



CONTENTS

Introduction

Health Services Patient Engagement (PE) Roadmap	4
Foreword	6
Why this Roadmap is needed	7
The purpose of the Roadmap	9
How to use the Roadmap	10
How the Roadmap was developed	12
Terms used in the Roadmap	13
Why Patient Engagement is important	15
Core Values underpinning Patient Engagement	18

Section 1 Essential Core Components of PE

Guiding Principles of PE	22
Essential Core Components	23
Commitment to engage	23
Assessing Readiness for engagement	24
Communication	28
What to avoid	33
Building in Evaluation	34
Training/Education	35

Section 2 Degrees of Engagement

Degree 1: Inform	42
Degree 2: Consult	44
Degree 3: Discuss and Deliberate	45
Degree 4: Collaborate	46

Section 3 Healthcare Levels

Part A: Healthcare Levels Explained	51
Part B: Individual Health and Healthcare Level	52
Part C: Healthcare service Design Delivery and Evaluation level	56
Essential steps for conducting meaning PE activities for Healthcare Services Design Delivery and Evaluation and Healthcare Policy Levels	57
Finding, Inviting and Selecting Patient Representatives	61
Checklist for Organisational requirements for meaningful PE	70
Checklist for meaningful PE in Policy Making	73

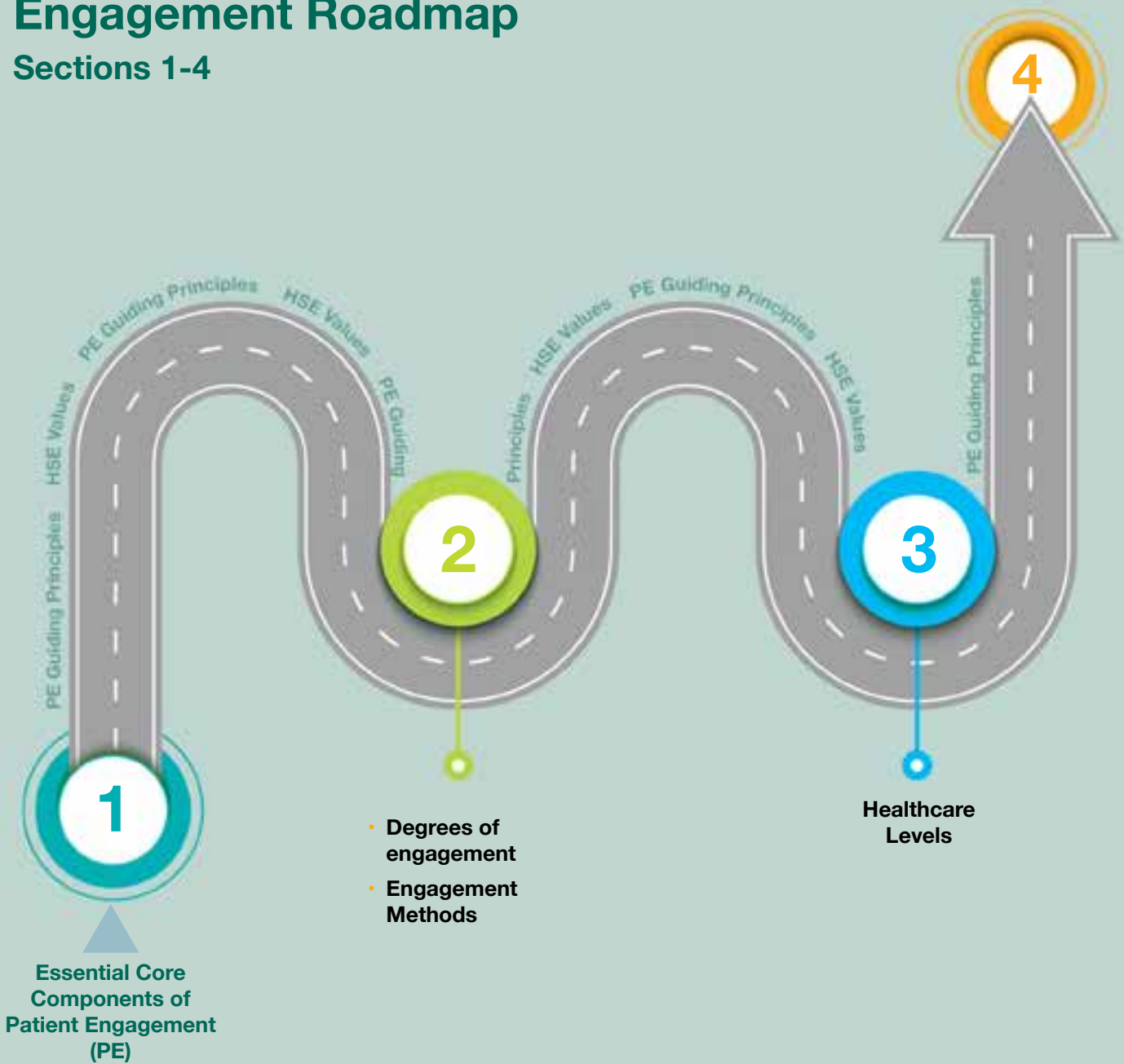
Section 4 Examples of PE across the HSE

Further reading	75
-----------------	----

The Patient Engagement Roadmap

Sections 1-4

Meaningful Patient Engagement (PE)



1

Essential Core Components of PE

- Commitment
- Readiness
- Communicaton
- What to avoid
- Evaluation
- Training / Education

2

- Degrees of engagement
- Engagement Methods

3

A: Healthcare Levels explained

B: Individual Health & Healthcare Level

C: Healthcare Services Design, Delivery & Evaluation Level

D: Healthcare Policy Level

4

Examples of Meaningful Patient Engagement

Section 1





Section 2

Section 3 (A, B, C, D)

Section 4

How to Navigate the Roadmap

This resource is created for all Clinical and non-Clinical staff. Sections relevant to you can easily be found by looking for the following symbols throughout this document. Find and follow the symbol that describes your healthcare setting.

-  All healthcare staff, clinical and non-clinical, working in a healthcare service.
-  All clinical healthcare staff who work with patients in individual health and healthcare.
-  All healthcare staff, clinical and non-clinical working in healthcare service design, improvement, delivery and evaluation.
-  All healthcare staff, clinical and non-clinical, working in updating and creating healthcare policy.

When we use the term “*patient*” we are referring to people who use, or are supported by healthcare services, their personal support network, communities and anyone who may use healthcare services in the future.



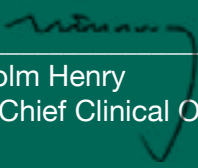
FOREWORD

Patient Engagement is recognised as a fundamental cornerstone of healthcare and a critical component of a safe, people-centred service. Patients tell us that while clinical effectiveness and safety is important, their experience of care matters to them just as much. In order to make informed decisions and choices about their care they want to feel listened to and supported.

Patients have a unique perspective which makes them invaluable partners in how we design, deliver and evaluate our health services. The involvement of patients requires us to view care from a patient perspective. Their insight is a largely untapped resource and one of the ways of harnessing this resource is through Patient Engagement. Patient Engagement is positively associated with improved health outcomes and improved satisfaction for patients and their families. It is essential that health services put processes in place to involve patients, their families and the public. Patient Engagement should be for every patient, every day by every member of staff.

The ultimate goal of Patient Engagement is to create an environment where patients and healthcare staff are all working together, as partners, to improve the quality, safety and experience of healthcare and ensure the care and treatment provided is person-centered.

This document sets out a Patient Engagement Roadmap for healthcare organisations and healthcare staff to proactively engage with patients, families and carers. It builds on and signposts organisations and staff to resources already available in the health service to support them to establish, progress and embed meaningful Patient Engagement practices.


Dr Colm Henry
HSE Chief Clinical Officer


Joe Ryan
HSE National Director,
Operational Performance & Integration



WHY THIS PATIENT ENGAGEMENT ROADMAP IS NEEDED

Engaging patients in their own individual medical decisions and also in the design and implementation of healthcare services is enshrined as a right of all people, as stated in the 1978 Declaration of the Alma-ata (WHO 1978).²

The Health Service Executive, along with healthcare systems around the world is responding to the demand of “nothing about me, without me” and the requirement to shift from “what’s the matter” to “what matters to me”³. There is a strong emphasis placed on meaningful Patient Engagement in the HSE, reflected in the HSE Corporate Plan 2021-2024.

Engaging with Patients to improve the safety and quality of services aligns with:

- **HSE Corporate Plan 2021-2024: Enabler 1** “Aims to create an environment where patients, families, carers are listened to and actively involved in making our services better and safer”.
<https://www.hse.ie/eng/services/publications/corporate/hse-corporate-plan-2021-24.pdf>
- **Commitment 1 of the HSE Patient Safety Strategy 2019-2024**
“Empowering and Engaging Patients to Improve Patient Safety: We will foster a culture of partnership to maximise positive patient experiences and outcomes and minimise the risk of error and harm. This will include working with and learning from patients to design, deliver, evaluate and improve care”.
<https://www.hse.ie/eng/about/who/nqpsd/patient-safety-strategy-2019-2024.pdf>
- **Patient-Centred Care Standard as per HIQA Safer Better Healthcare Standards.** (Quality Assessment and Improvement workbook)
<https://www.hse.ie/eng/about/who/qid/resourcespublications/qaandiworkbook1.pdf>
- **Assisted-Decision Making (Capacity) Act 2015**
<https://www.irishstatutebook.ie/eli/2015/act/64/enacted/en/html>
- **Open Disclosure Policy 2019**
<https://www.hse.ie/eng/about/who/nqpsd/qps-incident-management/open-disclosure/hse-open-disclosure-full-policy-2019.pdf>
as per Patient Safety Bill 2018
<https://assets.gov.ie/9987/b63d04b35ac94140984d8d7634b4baf6.pdf>
- **Health Services Change Guide- People’s Needs Defining Change**
<https://www.hse.ie/eng/staff/resources/changeguide/resources/change-guide.pdf>

- **Public Health reform, as per the National Service Plan 2022.**
<https://www.hse.ie/eng/services/publications/serviceplans/hse-national-service-plan-2022.pdf>
- **National Healthcare Charter**
<https://www.hse.ie/eng/about/who/qid/person-family-engagement/national-healthcare-charter/>
- **The Sláintecare Action Plan (DOH Ireland, 2019)** aims to provide “the right care, in the right place, at the right time”. Patient Engagement will play an essential role in the successful implementation of this action plan.



<https://www.gov.ie/en/publication/6996b-slaintecare-implementation-strategy-and-action-plan-2021-2023/>

This Roadmap has been designed to enable healthcare staff to:

- take a more considered and consistent approach to actively engage with people who use healthcare services
- learn about the needs, beliefs, experiences and preferences of people who use healthcare services to ensure safe, high quality, fit for purpose healthcare is delivered. Patient preference is a key cornerstone of patient-centred care.
- build on the current Patient Engagement processes, strategies and policies in use within Irish Healthcare services.
- share resources and examples of good practice.

The Roadmap reflects on the international and national literature in engaging patients and the wider public. The resources provided are considered to be the building blocks to create a solid foundation for meaningful Patient Engagement, but are by no means exhaustive.

This Roadmap is intended to be a live document that will expand and develop as the practice of Patient Engagement becomes embedded over time within healthcare services.

It is designed so that the reader can make it their own, choosing the sections that are relevant to the healthcare level and the local context in which they wish to engage with patients.



THE PURPOSE OF THE ROADMAP:

To provide the essential guidance and tools for healthcare staff to create a strong culture of meaningful Patient Engagement, where Patient Engagement is encouraged, expected and respected, where engagement becomes the norm:

**“ for every person, every day
by every member of staff ”⁴**

working together towards developing engagement-capable environments and a “we” approach to healthcare.

Who it is for?

This roadmap is for all healthcare staff (clinical and non-clinical) working at all levels of healthcare services. It is also for patients and their personal support network.

How to use it

The Roadmap is divided into 4 sections to help navigate your Patient Engagement journey. It guides you through the:

- rationale for and definition of Patient Engagement.
- essential elements for meaningful Patient Engagement.
- four degrees of engagement and corresponding engagement methods.
- three healthcare levels at which Patient Engagement occurs.
- actions required for meaningful Patient Engagement at the individual health and healthcare level.
- essential steps to take to set up and conduct a meaningful Patient Engagement method/activity for engaging with patients at the service design, delivery and evaluation level of healthcare and the policy making level of healthcare.
- organisation/service requirements to embed Patient Engagement as part of how we do our work.
- actions required for enabling meaningful Patient Engagement in policy making.

Section 1: The essential core components of meaningful Patient Engagement for all healthcare staff (clinical and non-clinical).

This section is relevant for all healthcare staff. It provides guidance on the essential core components required for meaningful engagement at every healthcare level, for every member of staff, across all degrees of engagement. There are checklists to self-rate against the essentials and resources to help achieve them.

Section 2: The degrees of engagement explained

In this section, the four degrees of engagement are explained and examples of engagement methods, and guidance on how to set them up and conduct them are given. Each degree varies in the level of influence the participants have in the decision making process. Approaches range from sharing information about services, to collaborating with patients to design and improve services together with healthcare staff. Each degree of engagement has its own value.

Section 3 Levels of healthcare at which Patient Engagement occurs

This section is divided into four parts.

Part A: The three healthcare levels at which Patient Engagement occurs: Individual Health and Healthcare level; Healthcare Service Design, Delivery and Evaluation level; and Healthcare Policy level, are explained.

Use this section to select the healthcare level and corresponding parts B, C or D of section 3 which are most relevant to the healthcare level at which you engage with patients.

Part B: Individual Health and Healthcare level: The focus in this setting is on engaging with patients in their own health and healthcare. This section is relevant for any clinical healthcare staff who work with patients in care encounters. It includes:

1. Checklist of actions to ensure meaningful Patient Engagement at the individual health and healthcare level. Assess yourself and/or your team against the actions and create an action plan for improvement.
2. Resources.

Part C: Healthcare service Design, Delivery and Evaluation Level

The focus in this setting is on engaging with patients in the design, delivery, improvement and evaluation of healthcare services. This is relevant for all healthcare staff participating in updating existing healthcare services and designing new and integrated healthcare services. It includes:

1. Essential Steps for conducting meaningful Patient Engagement activities in Healthcare design, delivery and evaluation. Use these steps to guide you in choosing, designing, conducting and evaluating your Patient Engagement activity/activities.
2. Checklist for organisational requirements for embedding meaningful patient engagement as part of how we work. Healthcare managers and leaders, assess your organisation against the checklist and create an action plan for improvement.

Part D: Healthcare Policy Making Level

The focus in this setting is on engaging with patients in updating and making policy, in writing governance and in writing strategy and is relevant for healthcare staff involved at this level of healthcare. It includes:

1. Essential Steps for conducting meaningful Patient Engagement activity/s in healthcare policy making. Use these steps to guide you in choosing, designing, conducting and evaluating your Patient Engagement activity/activities.
2. Checklist for embedding meaning Patient Engagement at the Policy Making Level. Healthcare managers and leaders, assess your organisation against the actions and create an action plan for improvement.

Section 4: Examples of good Patient Engagement across the healthcare services.

This section contains some examples of good Patient Engagement practice across the HSE



OF NOTE

Developing National Clinical Guidelines and National Clinical Audits

For the development of National Clinical Guidelines and National Clinical Audits, please see Framework for Public Involvement For Clinical Effectiveness Processes

<http://health.gov.ie/national-patient-safety-office/ncec/patient-and-public-q-and-a/>

Engaging with Children in healthcare

For healthcare staff engaging with children and young people, please use the Tusla Child and Youth Participation Toolkit if planning engagement with children. It includes the context and rationale for child and youth participation; guidance in the application of the Lundy model of participation and examples of activities that can support participation.

[https://www.tusla.ie/uploads/content/Tusla - Toolkit \(web version\).pdf](https://www.tusla.ie/uploads/content/Tusla - Toolkit (web version).pdf)

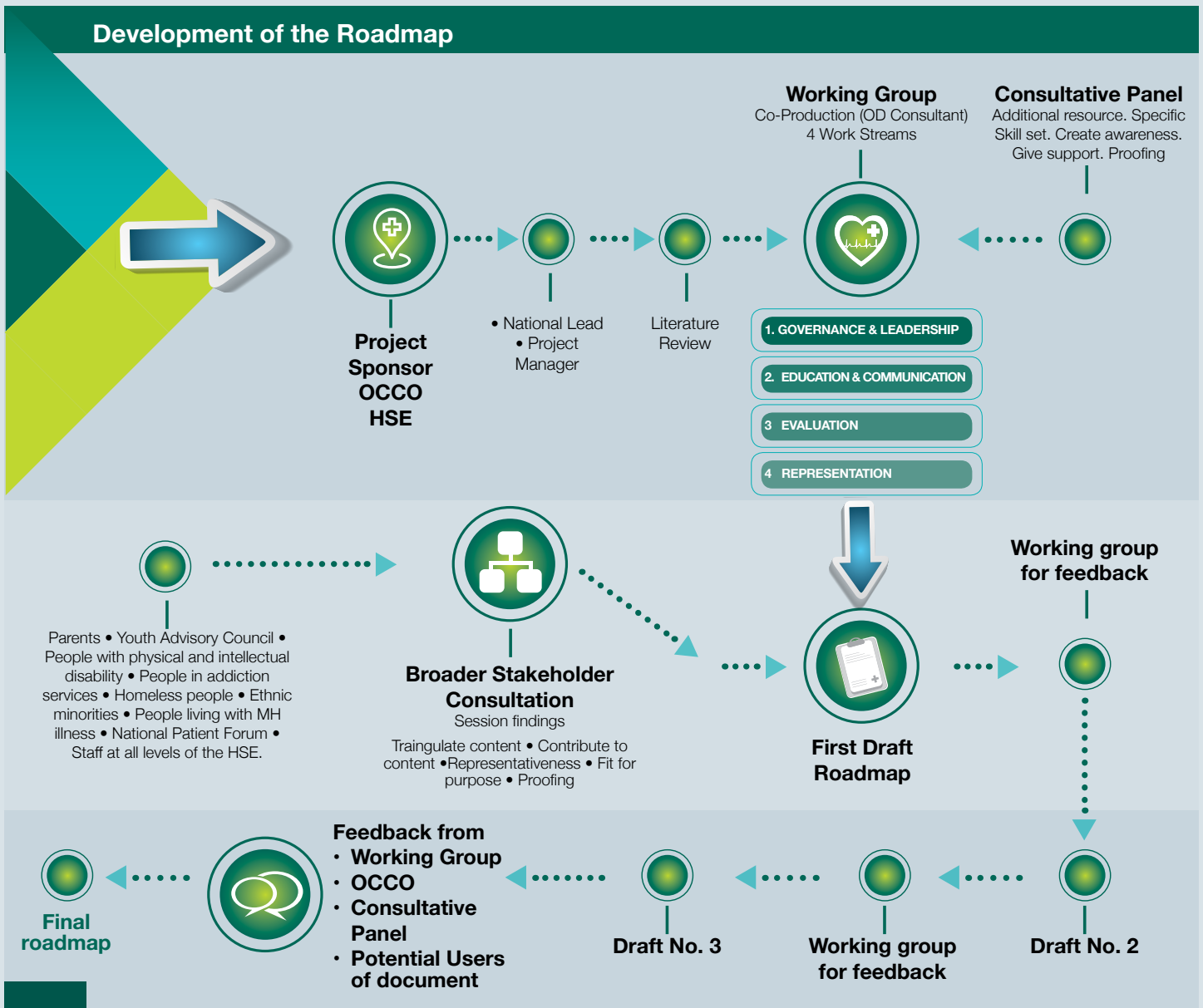
How the roadmap was developed:

A literature review was undertaken at the start of the process to ensure an evidence based approach and to identify core components required for meaningful Patient Engagement. (See [Patient Engagement in Health and Healthcare: A literature review](#)) Next steps involved establishing a working group to progress the development of the roadmap.

The working group had representation, in equal numbers, of patient representatives, healthcare staff and HSE experts who could help progress the work of the group. The engagement method used was co-production, working together from the outset of the project. Co-production is explained in appendix no.1. Membership of the working group is listed in appendix no. 2.

This group was supported by a consultative panel who have expertise in Patient Engagement and in health and social care service processes. Membership of the Consultative panel is listed in appendix no. 2.

Several stakeholder consultation sessions were conducted with patients, families and carers who use a variety of healthcare services and healthcare staff in a variety of roles. This was to ensure a diverse range of perspectives from many patients were heard, collated, and incorporated within the content of the Roadmap. (See appendix 1 for Summary report of the Stakeholder Consultation Sessions).



The terms used in this Roadmap defined

Who are “Patients”?

Different terms are used for people who attend health and social care services in different settings. The terms “patient”, “service-user”, “client”, “resident”, “person supported by healthcare services”, “consumer”, “the public” and “people who use healthcare services” are used across our health and social care services.

Our working group has chosen to use the word “patient” as it was felt this term makes it clear that this Roadmap is for use in healthcare services.

When we use the term “**patient**” we are referring to people who use, or are supported by healthcare services, their personal support network, communities and anyone who may use healthcare services in the future.

A patient’s **personal support network** includes family, friends carers and/or any other support persons, as identified by the patient.

When reading this document, please substitute the word “patient” with the term most appropriate for your healthcare setting.

What is Patient Engagement?

Patient Engagement (PE) means different things to different people, with different terms being used such as involvement, participation, partnership, collaboration, co-production and engagement.

The term “engagement” encompasses all of these terms and brings into focus the human connections between people using healthcare services and those providing the service.

Below are the words that emerged most frequently when we asked patients and healthcare staff to define what engagement meant to them:



Patient Engagement is a term used to describe the ways in which healthcare staff work together with patients and their personal support network to actively involve them in decisions made about their own health and healthcare; healthcare service design, delivery and evaluation; and healthcare policy.

It means patient's needs, preferences, beliefs, experiences and expertise are heard and acted upon and that all participating have influence on the decisions being made.

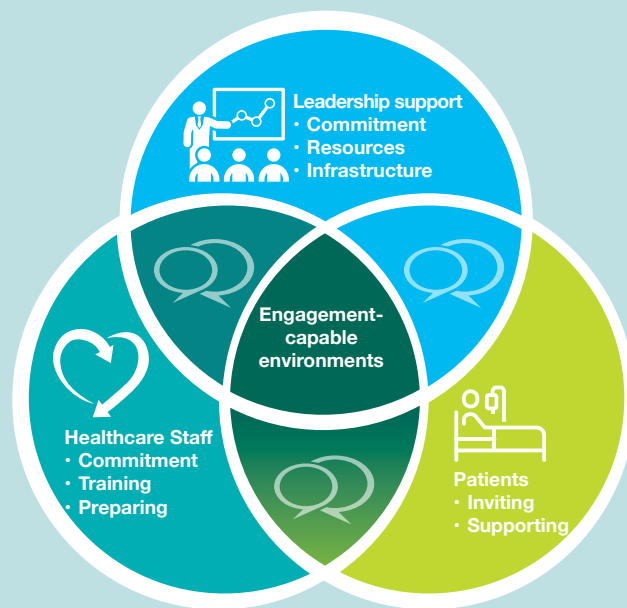
Patient Engagement is multifaceted and complex and can be described as both a process and a behaviour. It is about creating, maintaining and sustaining relationships and making human connections. The interactions, trust and respect that are developed in these relationships between patients, healthcare staff and healthcare leaders create the glue for engagement-capable environments ⁵.

Engagement-Capable Environments

The term “engagement-capable environments” refers to organisations who have enabled meaningful engagement and established the cultural change that is needed to support engagement efforts.

In order to create engagement-capable environments, it is necessary to:

1. invite and support patients to engage.
2. train and prepare staff for engagement.
3. ensure leadership support of engagement activities by providing commitment, resources and infrastructure ⁶.



This approach ensures that resources, structures and a common commitment is present at all levels of the organisation, and not simply a mandate from the top down. Strong relationships among leaders and with their teams are seen as a key dependency to enable change ⁷.

There is no “one size fits all” approach to Patient Engagement, as each engagement activity will have its unique context and aims and the method/s of engagement chosen will be tailored to achieve those aims.

Meaningful Patient Engagement sets the culture for creating a “we” approach to healthcare, where the experience and expertise of both patients and healthcare staff are recognised, valued and acted upon.

Why is Patient Engagement important?

Patient Engagement is the right thing to do:

“Engaging patients in their own individual medical decisions and also in the design and implementation of healthcare services is enshrined as a right of all people”². “Patient Engagement introduces a higher level of transparency and accountability”^{8,9}.

Health Information and Quality Authority (HIQA) have developed a guidance document for staff to promote a Human Right’s-based approach to care and support for adults in all Health and Social Care services. This approach is underpinned by the FREDA principles of Fairness, Respect, Equality, Dignity and Autonomy.

<https://www.hiqa.ie/sites/default/files/2019-11/Human-Rights-Based-Approach-Guide.PDF>

“

There is increased recognition & acceptance

that users of health services have a rightful role, the requisite expertise and an important contribution to design and delivery of healthcare services.¹⁰

”

”

Benefits of Patient Engagement for patients, healthcare staff and healthcare services

Patient Engagement is an essential component of today’s healthcare system where the delivery of patient directed and person-centred care, improved safety and quality of services, trust and confidence, and greater transparency are being prioritised.

There are many benefits of meaningful Patient Engagement. They include:

- improvements in patient safety and the quality of healthcare^{3,5,11,12,13,14,15}.
- the design of healthcare services that are fit for purpose and optimally accessible to those who need to avail of them¹⁶.
- developing priorities and making improvements based on needs identified by the patients rather than on the assumptions of healthcare providers^{3,16}.
- enhanced person-centred care^{3,13} where patients are actively encouraged and given the tools and autonomy to self-manage and lead their own care.
- creating healthcare services that are supported & utilised – people support the change they help to design.
- better patient experiences and satisfaction with care received^{5,11,16,17}.
- improved health outcomes for patients^{12,15,18}.
- increased healthcare staff satisfaction and retention^{3,11,13}.
- lower healthcare costs¹¹.

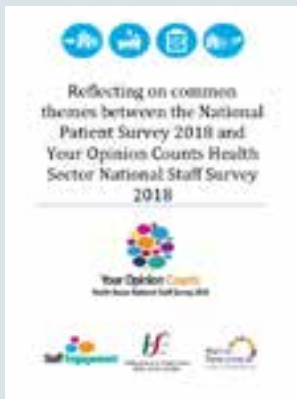
Relationship between staff engagement and Patient Engagement

There is a direct connection between Patient Engagement and staff engagement. Engaged staff result in better patient experience. Staff engagement has been defined within the HSE by the National Staff Engagement forum as:

“Staff are engaged when they feel valued, are emotionally connected, fully involved, enthusiastic and committed to providing a good service...when each person knows what they do and say matters and makes a difference”

The same can be said from a patient perspective. Patients feel more engaged when they feel valued, heard and respected; when they know what they do and say matters and makes a difference to the decisions made about their healthcare.

“Patient experience and workforce engagement are intertwined, but few providers integrate and analyze these data to really understand the connection”¹⁹



“Cultures of engagement, positivity, caring, compassion and respect for all-Staff, Patients and the Public-provide the ideal environment within which to care for the health of the nation”²⁰

Good teamwork results in positive effects on staff wellbeing, decreased levels of stress and improved patient outcomes.

Healthcare staff working in real teams is associated with lower levels of patient mortality and sickness absence. “Real teams” are defined as teams whose members have clear shared objectives, work closely and effectively together and meet regularly to review performance.

Patients are more satisfied with the care they receive when it is provided by teams where the members communicate effectively, make decisions together, take time out to review what they are trying to achieve and the processes they use²².

Challenges and Barriers to Patient Engagement.

It is useful to consider how to navigate the challenges and barriers that are known to impede successful and meaningful Patient Engagement.

- Lack of trust: Previous experience of tokenistic engagement where patients are invited to be involved when the decision is already made and there has been no feedback regarding the outcome of patient and healthcare staff's input.
- Traditional routines and standardisation of practices on a backdrop of resistance to change poses a barrier to enabling Patient Engagement²³.
- Competing resources and priorities for healthcare staff, where the focus is on the quantity of service delivered rather than the quality of the care or the patient's experience.
- Timing of engagement. If people are invited to be involved when decisions have already been made or they do not have adequate time to make a meaningful contribution, it can feel insincere and tokenistic.
- The accessibility and the physical environment of the chosen location for the engagement can impact negatively.
- Individual knowledge, attitudes and beliefs, and motivations for choosing to become involved may hinder meaningful engagement.
- Individual's lack of confidence in dealing with health services, language or cultural issues, low health literacy, lack of personal resources e.g. low income, decreased access to technology, lack of access to transport/childcare may hinder engagement. (from "Paper to Inform National Social Inclusion Office Involvement in Service User Consultation and the Development of Service User Frameworks, 2019)
- Inadequate support for staff from organisations. such as relevant resources, time, tools, and training.
- Lack of understanding regarding engagement, expectations, roles, responsibilities and lack of capacity building for patients and staff involved.
- The inherent power imbalance in healthcare where patients do not feel they are equal partners in the engagement activity, feel their voices are not being heard or their opinion, experience or expertise not valued.
- Fear: Patient Engagement requires a practice culture that is receptive to making processes more transparent to patients, while inviting and supporting them to suggest how those processes may improve. It requires the yielding of some control. Staff, including service managers and the organisation, can be anxious about patients having a view which differs from theirs. They can also be concerned that they may not be able to meet patient's expectations and requests.



Core values underpinning meaningful Patient Engagement

The HSE core values reflect themes that emerged from the literature review and the response from patients and staff when asked to describe behaviours and experiences where they felt engaged.

Adopting the following core values when engaging with patients ensures engagement is meaningful.

HSE Values

Care: We will provide high quality care by attending to the needs and preferences of the patient using an evidence base.

Compassion We will be sensitive to distress and have the commitment, courage and wisdom to do something about it. We will treat everyone participating with empathy and sensitivity, kindness and humanity. We will provide hope and encouragement when appropriate.

Trust will be built through openness and transparency. This means that healthcare staff will be honest and open about their concerns, their resource limitations, knowledge gaps and errors made when engaging with patients and the public.

Learning All those participating in any engagement activity should expect to learn about each other's perspectives, each other's experiences, their knowledge about the issue being discussed and about how services may be improved.

HSE Values in Action

Values in Action has translated the HSE core values of care, compassion, trust and learning from words into nine behaviours (or actions) that we can all demonstrate. It's about all of us, irrespective of role or grade working together to change our workplaces for the better.

“Bringing our values to life in the health services is key to providing safer better healthcare, better workplaces for staff and to delivering better experiences for the people who use our services” Health Services Change Guide.

Values in Action seeks to increase both staff engagement and good patient experience. Leaders that embody these values create compassionate cultures where people flourish and give of their best.



<https://www.hse.ie/eng/about/our-health-service/values-in-action/>

HE



IN THIS SECTION



Section 1

▶ **Essential Core Components
for Meaningful Patient Engagement**



Better Together

Health Services Patient Engagement Roadmap

This section of the roadmap provides guidance on how to achieve the essential core components for meaningful engagement. This section is relevant for every member of staff who engages with patients, as Patient Engagement is everybody's business "For every patient, every day by every member of staff"

The first encounter any patient has with a healthcare service leaves a lasting impression. Therefore, it is essential that the first encounter is positive, engaging and inspires hope. This first encounter may be a phone-call to offer an appointment, a phone-call to deliver a diagnosis, a first clinic visit, or arriving in the emergency department.

Guiding Principles for Meaningful Patient Engagement (PE):

Adopting the following guiding principles is essential to ensure engagement is meaningful.

DIGNITY AND RESPECT means remaining non-judgemental and accepting another person as a unique and valued individual. It means listening to and honoring patient's suggestions and choices openly and using patient and family knowledge, values, beliefs, perceptions and cultural backgrounds to improve care planning and delivery. Language that everyone involved understands must be used and jargon will be avoided.

PARTNERSHIP This is an explicit statement indicating willingness of healthcare staff to work collaboratively with patients. Meaningful Patient Engagement needs authentic, timely and mutually respectful connections forged between patients, families, healthcare staff and the organisations they work with. It is about doing things "with" rather than "to" people where every participant's input of their unique expertise is valued and considered equally important. This approach helps to address the power imbalance between patients and healthcare staff.

INVOLVEMENT This means encouraging, supporting and enabling patients to be involved in care and decision making to the degree they choose. It means working with the patient to support them to achieve the care and treatment outcomes that matters to them.

INCLUSION Being inclusive means including people with different social backgrounds, culture, ethnicity, age, gender, skills, beliefs, knowledge and experience.

RESPONSIVENESS; ACTION-FOCUSED Being responsive means that healthcare staff and organisations act upon feedback from patients and the general public in ways that demonstrate the positive impact of their input - how things have changed as a result of their involvement.

ENABLING Patients should be invited, encouraged and enabled to openly express their needs, perspectives, concerns and views without any fear of negative repercussions and to make informed decisions confidently.

INFORMATION SHARING This means communicating and sharing complete and unbiased information with patients and families. Patients and families receive timely, complete, and accurate details so they can take part in decision- making. Information will be available in clear and understandable formats and in a language that everyone involved understands.

These guiding principles also apply to healthcare staff engagement. If staff are engaged, this will be mirrored in their interaction with patients.

When we use the term "*patient*" we are referring to people who use, or are supported by healthcare services, their personal support network, communities and anyone who may use healthcare services in the future.

“
The person you meet as soon as you land
 in the service has a big impact.
 (Quote from stakeholder consultation session)
 ”

Essential Core Components



The essential core components for meaningful Patient Engagement listed here are informed by international best practice, patients and staff in our working group, and the information gathered during the wider stakeholder consultation sessions.

01

1. Commitment to Engage

Active patient involvement requires organisational preparation and continuous ongoing commitment.



(a) Leadership commitment

The absolute commitment of leaders, their recognition, support and active involvement to implement and embed meaningful Patient Engagement and to address the cultural change required is key.

There are a number of ways for leaders to demonstrate a commitment to organisational sustainability of engagement, such as:

- making Patient Engagement a strategic priority, (set out in service and operational plans).

01

- providing resources and infrastructure for Patient Engagement.
- supporting and advancing the Patient Engagement agenda through policies, procedures and an agreed clearly defined action plan.
- Having performance measures to identify if meaningful engagement is happening, actively monitoring Patient Engagement and taking action where required.

Having leaders and champions in Patient Engagement across all levels of the organisation, provides:

- strategic focus at the organisational level.
- support for the implementation of engagement initiatives and efforts to involve patients in activities and decision-making at local level.

(b) Individual and team commitment

Successful engagement requires a commitment to developing and supporting a strong partnership between all stakeholders. Mutual respect, trust, honesty, equity, dialogue, humility and negotiation are essential elements for successful collaboration.

Ways to demonstrate individual and team commitment to meaningful Patient Engagement include:

- Inclusion of Patient Engagement on meeting agendas.
- reviewing the “as is” of PE in your department and as individuals.
- evaluating the process and impact of PE.

02



2. Assessing Readiness for engagement

This section has three strands. This can be done as an individual, in a team or service, or as an organisation.

1. Assessing readiness to engage with patients.
2. Assessing readiness for change.
3. Assessing the “as is” or mapping your current Patient Engagement activities/practice.

(a) Assessing readiness to engage:

This is an important first step for healthcare staff and patients. Checking in with personal beliefs and values is important to help us be aware of our attitude and unconscious biases towards meaningful engagement.

This can be done individually and as a team. If you answer no to any of the questions, you need more time to discuss what support you need to feel prepared and able to engage with patients in a meaningful way with your line manager or within your team. (See educational resources listed in appendix no.7)

An honest assessment of you/your team’s readiness for meaningful engagement is important as it sets the stage for a successful partnership with patients.



An honest assessment of you/your team's
**readiness for meaningful
engagement is important
as it sets the stage for a
successful partnership
with patients.**

02

Assessing readiness for meaningful engagement	Yes	No
Do I/we believe patients and their personal support network bring unique and important perspectives and expertise to their own healthcare?		
Do I /we work to create an environment in which patients and their personal support network feel supported enough to speak freely?		
Do I/we listen respectfully, openly and actively to the opinions of patients and their personal support network?		
Do I/we invite and encourage patients and their personal support network to participate and lead in decision-making about their care?		
Do I/we consistently let colleagues know that I/we value the insights of patients and their personal support network?		
Do I/we believe that patients and their personal support network bring a perspective to service design, delivery, improvement and evaluation that no-one else can provide?		
Do I/we believe in the importance of patient and their personal support network participation in planning and decision making at the service design and policy making level?		
Do I/we believe patients and their personal support network (family/friend/carer as identified by the patient) can look beyond their own experiences and issues?		
Do I/we believe that the perspectives, expertise and opinions of patients and their personal support networks and providers are equally valid in planning and decision making at service and policy level?		
Do I/we have experience working with patients and their personal support networks as partners and/or members of improvement or other teams?		
Do I/we understand the role of patients and their personal support network (family/ friend/carer as identified by the patient) who serve as advisors and or members of improvement or other teams?		
Do I/we clearly state what is required and expected of patients and their personal support network in their role as advisors/ members of improvement or other teams?		
Do I/we support patients and their personal support network in their roles?		
Do I/we feel comfortable giving responsibility to patients and family advisors and improvement team members to carry out their tasks in order to achieve the aim of the work?		
Do I/we understand that a patient representative being unwell or having other family demands may require patients and their personal support network to take time off from their responsibilities on these teams?		

(See Appendix 3)

Our attitudes and values, combined with the self-awareness of the influence of our own personal values, all impact our thinking, feelings and actions in our workplace.

Take time to reflect on your values:

People’s Needs Defining Change Health Service Change Guide- Guidance on Defining your Personal Values Template ^{6.2.4.}:

<https://www.hse.ie/eng/staff/resources/changeguide/resources/template-624-guidance-on-defining-your-personal-values.pdf>

02



O'Neill 2015.
Resource: Adapted from Professional Supervision Training Programme for HSCP Supervisor Resource Pack (HSE National HSCP Office and Eileen O'Neill, Independent Trainer and Consultant). Used with permission.

Your Self-Awareness

Self-awareness is more than the ability to identify one's skills and strengths and being able to name one's limitations, it includes:

- Alertness to and challenging of personal bias, prejudice and judgments.
- Questioning of oneself and an openness to being questioned by others.
- Curiosity about what experiences and people mean to us and how these influence our practice and development.
- Conscious consideration of the messages and feedback we get from others – both formally and informally.
- Ongoing reflection on the impact of personal values and potential tensions between personal & professional values.

(b) Assessing readiness for change.

Working together in partnership with and involving patients in their personal health and healthcare is a new way of working for many healthcare staff.

Assessing readiness for change as individuals and as a team is important in preparing for, or progressing meaningful Patient Engagement.

Peoples Needs Defining Change Health Services Change Guide- Personal Readiness for Change Template ^{6.2.6}[Peoples Needs Defining Change Health Services Change Guide- People and Culture Change Platform Readiness Factors Change Template](#) ^{6.2.8}

(c) Map the current Patient Engagement Activities in your practice/team/service.

Recording the Patient Engagement practices, activities and structures currently in place provides a baseline of where you or your service are in terms of your Patient Engagement journey. It gives you the opportunity to reflect on how well you are doing and where you could improve and to create an action plan to achieve the improvements you want to make. (See Appendix 4)

Hospital/CHO	Service	PE Activity/ Structure	Duration	How well is this working/ outcome of evaluation	Lead contact person
e.g. Tallaght University Hospital	PALS	Patient and Community Advisory Council			

Improvements Action Plan: Core Component Name (e.g. communication)					
Goals (In order of priorities)		Short Term	Medium Term	Long Term	Person/s responsible
	1				
	2				
	3				

(See Appendix 5)

03

3. Communication modes and skills for meaningful PE

The importance of effective communication as an enabler of meaningful Patient Engagement was a theme highlighted throughout the literature review and discussions in our working group and the wider stakeholder consultation sessions. How people are communicated with has a significant impact on how engaged and respected they feel.



It's all about communication

(Quote from stakeholder consultation session)



How we communicate with people has a significant impact on how we relate to one another. The aim of any interaction is to communicate with people with respect and in a way that they can understand. The focus of the interaction is the person, not their health issue. It is essential to take time to actively listen, to ensure the patient's concerns, needs, preferences and expertise have been heard and understood.

Effective communication skills are important for both healthcare staff and patients to help build confidence to participate in engagement activities. The ability to establish meaningful interactions between healthcare staff and patients depends on:

- the healthcare staff's ability to communicate effectively with the patient.
- the patient's ability to communicate their lived experience and knowledge of their own health.

This reflects the relational aspect of Patient Engagement.

There are a number of key communication styles and skills which are essential for meaningful Patient Engagement.

All communication should be underpinned by the HSE values of Care, Compassion, Trust and Learning (page 18) and guiding principles outlined at the beginning of this section.

1. The language used:

What our patients say:

“healthcare professionals speak a different language...

Very different than what the average [patient] can understand.

They have to let go of the medical jargon and explain things to people”.

(quote from stakeholder consultation sessions)

03

In all communication with patients and the public it is important to:

- Consider health literacy needs.
- Use plain/simple English, language that everyone can understand.
- Avoid the use of acronyms and jargon.
- When you have to use clinical terms, use jargon busters to explain what these terms mean.
- Have a system in place that makes it easy for people to let you know when they do not understand terminology being used.
- For patients who are not fluent English speakers, have written information available in different languages and arrange to have an interpreter present when required.
- For patients who may be dyslexic, it is recommended to use dark coloured text on a light but not white background, use sans serif fonts e.g arial and font size of 10-14, avoid underlining and italics and use bold for emphasis, among other recommendations.

Resources:

See the HSE Guidelines for Communicating Clearly:

<https://www.lenus.ie/bitstream/handle/10147/622764/Guidelines-for-Communicating-clearly-using-Plain-English.pdf?sequence=1&isAllowed=y>

See the HSE Social Inclusion Office resources:

[HSE Lost in Translation? Good Practice Guidelines for HSE Staff in Planning, Managing and Assuring Quality Translations of Health Related Material into Other Languages](#)

[HSE Social Inclusion Translation Hub](#)

[my health my language](#)

2. The mode of communication chosen:

Consider the individual needs of those with whom you are engaging. This may require the use of different methods of communication.

- **“Embarrassing to get written information when you can’t read”***.
For patients who cannot read or write, use visual / pictorial aids.
- **“Nothing user friendly for blind people- no braille- all communication in print- useless- emails work through use of adaptive technology- improves accessibility”***
For someone who is blind, written information is not accessible to them unless brail is used. Emailing information means computer programmes can be used to convert them



to auditory messages. Consider the need for guide dogs to accompany people with visual impairment to their appointments.

For patients who are deaf, use written communication if they can read/ use sign language, consider sign language interpreters, closed captioning and amplified hearing devices.

- **“It’s important to have knowledge of where a person is coming from- ask does post get delivered to their home”***

When information is being posted: Can people access their post? Are addresses up to date and correct?

(*Quotes from patients during stakeholder consultation sessions)

3. Effective communication skills

The more effectively healthcare staff communicate verbally and non-verbally, the more likely patients are to feel safe. This supports patients to be more comfortable to share the physical and emotional aspects of their illness so they can make fully informed decisions about their own health and healthcare. It gives patients the encouragement and confidence to engage.

(a) Listening:

Listening is one of the most valuable skills a healthcare provider can develop.

Effective listening shows respect for the person speaking, displays interest in the content being communicated and in the person communicating the content. “Interaction without quality listening can be experienced as just going through the motions and this is a waste of a valuable resource for all involved”. (HSCP Professional Supervision Training Programme).

Tips for effective listening

- **Listening to understand:**



Solving problems is a key role for healthcare staff. Focussing on finding a solution can lead to the practice of listening to respond, rather than listening to understand. The practice of inquiry helps to arrive at a shared understanding. This means asking questions, but not too many, being curious and being attentive.

- **Active listening**



Active listening is where you make a conscious effort to hear not only the words that another person is saying but, more importantly, the complete message being communicated. It involves “ears for hearing, eyes for observation and objective awareness with attention to feelings”. It includes: avoiding interruptions, withholding judgement, training the mind and not being distracted, practicing silence, taking time to hear what the person is saying, taking non-verbal cues. (HSCP Professional Supervision Training Programme). Verbal skills used in active listening include paraphrasing, clarifying meaning, using open-ended questions. Nonverbal communication is important, as it can improve a person’s ability to relate, engage, and establish meaningful interactions in everyday life.

(b) Non verbal communication

Nonverbal communication cues—the way you listen, look, move, and react—tell the person you’re communicating with whether or not you care, if you’re being truthful, and how well you’re listening. When your nonverbal signals match up with the words you are saying, they increase trust, clarity, and rapport. When they don’t, they can generate tension, mistrust, and confusion. Therefore, it’s important to become more aware and open not only to the

03

body language and nonverbal cues of others, but also to your own.

Non-verbal communication includes facial expression, eye contact, body language, gestures, movement, touch, space and pitch, pace and tone of your voice.

See link below on Building Relationships and Core Consultation Skills from the national healthcare communication programme for guidance on non-verbal behaviours.

<https://www.hse.ie/eng/about/our-health-service/healthcare-communication/module-1-making-connections/building-the-relationship.pdf>

<https://www.hse.ie/eng/about/our-health-service/healthcare-communication/module-2/>

(c) Communicating with compassion and empathy



**Compassion
is one of the 4 HSE
core values**

and has been described as “A sensitivity to distress together with the commitment, courage and wisdom to do something about it”²⁴.



Communication is referenced in this core value:

“we will show respect, consideration and empathy in our communication and interaction with people”; “we will be courteous and open in our communication with people and recognise their fundamental worth”.

Empathy is the ability to recognise and respond to emotions. Empathy and compassion create a safe and secure space for meaningful interactions between healthcare staff and patients.

Challenges to communicating with empathy include time pressure and concerns about responding appropriately to patient’s different emotions:



Time Pressure

While time is a major challenge in healthcare settings, research shows that patients usually need only 90 seconds or less at the beginning of a conversation to state their concerns. Taking the time to ask a patient what matters to them and providing time to respond establishes a foundation for trust and disclosure. It also saves time in the long run by strengthening the provider-patient partnership which can make care more efficient.^{25,26}



Worrying about Patients’ Emotions

Emotions expressed by patients can make healthcare staff uncomfortable. In moments like this, a response of genuine respect and curiosity as well as naming the emotion is enough. e.g. ‘I can see you are upset’. It is not necessary to “fix” an issue or solve a problem right away. When healthcare staff show they are emotionally in tune with their patients, patients feel more comfortable and

03



trusting and strategies will surface within a non-judgemental care environment. To help build a relationship with patients, healthcare staff need to be able to respond to emotion effectively. When they address and acknowledge emotion, it helps to build strong relationships.

Further information regarding listening skills, open-mindedness and openness, empathy and compassion are included in the link below adapted from Professional Supervision Training Programme for HSCP Supervisor Resource Pack (HSE National HSCP Office and Eileen O Neill Independent Trainer and Consultant). (See Appendix 6.5)

Further information regarding the National Healthcare Communication Programme can be found in this link:

<https://www.hse.ie/eng/about/our-health-service/healthcare-communication/about/>

Effective communication within and between teams caring for patients was identified as being critical for meaningful Patient Engagement by patients who attended stakeholder consultation sessions.

Checklist for effective communication

This checklist is relevant in all healthcare settings for all healthcare staff (clinical and non-clinical). You may find some of these questions reoccur in the individual healthcare setting checklists in section 3.

	Yes	No	N/A
Have you used the Communicating Clearly guidelines?			
Does your team/ service/ Community Healthcare (CHO) Organisation/ Hospital have a health literacy policy or health literacy committee			
Have you checked if the written information you give to patients adheres to plain English guidelines?			
Do you avoid the use of acronyms in written and spoken communication?			
Do you use jargon busters?			
Do you have a system in place to make it easy for patients to ask you to explain terms they do not understand?			
Do you have access to interpreters? Do you know how to book and work with an interpreter?			
Is there a question included on pre-admission/appointment information to ask if patients have any literacy needs?			
Do you use a variety of communication modes?			
Do you communicate with empathy and compassion?			
Have you/your team completed effective communication training?			
Have you /your team completed the National Healthcare Communication Programme modules?			
Do you have a communication plan for within your team and across other teams who may be involved in your patient's care? (See appendix 6.8)			

(See Appendix 6)

<https://www.hse.ie/eng/about/who/communications/communicatingclearly/guidelines-for-communicating-clearly-using-plain-english.pdf>

04



4. What to avoid when engaging with patients:

1. Tokenism

Tokenism can occur at any degree of engagement²⁸ and is defined as “the difference between..... the empty ritual of participation and having the real power needed to affect the outcome”²⁷.

“Some engagement is not better than no engagement”.

If the inclusion of patients is tokenistic, if the engagement is not authentic and patients are included but not considered, or if decisions are already made before including patients, then the engagement will not be perceived to be meaningful⁵. Therefore, it is essential to avoid tokenistic engagement. It is preferable to have no engagement rather than having tokenistic engagement.

Tips to ensure engagement is genuine:

- Establish clearly defined goals. Be clear why are you seeking to engage patients, families and carers.
- Ensure the degree of engagement is consistent with the goals for any given engagement activity.
- Engage Patients early i.e. from the design stage of the engagement activity.
- Do not engage when the decision has already been made.
- Have a minimum of two patient representatives, but ideally strive for a 50% /50% mix of people who attend healthcare services and healthcare staff in any engagement activity.
- Develop a shared mission, clear purpose and intent.
- Use techniques such as values and belief exercises and narratives to facilitate shared understanding.
- Identify expectations and concerns of all involved at the outset of the engagement activity.
- Clarify roles and responsibilities of patient and staff representatives in engagement activities/ have role descriptions.
- Agree rules of engagement- how the group will work together.
- Be authentic, ensure your intent to engage is genuine.
- Level the power gradient:
 - ensure all relevant information is shared openly with all who are involved in the engagement activity.
 - use language that everyone can understand and avoid the use of clinical jargon.
 - build capacity - support all involved to participate fully in the activity.
 - Ensure all involved have an equal voice in all aspects of the engagement activity.
- Close-the-loop: communicating back the impact of people’s input and feedback.

04

2. Making incorrect assumptions that Patients:

- have an axe to grind.
- are too emotionally overwrought with their illness.
- will find technical details boring.
- won't have anything to add.

3. Consultation Fatigue

Consultation fatigue does not result from patients being asked their opinion on several occasions. It occurs from patients being asked their opinion about healthcare services or issues when their input is not used or the feedback to close the communication loop is not used. Feeding back, closing the loop is very important and can be done on an individual or a group basis.

- (see Appendix no.19 for further information and Close-the-loop template)

Patient Engagement is not always appropriate:

- if the patient is disempowered by the process²⁹.
- in instances of forced responsibility where a patient is incapable of, or is forced to make a decision they don't want to.
- if manipulation occurs where patients are invited to be involved in forums to legitimise policies rather than engage the patient ²⁹.

05

5. Building in Evaluation

Evaluation of both the process and outcome of Patient Engagement is important.

Process evaluation can be used to monitor the implementation and development of PE practices and to ensure the integrity of the guiding principles in practice.

The outcome evaluation of Patient Engagement can demonstrate its value beyond it being the right thing to do. It can also demonstrate the effectiveness of the engagement activity while helping to understand what does and does not work, why and the impact.

A combination of qualitative and quantitative measures should be used. Involving patients in developing outcomes measures makes findings more contextually relevant and captures what matters to the patients.

Evaluation measures should be decided upon before commencing any engagement activity. An "As is" assessment of existing Patient Engagement activities and processes as the baseline is useful.

Templates for evaluation can be found in Appendix no.17

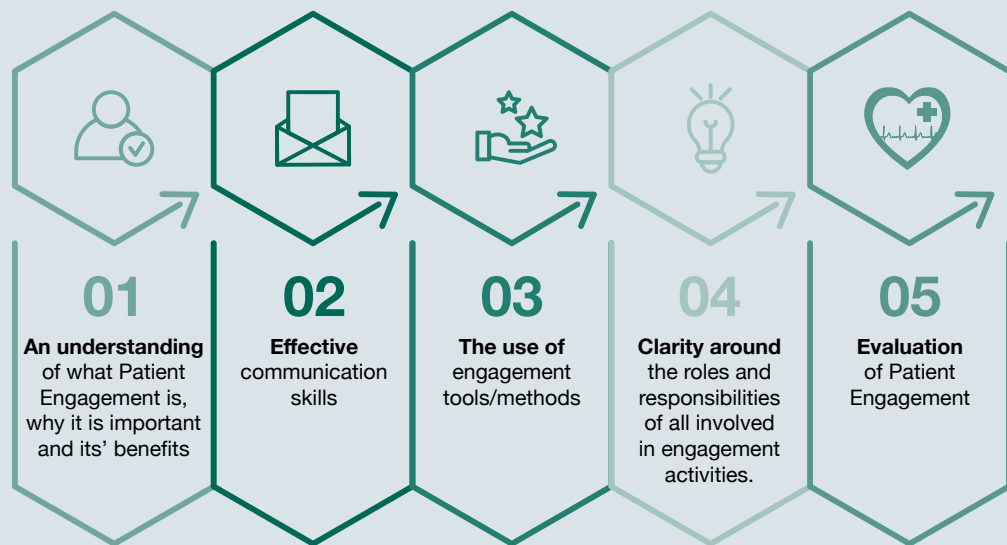


06

6. Training/education

Training for healthcare staff, patients, families and the public at all levels of the healthcare system is a core component for building capacity for meaningful PE.

Education should include:



This training plays a role in capacity building and creating readiness for engagement which helps ensure implementation of meaningful engagement.

In addition, healthcare staff need to be trained in:

- cultural competence: in order for a system to provide care and engage patients with diverse beliefs, staff need to have an understanding of the beliefs, values and behaviours such as the patient's social, linguistic and cultural needs and value systems.
- attitudinal awareness to enable them to move from paternalistic methods to those of patient-as-partners.

All healthcare staff training should be multidisciplinary and include all staff (clinical and non-clinical).

Healthcare staff and patients attending training together helps to build engagement practices while also levelling the playing field in the context of the power imbalance inherent to healthcare services. Being able to build relationships and learn together begins to break down hierarchies that exist within teams and within the broader system. Patient Engagement training should be co designed between staff and patients to ensure it meets the needs of both groups, where possible.

Conduct an "as is" of current training related to the topics noted above in your service/organisation and identify the gaps.

Additional educational resources for the core components outlined above are listed in appendix no.7

06

Cultural Competence

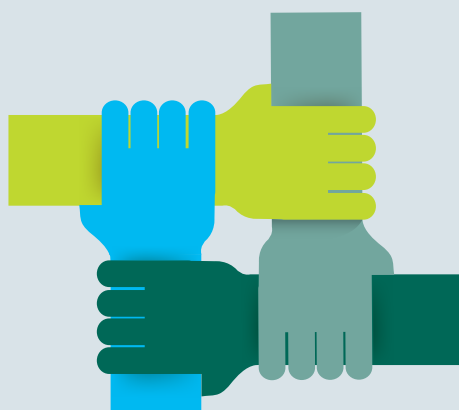
Getting to know a patient’s background, cultural beliefs and practices is an important step to engaging with the patient and in aligning care provided with their preferences, wishes and needs. It is important to understand what matters to a patient within the larger context of their lives. **“No patient wants to be seen as a list of symptoms, but rather as a whole person”**. Intercultural resources in the HSE:



Cultural safety is an outcome based on respectful engagement that recognises and strives to address power imbalances inherent in the healthcare system. It results in an environment free of racism and discrimination where people can feel safe when receiving healthcare. HSE Intercultural Awareness Training Programme is available on HSeLand.

Mental Health Services also have a cultural competence toolkit for staff. <https://www.mentalhealthreform.ie/cultural-competency/>

Ethnicity and Ethnic Equality Monitoring



Ethnicity is a measure of a close cultural connection, as opposed to ‘race’, nationality or citizenship.

What is Ethnicity?

Ethnicity is a measure of a close cultural connection, as opposed to ‘race’, nationality or citizenship. It involves sharing certain background characteristics, such as a shared history, common ancestors, geographical origin, language, culture and religion. This provides people from an ethnic group with a distinct identity as seen by both themselves and others.

How does Ethnicity impact on health?

An important issue that influences health is whether a person belongs to a majority or minority ethnic group.

People from minority ethnic groups can often experience poorer health than the rest of the population. Low incomes, poor working and housing conditions, poor social networks and nutrition as well as

06

lack of access to health services can impact on the health of those from minority ethnic groups who have immigrated to a new country. This also affects the health of their children and future generations.

What is Ethnic Equality Monitoring?

Ethnic Equality Monitoring is the process of collecting, recording and analysing information (data) that we collect from patients. Ethnic Equality monitoring or EEM helps to identify and measure if our health system is serving everyone equally and makes sure that our services meet the needs of a diverse population including Ethnic Minorities.

<https://www.hse.ie/eng/about/who/primarycare/socialinclusion/intercultural-health/ethnic-equality-monitoring/updated-eem-poster-english-010922.pdf>

See HSE link below for further information on Ethnicity and Ethnic Equality Monitoring
<https://www.hse.ie/eng/about/who/primarycare/socialinclusion/intercultural-health/ethnic-equality-monitoring/what-is-ethnicity-and-ethnic-equality-monitoring.html>

“

**No patient wants
to be seen as a list
of symptoms,
but rather as a whole person**

Quote from Stakeholder Consultation Session

”



IN THIS SECTION



Section 2

Degrees of Engagement



Better Together
Health Services Patient Engagement Roadmap

Degrees of Engagement

There are four degrees of engagement, ranging from informing to collaboration. Every degree of engagement or involvement has its own value.



(Adapted from Patterson Kirk Wallace Public Consultation Design)

“

All engagement activities must be underpinned by the core values

of Care, Compassion, Trust, Learning and the guiding principles outlined in the essentials (section I Page 22)

”

For each degree of engagement, the goal, direction of information, and degree of influence is explained. Examples of engagement methods for each degree are listed. Information on how to conduct each method, the pros, cons and resources required are found in the Engagement Methods Toolkit in appendix no.8.

When we use the term “patient” we are referring to people who use, or are supported by healthcare services, their personal support network, communities and anyone who may use healthcare services in the future.

Choosing degree/s of engagement:

The aim of your work will influence which degree/s of Patient Engagement you need to choose. It is important to clarify how much influence or decision-making power patients will have. You may wish to involve patients at different steps of the process as decisions will need to be made at a number of points throughout your work. It is essential that engagement happens before decisions are made.

Often, more than one degree will be required to achieve the intended goal. Using a combination of degrees of engagement allows the inclusivity of many voices and experiences ensuring representativeness, while also achieving representation at the degree of collaboration. This ensures the pool of ideas for improvements and the opportunity to break cycles of suboptimal care is not curtailed¹⁷.

Some engagement methods are listed more than once, as they can be conducted in different ways to meet the purpose of the engagement. e.g a focus group can be used to gather information at the Consult degree of engagement (Degree 2) or it can be used to deliberate a range of potential solutions with patients at the Discuss degree of engagement (Degree 3). The approach used within the focus group will be determined by the purpose of engagement.

FOR EACH DEGREE OF ENGAGEMENT CONSIDER:

Language:

All information being shared by healthcare staff should be easy to understand. Health literacy should be considered. Avoid the use of jargon. Plain English guidelines should be used. Make information available in different languages and have interpreters available to enable inclusion of those whose first language is not English.

A system to encourage requests to clarify any terms not understood should be agreed at the outset where appropriate. A system where people can be supported to contribute that doesn't involve writing should also be included.

Healthcare staff skillset required for meaningful Patient Engagement:

- ability to use plain/simple English and other languages;
- ability to work with an interpreter.
- preparation of content of information being shared.
- survey design, GDPR compliance.
- collection and analysis/interpretation of data, dissemination of findings.
- run a focus group/working group.
- facilitation skills.
- understanding of the value that engagement brings.
- clarity of roles of staff patient and other stakeholders in the process.

Resources required:

- venue, staff, catering, remuneration for patients.
- see HSE Policy for reimbursement of expenses: <https://www.hse.ie/eng/about/who/qid/person-family-engagement/resourcesqid/policy-for-the-reimbursement-of-service-user-expenses-2017.pdf>
- budget for the cost of the engagement method. See Appendix 20 for costs to consider.

Timeframes for engagement activity: include

- time to invite and select interested parties, developing recruitment criteria, administering the recruitment process, and reviewing applications.
- the number and frequency of meetings.
- the duration of the engagement e.g. once off / working group for 6-12 months.
- the time required to do further work between meetings
- time for responses to surveys, time to collate, analyse and interpret data.
- your timelines and deadlines.
- participation from the beginning, or the design phase of the project.

Accessibility for participants

- how easy is it for patients and staff to attend/access.
- how flexible can you be regarding meeting times and venues.
- cost of attendance.

Supports to consider:

What supports do patients and healthcare staff need to be able to attend and to participate in a meaningful way? What supports regarding clarity of process and role patients and staff need to participate will be determined by the purpose and degree of engagement activity?

(See Essential Steps, Appendix 10)



Degree 1: Inform - Sharing Information

GOAL:

At this degree the goal is for healthcare staff to provide clear, accurate, balanced, objective, easy to understand and timely information to patients and the public about a health issue/service/policy. Information given should be easily accessible and available in a wide variety of formats, languages and communication methods. It should be communicated out to the public in a way that it is easily found. Sharing information in this way helps to level the inherent power imbalance in healthcare settings and avoid tokenism. (See page 33).

The information shared can be used to support personal health decisions and also to support engagement about a service or policy.

DIRECTION OF INFORMATION:

The direction of information is one way only from healthcare staff to patients.

DEGREE OF INVOLVEMENT / INFLUENCE:

The degree of involvement and influence in decision making is low at this level, as the goal is to share information with patients about an existing healthcare service, issue or decision that has been made. There is no opportunity to influence the final outcome.

Although there is no opportunity to influence the final outcome, this degree of engagement can be used for close-the-loop communication to inform participants of the impact of their participation. This is an important step in order to avoid tokenistic engagement and consultation fatigue. (See page 33-34).

EXAMPLES OF METHODS: Connect with your local Communications Lead

- Information Leaflets, Fact sheets; Newspaper articles (see posters and leaflets Appendix 8).
- Radio adverts; TV adverts; Social media posts; Youtube videos; Press releases.
- HSE Website/s.
- Open house, Fairs, Events. (See Partner Events Appendix 8).
- Identify designated contacts for patients and the public.
- Dedicated Hotline e.g HSElive.
<https://www2.hse.ie/services/contact-the-hse/>
- Panel discussions +/- moderated (see appendix 8).
- Template to inform patients and the public regarding feedback received and how it has been incorporated into decisions made. (See closing-the-loop examples Appendix 18).



Helpful hint:

A Toolkit describing how to conduct each of the engagement methods listed for each degree of engagement is in Appendix 8.



Degree 2: Consult: Listen, Gather Information

GOAL:

At this degree of engagement the aim is to obtain patient and public feedback on:

- their personal experience of a service.
- their opinion regarding delivery of a service.
- their recommendations for improving the service.
- information provided.
- health issue or policies.

before decisions are made, to inform shaping of the decision regarding future planning of services/ writing or updating of policies.

DIRECTION OF INFORMATION:

At this level, information flow is one-way from patients to healthcare staff.

DEGREE OF INVOLVEMENT / INFLUENCE:

The degree of involvement and patient influence in decision making is low at this level. Healthcare staff make decisions taking the information gathered into account, but patients do not have a say regarding how or whether their input influences the decisions made.

EXAMPLES OF METHODS:

- Focus groups.
- Patient Experience Surveys (e.g National Patient Experience Survey in Acute Hospitals <https://www.hse.ie/eng/about/who/acute-hospitals-division/national-patient-experience-survey/>; HIQA survey hub: <https://yourexperience.ie/survey-hub/>)
- Compliments, Comments, Complaints (Your Service Your Say). <https://www2.hse.ie/services/hse-complaints-and-feedback/your-service-your-say.html>
- Your Voice Matters: <https://www.hse.ie/eng/about/who/cspd/patient-narrative/your-voice-matters/>
- Patient narratives/stories e.g “Let’s talk care experience” from the National Care Experience Programme <https://yourexperience.ie/about/podcast/>
- Patient Shadowing.
- Patient diaries.
- Telephone hotlines e.g HSElive hotline: <https://www2.hse.ie/services/contact-the-hse/>
- Web based response polls e.g Mentimeter <https://www.mentimeter.com/> for within meetings.
- Town Hall/ World Café meetings (see partner events).
- Comment forms (see Suggestions and comments boxes; Talking Walls and Surveys and Questionnaires).
- Exit Interviews for Patients.



Degree 2:

Consult: Listen, Gather information



Degree 3: Discuss and deliberate - work to involve patients

GOAL:

At this degree of engagement, the goal is for Healthcare staff to:

- engage patients to discuss and deliberate a particular aspect of healthcare, such as a healthcare service, issue or policy.
- consider the concerns, view, issues and ideas of all participants.
- explore potential options and preferred solutions in an interactive process.

Working together ensures that issues and concerns of both patients and healthcare staff and are heard, understood and considered.

DIRECTION OF INFORMATION:

Two-way dialogue, an interactive process.

DEGREE OF INVOLVEMENT / INFLUENCE:

At this level, degree of involvement and influence is moderate. There is an opportunity to influence the final decision or outcome and input may shape service design, delivery and evaluation or policy direction.

EXAMPLES OF METHODS:

- Focus groups.
- World café events (see Partner Events).
- Public meetings (see Meetings).
- Online meetings (see Meetings).
- Seminars (see Partner Events).
- Working groups (see Terms of Reference Appendix 17).
- Active members of service and policy development groups (See TOR document Appendix 17).
- Patient and Family Experience Advisory Councils (See example TOR Appendix 17).



Degree 4: Collaborate – work in partnership

GOAL:

At this degree the goal is for patients, healthcare staff, healthcare planners and organisations to work in equal partnership, to find and implement solutions to healthcare issues, services or policies. At this level, people work together using a co-production/ co-design approach. There is shared responsibility.

DIRECTION OF INFORMATION:

Multi-directional dialogue.

DEGREE OF INVOLVEMENT / INFLUENCE:

Patients can influence and determine outcomes. Patients can shape decisions made regarding policy and healthcare service design.

EXAMPLES OF METHODS:

- Patient and Public representatives (See page 61-68 and Essential Steps, App 10).
- Recruitment of Staff.
- Community forums.
- Community partnerships.
- Joint community initiatives: provision of service for community groups.
- Planning workshops (see Partner Events).
- Patient Advisory Groups/ Committees (See sample TOR document Appendix 17).

HE



IN THIS SECTION



Section 3



Healthcare levels



Better Together

Health Services Patient Engagement Roadmap



This section is divided into 4 parts:

Part A: Healthcare Levels explained

PART B: Individual Health and Healthcare Level

1. Checklist of actions to ensure meaningful Patient Engagement at individual health and healthcare level.
2. Resources.

PART C: Healthcare Service Design, Delivery and Evaluation Level

1. Essential Steps for conducting meaningful Patient Engagement activity/s in Healthcare design, delivery and evaluation.
2. Checklist for organisational requirements for embedding meaningful Patient Engagement as part of how we work.

Part D: Healthcare Policy Making Level

1. Essential Steps for conducting meaningful Patient Engagement activities in healthcare policy making.
2. Checklist for embedding meaningful Patient Engagement at the Policy Making Level.

When we use the term “patient” we are referring to people who use, or are supported by healthcare services, their personal support network, communities and anyone who may use healthcare services in the future.



A

Part A: Healthcare Levels explained

This section will help you decide the healthcare level at which you are engaging with patients and guide you to the relevant section B,C,or D accordingly. Patient Engagement occurs at different healthcare levels¹²:



- Individual Health and Healthcare level.
- Healthcare Service Design, Delivery and Evaluation level.
- Healthcare Policy Making level.

Individual Health and Healthcare Level:

The focus in this setting is on engaging with patients in their own health and healthcare. This section is relevant for any clinical healthcare staff who work with patients in care encounters. A checklist of actions to ensure meaningful Patient Engagement at this healthcare level is included. Assess yourself and/or your team against the actions and create an action plan for improvement.

Healthcare Service Design, Delivery and Evaluation Level

The focus in this setting is on engaging with patients in the design, delivery, improvement and evaluation of healthcare services. This is relevant for all healthcare staff participating in updating existing healthcare services and designing new and integrated healthcare services.

It includes:

1. The essential steps for designing and conducting meaningful Patient Engagement activities for engaging with patients in healthcare service design, delivery, improvement and evaluation. Use these steps to guide you in choosing, designing, conducting and evaluating your Patient Engagement activity/activities.
2. For organisation leaders: A checklist of actions, policies and protocols required by an organisation to support staff to embed meaningful Patient Engagement across your organisation's healthcare levels. Assess your organisation/ team against the actions and create an action plan for improvement.

Healthcare Policy Making Level

The focus in this setting is on engaging with patients in updating and making policy, in writing governance and in writing strategy and is relevant for healthcare staff involved at this level of healthcare.

It includes:

1. The essential steps for designing and conducting meaningful Patient Engagement activities for engaging with patients in healthcare policy making. Use these steps to guide you in choosing, designing, conducting and evaluating your Patient Engagement activity/activities.
2. A checklist of actions to ensure meaningful Patient Engagement at this healthcare level. Assess yourself and/or your team against the actions and create an action plan for improvement.



B

Part B: Individual health and healthcare Level

At the individual health and healthcare level, Patient Engagement is about working together with patients in their own health and healthcare decisions.



The focus is on providing the opportunity, information, support and resources for patients to engage effectively in ways they want and to the degree they want in their own health and healthcare. Meaningful engagement means gaining an understanding of how engaged a patient is in their health and healthcare, taking into consideration their desire and ability to engage, along with their specific needs, concerns, beliefs, expertise and requests. To achieve this, it is important to tailor the engagement activity to make it accessible to those who wish to be involved.

This includes:

- involving the patient in decision making about their own health and healthcare.
- capacity building to encourage and enable the patient to lead on identifying their own health care needs supported by the treating team, including providing the patient with all the information they require.
- including the patient as a member of the healthcare team.
- capacity building to encourage and enable the patient to be responsible for self-management of their own health.
- assisting patients to navigate the healthcare services.
- healthcare staff considering what they may need to do to ensure they are fully present for each patient in every interaction.

Individual Health and Healthcare level checklist to enable meaningful Patient Engagement.

This checklist is relevant for every healthcare staff member working in care encounters with patients. It has been based on the definition of healthcare levels described in the Carman Framework ¹², the literature review and consultation sessions. Please read section I before completing the checklist.

Complete the checklist, identify the gaps and create an action plan for improvement. (See Appendix 5). You can prioritise your action plan and add dates for completion.

When we use the term “**patient**” we are referring to people who use, or are supported by healthcare services, their personal support network, communities and anyone who may use healthcare services in the future.

1. Checklist of actions to ensure meaningful Patient Engagement at the individual health and healthcare level.

Actions and questions to ensure meaningful Patient Engagement within a specific clinical care encounter:	Yes	No	Some	N/A
In all interactions with patients, communication is key. (see also communication checklist appendix 6)				
Do you use plain language to communicate health related information?				
Are you aware of your body language and eye contact during all your patient interactions?				
Do you tailor your communication and education supports to meet the patient's needs?				
Do you use visual aids and/or interpreters for patients who cannot read or do not understand English?				
Have you asked the patient what communication method works best for them?				
Do you use active listening techniques to ensure the patient has been heard and understood? (see page 30 Section 1 of Roadmap)				
Have you reinforced and reiterated the information you are giving patients about their condition?				
Have you checked the patient's understanding of the information you have given them e.g teach-back?				
Involving patients in decisions made about their own health and healthcare				
Have you identified the patient's needs, concerns, beliefs, expertise and preferences?				
Have you invited the patient to become involved in their own healthcare and have you outlined the benefits?				
Have you used a decision making aid with your patient? (see links to decision aids below)				
Supporting patients in the self-management of their own health				
Have you asked about the patient's priorities for their health?				
Have you explored barriers to and enablers for self-management?				
Have you set goals that reflect the patient's priorities to improve their health?				
Have you incorporated the patients lived experience in goal setting?				
Have you tailored your advice to meet the needs of the patient?				
Have you signposted your patient to existing on-line information resources?				
Have you signposted the patient to existing supports within the HSE? e.g the Living Well programme.				
Have you provided guidance about navigating the healthcare system for your patient?				
Additional measures to assist patient involvement in their own healthcare.				
Have you developed condition-specific patient reported outcome measures that reflect their goals?				
Do you have a system in place for collecting more personalised data about patient experience and outcomes? e.g in pre-assessment questionnaire				
Do you have training / tools for staff to support Patient Engagement regarding the patient's own healthcare? e.g documentation in charts regarding patient preferences etc				

(See appendix 9)



Actions and questions to ensure meaningful Patient Engagement within a specific clinical care encounter:	Yes	No	Some	N/A
Including patients as part of the healthcare team				
Do you have a process in place for inviting patients and carers to actively take part in bedside rounds or OPD appointments?				
Do you have a patient centred discharge planning programme that involves the patient and their personal support network?				
Does your organisation have a policy that encourages patients and their personal support network to be full members of the healthcare team?				
Do you use technology to support enhanced communication with patients? e.g tele-health options				
Do you have health passports for patients?				
Transparency and Accountability				
Have you provided unbiased evidenced based information to the patient?				
Have you given all the information that the patient requires regarding treatment options to make an informed decision?				
Have you discussed how the care/intervention/treatment option will help meet the patients goals?				
Have you documented the information shared with the patient during the care encounter in their healthcare record?				
Does the patient have access to their own healthcare records? Can they contribute to or correct them?				
Outside the specific care encounter				
Is there a process in place to allow you to tailor the patients appointment time to suit them?				
When delivering bad news, do you ensure you have time with the patient to answer their questions?				
Do you offer patients the opportunity for another appointment following bad news?				
Does your organisation support patients to navigate and interact with the wider health care system?				
You/ Your team's understanding of Patient Engagement				
Do you and your team have an understanding of what Patient Engagement is and why it is important?				
Do you and your team have an understanding of how to select and conduct Patient Engagement activities?				
Have you conducted a needs analysis regarding capacity building for Patient Engagement for your team?				
Does your service/ hospital/CHO have access to training and education regarding Patient Engagement?				
Does your service/ hospital/CHO have access to training and education regarding Patient Engagement?				
Does your service/hospital/CHO/ manager support a culture of Patient Engagement?				

B

2. Resources

Links to resources relevant for above sections:

Shared decision making tools from National HC Communication Programme

<https://www.hse.ie/eng/about/our-health-service/healthcare-communication/nhcp-shared-decision-making-skills-card-for-staff.pdf>

Ottawa Personal decision guide for one and for two people:

(Adopted with permission)

<https://decisionaid.ohri.ca/docs/das/OPDG.pdf>

<https://decisionaid.ohri.ca/docs/das/OPDGx2.pdf>

Information regarding Health Conditions:

<https://www2.hse.ie/az/>

Supporting patients in the self-management of their own health: Making Every Contact Count (MECC), Self-management Support (SMS), Motivational Interviewing, Living Well with a long-term health condition Programme, Person-centred planning for persons with a disability

<https://www.hse.ie/eng/about/who/healthwellbeing/making-every-contact-count/>

<https://www.hse.ie/eng/health/hl/selfmanagement/>

<https://www.hse.ie/eng/about/our-health-service/healthcare-communication/motivational-interviewing/nhcp-motivational-interviewing-skills-card.pdf>

<https://www.hse.ie/eng/health/hl/selfmanagement/living-well-programme/>

<https://www.hse.ie/eng/services/list/4/disability/newdirections/framework-person-centred-planning-services-for-persons-with-a-disability.pdf>

Effective Communication- see information in section 1 of roadmap.

See link below for OARS- another example of an essential communication skills tool. (Source: Reproductive Health National Training Centre. US)

https://rhntc.org/sites/default/files/resources/rhntc_oars_model_job_aid_12-20-2021.pdf

Sign posting to information about the Irish Health Services:

[About the Irish Health System, a Guide for Refugees and other migrants available in English and 14 other languages](#)

What Matters to you (WMTY)

“What Matters to You” is an initiative that supports person-centeredness in care. It is a simple approach to capturing issues that are important to the individual in the hospital and when known by staff can improve patient experiences. See the link below for the suite of documents which provide an overview of the concept “What Matters to You (WMTY).

<https://www.hse.ie/eng/about/who/qid/person-family-engagement/resourcesqid/what-matters-to-you-person-and-family-engagement.html>



Part C: Healthcare Service Design, Delivery and Evaluation Level

Patients make valuable contributions to health services beyond participation in their own care. They can also help to inform and improve services, facility design and the health service's broader community engagement.



At Healthcare Service design, delivery, and evaluation level engagement is about:

- Integrating the views, experiences and perspectives of patients into the design, delivery and evaluation of healthcare services.

This means involving patients to become active partners in:

- Design, planning, delivery and evaluation of healthcare services.
- Design of healthcare facilities.
- Strategic or operational planning.
- Design and implementation of quality improvement projects.
- Assist with staff hiring, training and development.
- Serving as patient experience advisors, patient navigators, on organisation councils and Boards.

Organisational policies or practices for engagement can enable patients to become active partners, such as rounding at the bedside or by creating patient experience advisor and partner roles in decision-making teams around quality improvement, patient safety committees and patient councils ^{12,17}.

1. Essential Steps for conducting meaningful Patient Engagement activities in healthcare service design, delivery and evaluation

This section is relevant for healthcare staff involved in service design, delivery, improvement and evaluation. Please read section I before completing the checklist.

Preparing well for engaging with patients can help set the engagement activity up for success. Following the essential steps helps ensure your engagement activity is meaningful and each step should be considered in detail before the engagement commences.



All steps should be underpinned by the HSE values & guiding principles

outlined earlier in the Roadmap. (See page 22) Please read section I prior to planning your engagement activity.





Checklist for Essential Steps for conducting Meaningful Patient Engagement activities at Healthcare Service Design, Delivery and Evaluation and Healthcare Policy levels.

Step 1: Establishing the aims

It is important to clearly state the aims of the work you are asking people to become involved in and the purpose of the engagement. The overarching aim of Patient Engagement should always be to increase informed decision-making and patient choice, to improve the quality and safety of healthcare, to improve patient experience and to utilise patient expertise. Engagement activities should be mutually beneficial.

What are the aims of your work?

What are the aims of engaging with patients in this work?
How will engagement contribute to meeting the aims of your work?
What decisions can be influenced and informed by engagement?

Will the engagement activity be mutually beneficial?
Will it result in improved services, improved health outcomes, improved safety and improved patient experience of services?

Step 2 : Who needs to be involved and why?

“Patients are the ultimate stakeholders – the ones who live or die, suffer or improve, based on how it all works out”.
Dave de Bronkart Let Patients Help

Stakeholders (see links for stakeholder mapping templates page 61)

- Who will be affected by this work?
- Who will benefit from it?
- Who may be impacted negatively or positively?
- Who can bring additional expertise and best practice knowledge? (include both patients and staff here)

Diversity and Inclusion:

- Are a diverse range of patient voices included?
- Who has difficulty accessing your services?
- Whose voices are seldom heard?
- Which minority groups are in your patient population?
(Consider ethnic equality monitoring data that may be available)
- Who is likely to be excluded?
- Who can help you reach out to these people? e.g. local social inclusion office/ Healthy Ireland links/community resource centres.
- Who needs to be involved in supporting, delivering and contributing to the project/work/committee?
- Think about influence and interest: Use the templates below from the Health Services Change Guide to map your stakeholders.

Think about the information already available and avoid duplication

- What do you already know? e.g information from the National Patient Experience Survey.
- What information do you already have?
- What do you not know- where are the gaps?

STEP 3: Choose degree/s of engagement and engagement method/s	
Having identified the aims of your work and established who needs to be involved, your next step is to choose the appropriate degree/s of engagement and the engagement method/s. (See section 2).	
Why are you asking patients to become involved? What are you asking them to do? It could be more than one of the four degrees.	
Degree 1: Inform: Do you want to share information with patients about a health service, a health issue or a policy?	Yes/no? Why?
Degree 2: Consult/Listen: Do you want to hear about a patient's: <ul style="list-style-type: none"> • personal experience of a service • opinion regarding delivery of a service, • recommendations for improving the service • information provided • health issue or policy 	Yes/no? Why?
Degree 3: Discuss: Do you want patients to discuss and deliberate healthcare services, issues or policies and explore potential options and preferred solutions with healthcare staff? Working together ensures that issues and concerns of patients and healthcare staff are heard, understood and considered.	Yes/no? Why?
Degree 4: Collaborate – work in partnership Do you want patients, healthcare staff, healthcare planners and organisations to work in equal partnership, to find and implement solutions to healthcare issues, services or policies? At this level, people work together using a co-production/ co-design approach. There is shared responsibility.	Yes/no? Why?
Step 4: Inviting, selecting and recruiting patients (see pages 61-65)	
Invitation approach.	
Open invitation.	
Targeted invitation.	
Combination of open and targeted.	
What information will you include in your invitation?	
Do you have easy to understand, unbiased information regarding the context and aim of the engagement activity?	
Will you need to use an application form?	
Are there inclusion criteria for participants you need to consider?	
How will you select representatives if numbers interested exceed numbers requested e.g randomly select within the demographic of the population being represented?	
Step 5: The Engagement activity (see page 68 for further information)	
Do you have easy to understand, unbiased information regarding the context and aim of the engagement activity?	
Conduct the sharing expectations questionnaire with all participants prior to the kick-off meeting	



Step 5: Continued	
What are your ways of working/ Terms of Reference: Co-design your ways of working with participants.	
Identify what supports patients and staff require in order to participate fully and meaningfully.	
Step 6. Timescales: Considerations	
• What needs to happen and by when?	
• The duration of the engagement activity- short, intermittent or sustained.	
• The time commitment required – how many meetings, the duration of the meetings, the work and commitment required between meetings.	
• Time for invitation, response and recruitment process. Give advance notice of first meeting.	
STEP 7: Data	
• Consider data capture: how are you going to capture feedback / input e.g paper/ electronic questionnaires?; minutes from meetings; information from focus groups.	
• How are you going to analyse the data? How will different types of data be analysed together?	
• Who is going to analyse the data?	
• How are you going to use the data?	
• How will you give feedback to the people who have been involved and to the relevant stakeholders? (see close-the-loop feedback template Appendix 19).	
Step 8: Evaluation of Engagement (see page 69 for resources)	
• When will you carry out evaluation?	
• How will you measure how successful the process of the engagement activity was?	
• How will you measure the quality of the engagement throughout the activity?	
• How will you measure the outcome of the engagement activity?	

Resources:

- **Sharing Expectations Questionnaire**

This questionnaire is a useful exercise to conduct with all members of working groups prior to commencing the engagement. It helps to gain an understanding of member's expectations, hopes and fears for the group and to generate ideas for ways of working and what is required to ensure the work gets done. This can then be included as part of an agreed terms of reference for the group.

Source:

Team Building: Proven Strategies for Improving Team Performance. William G. Dyer, W. Gibb Dyer, Jr., Jeffrey H. Dyer John Wiley & Sons, 28 Dec 2010 - Business & Economics - 272 pages
https://books.google.ie/books/about/Team_Building.html?id=5iulPZrHIQ8C&redir_esc=y

Sharing Expectations Questionnaire

(see Appendix no.13)

Name of group:

Please complete this short questionnaire regarding your expectations and concerns of being a member of _____ group and return by email to: _____ by _____.

How would this group function if everything went just as you hoped?

What would this group be like if everything went wrong?

What worries you most, or what is your biggest concern about working on this group?

What actions do we need to take to ensure we achieve our aims?

Suggested ways of working:



C

Stakeholder mapping resources:

Peoples Needs Defining Change Health Services Change Guide- Interest Influence Mapping Grid Template ^{6.1.1}

Peoples Needs Defining Change Health Services Change Guide- Guidance on Stakeholder Mapping and Analysis Template ^{6.1.2}

Finding, Inviting and Selecting Patient representatives:**Who can be patient representatives?**

Patient representatives may be patients themselves, members of their personal support network or people who may use healthcare services in the future.

What is the role of the patient representative?

The role you wish the patient representative to take should be clarified at the outset of the engagement activity.

1. Representing themselves and their experience of healthcare services.
2. Representing a group of patients, patient organisation or patient support group.
3. Representing both themselves and a wider group of patients.

Patient representatives are not expected to be experts in clinical matters. Their experience as a patient provides them with a unique perspective of healthcare services, and this, combined with the expertise from their lived experience needs to be harnessed in improving healthcare services.

An individual experiencing an illness or a service may not be able to understand the experience of someone else who is at a different stage of the illness or is from a different socio-economic or cultural background.

It is important to ensure that there is diverse representation in engagement activities in service design and policy making that is consistent with the broader population served by that service. e.g If the service is a paediatric service then children and parents should be involved; If the service is predominately delivered to either males or females, a 50/50 gender balance is not necessarily required.

Where to find patients and families to participate in engagement activities

There are three key approaches to finding potential patient representatives.



As per G-I-N Public Toolkit for patient and public involvement in guidelines: <https://g-i-n.net/toolkit/> the key invitation approaches are:

1. Open invitation
2. Targeted and nominated invitation
3. Combination of both



Think about current patient representative forums already established. e.g.

- The HSE has a National Patient Forum and a National Patient Representative Panel.
- Your service/ hospital/ CHO may have Patient experience advisory councils, known patient representatives or contact persons for patient organisations who may be able to participate in your engagement activities.

Factor in the time it will take to choose and conduct an invitation approach.

<p>Open Invitation: This involves advertising an invitation to become involved in an engagement activity to the general public.</p>		
<p>Methods include:</p> <ul style="list-style-type: none"> • TV, radio and social media adverts. • Extend invitations through community networks or existing communication channels e.g national or local HSE communications teams/ your service's communications team/ strategy. • Consider advertising through rural development public participation networks. • Post notices in appropriate language on bulletin boards in reception areas in clinic, hospitals, GP practices. 	<p>Advantages:</p> <ul style="list-style-type: none"> • Opportunity to hear from all viewpoints. • Transparency. 	<p>Disadvantages:</p> <ul style="list-style-type: none"> • People may miss the advertisement as they may have no access to it e.g may not buy papers, listen to radio or watch TV; may not have access to technology to avail of social media or online advertisements, may have literacy or sensory impairments. • People may not have the technological resources to respond to the invitation. • People may not have the time or money to become involved. • Personal bias: self-selected participants with either a very positive or negative experience may respond and be included. Professional patients may apply.* • There may be an overwhelming or very limited response to the invitation.

* (Professional patients: where those with experience and knowledge of the health service are considered to have too much insider knowledge and therefore no longer bring a naive perspective³⁰.)



C

Targeted Invitation

This involves extending an invitation to engage to all relevant stakeholder organisations, or to groups and individuals with relevant interest. This approach may be more effective in generating responses.

Methods include:

- Patients known to healthcare staff can be approached. The best representatives may be the people who have experienced care in the specific service you are interested in improving. You may already have relationships built.
- Specific representative organisations / support groups can be approached to ask to nominate someone, who they feel can reflect and understand patient issues in the context of the work. In this situation the patient organisation is responsible for recruiting.
- Connect with stakeholder groups who represent minority/ vulnerable groups.
- Request representatives from the national patient forum or from the patient representative panel through the National Patient and Family Engagement Office.
- Ask Community healthcare network staff.
- Include information about opportunities for Patient Engagement in patient experience surveys and/ or on correspondence to those currently using services with the relevant links/ contact person.
- Connect with people in the community who are knowledgeable about patient's needs and are a link to other patient groups.
- Ask patients who are already involved if they can suggest someone who they know may be interested in participating.

Advantages:

- Requires less resources
- Patient organisations identifying a representative means:
 - you have no influence on the choice of nominee as you would do if you were to conduct selective recruitment.
 - increasing the chance of recruiting patients you may not have considered
 - respecting patient autonomy.
 - they may have experience of working in groups and may have received training in representing patient perspectives.
- Can facilitate reaching specific seldom heard groups and provide guidance about how best to engage with people from these groups.
- The volume of feedback should not be overwhelming.

Disadvantages:

- Only those associated with the stakeholder organisations or those known to healthcare staff will receive the invitation, therefore important viewpoints may be missed unless this approach is combined with an open invitation.
- Organisations and individuals invited may not wish to be involved or may be unable to respond to the invitation within requested timescales.
- Healthcare staff may invite patients who are positive about the service and who are inclined to agree with the view point of healthcare staff.
- Doing an internet search for relevant stakeholders may miss those groups who do not have an online presence.



A mix of both methods can be used

This involves advertising the opportunity to become involved in an engagement activity to the general public alongside extending an invitation to engage to all relevant stakeholder organisations or groups and individuals with relevant interest.

Note: Patient organisations, support or advocacy groups from whom you seek a nomination should have a communication structure that reflects true representativeness of all of its members. This ensures a breadth of views and experiences of the service, as well as diversity in factors such as gender, age, severity of the condition and socio-economic and cultural background. Be aware that not all patients are members of such groups.

Advantages:

This approach combines openness and transparency with reaching all relevant stakeholder organisations or targeted groups or individuals.

Disadvantages:

There is a risk that the volume of feedback may be overwhelming and will be time consuming to work through.

Information to consider including in an invitation to patients and healthcare staff

- Background of your work.
- Aim of your work.
- Who is involved in the work?
- The reason for the invitation to engage (purpose of the engagement) Why patient and public involvement is being sought. e.g hear the views of people using the service.
- The patient representative’s role- what are you asking them to do? e.g complete a survey/attend a focus group/ become a member of a working group.
- What skills would be useful to have, if required. e.g experience of an illness, literary skills.
- Training available.
- Support available e.g can be accompanied by a support or key worker/ interpreter available/ will be allocated a contact person for support.
- How the engagement activity be run?
 - The time frames – meeting times, frequency, duration of the engagement activity, time commitment between meetings, communication methods with group between meetings.
 - The location of the engagement activity- physical location/online.



C

Information continued

- Terms of reference for the group/committee. e.g. How decisions will be made within the group. What is the communication process for feedback from group to decision makers.
- Job specification where indicated. You may want to conduct interviews.
- How the information gathered will be used.
- The application process if relevant.
- Selection process.
- Reimbursement of expenses.
- The contact person for queries and their contact details.

(See appendices 14, 15 and 16 for Advert, Invitation and Application Form templates and examples, respectively)

(See appendix 17 for Terms of Reference)



Selection of representatives

Consider how you will select representatives if numbers interested exceed numbers requested e.g random selection. You may need to randomly select participants based on the representativeness of the patient population your work will affect.

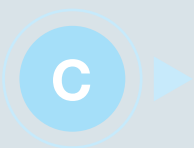
Consider if you can offer those not selected the opportunity to engage in another way/degree e.g, survey/ focus group if not selected for a committee / working group or sense check parts of work being done by a committee.



Recruitment methods:

The method of recruitment will vary depending on the degree of engagement and the method or activity. (e.g recruitment for a long-term role in a committee at policy level would be more formal recruitment including job specifications and selection criteria, than for a more short-term working group or focus group).

Whatever method is selected it should be an accepted, transparent, and justifiable approach that can be documented.



Additional considerations for recruiting patients and the public and healthcare staff in line with the purpose of the engagement include:

- Have a balance of patients and public who have had both negative and positive experiences of the service. It is important to hear about what works well, as well as areas for improvement.
- Number of patient representatives you need. A minimum of 2 is advised, but aim for 50% mix of healthcare staff and patient representatives.
- Will there be any incentives / remuneration for the patients who decide to become involved? HSE Expenses Policy.

<https://www.hse.ie/eng/about/who/qid/person-family-engagement/resourcesqid/policy-for-the-reimbursement-of-service-user-expenses-2017.pdf>



C

Desirable characteristics / criteria to consider for membership of working groups/ committees/attending focus groups:

For patient representatives:

- Have recent experience (generally within 3 years) of accessing health care.
- Lived experience of a particular condition with the ability to share insights and information about their experience in ways that others can learn from them.
- The ability to see beyond personal experience and use personal experience constructively.
- Feels that engagement is valuable and that becoming involved will benefit in planning and delivery of safe and high quality service for the patient.
- Be a member of a larger patient organisation or patient advocacy group whose input you need, with the ability to communicate the perspective of patients, survivors and family members effectively and have an understanding of the issues that matter to people with that condition.
- Previous experience in engagement activities- consider whether this was negative or positive.
- Have a good self-care program that will help the person manage any stress or triggers that the participation may bring up.
- Have external supports e.g a key worker / support worker available to accompany them.

For patient and staff representatives:

- Ability to be objective, to challenge ideas, to avoid group think.
- Ability to influence.
- Good communicator, (may need support if communication is challenging due to a health issue).
- Good team-working skills.
- Listens and respects other's perspectives.
- Comfortable speaking in a group and interacting with others, or be supported to build confidence in same.
- Willing to share opinions and to work within a collaborative approach in a group forum that includes health professionals, senior administrators and others.
- Will be able to dedicate the time and commitment to attend the meetings and complete associated work.
- Has a positive outlook.
- Agrees commitment to maintain confidentiality.
- Desire to expand knowledge and skills.
- Desire to participate in bringing about meaningful change.
- Ability to correspond by email is an asset but should not exclude anyone.

(See appendices 14, 15 and 16 for Advert, Invitation and Application Form templates and examples, respectively)

Further resource:

<https://www.hse.ie/eng/about/who/qid/person-family-engagement/resourcesqid/guidance-for-recruiting-patient-representatives-groups-committee.pdf>



The Engagement activity

Conduct the sharing expectations and concerns exercise at the outset. (see appendix no.13)



Agreed ways of working to include in the Rules of engagement / Terms of Reference for the engagement activity as required*.

- How will you work together?
- How will decisions be made?
- How will conflicting opinions be reconciled?
- How will various perspective be captured and encompassed?
- How will you manage expectations?
- What ways of working will be used?
- How will you ensure everyone has access to the same information?
- What system will you use to ensure all terms are understood or explained?
- What do members need to do to ensure meetings are productive and the work is progressed?
- What commitments do members need to make in order for the group to fulfil its work?



Supporting patients and staff to participate fully and meaningfully

- Make meeting times suitable for all.
- Make information available and accessible.
- Explain organisational structures and existing procedures and policies.
- Minimise jargon and explain terms when not understood.
- Consider including hints and tips regarding gaining confidence to speak up in a large group, in induction materials training, and also in catch-up calls with the key support person.
- Peer support from other patient representatives who have experience can help build patient representatives' confidence.
- To ensure Patients are respected, seen as equal, and feel valued:
 - Ensure that the group's chair understands group dynamics and ensures equal power balance, including a right to vote to reach consensus and providing feedback on patient contributions.
 - Include a specific slot for patient and public members to provide input during discussions.
 - Encourage relationship building between patient and public members on the same group or with health professionals to build allies.

*(See appendix 17 for Terms of Reference Template and example Terms of Reference)



C

EVALUATION of ENGAGEMENT

Evaluation of both the process and outcome of Patient Engagement is important.

When will you carry out evaluation?**Evaluating the Process of Engagement**

- Did meetings happen as planned?
- Did the Patient council meet as planned?
- How many meetings etc?
- Were the surveys conducted? What was the response rate?
- Were the participants representative of the population impacted by the service?
- Were there any groups not represented?

Evaluating the Quality of Engagement

- How good was the engagement experience?
- Did participants feel heard?
- Did participants feel respected?
- Did they get a chance to speak?
- Were they given the support and training they needed to be able to participate fully?
- Was jargon used? If yes, was it translated/ explained?
- Was the session well facilitated?
- Was the content of the survey easy to understand? Was it relevant?

Evaluating the Impact of Engagement

- Did participants get feedback after their involvement? Was there a Close-the-loop communication?
- Did participants feel their input was incorporated? If not, was there an explanation as to why it wasn't?
- Is there evidence of change / improvement?
- How will you know if you have achieved your initial aim / outcome?

(See appendix 18 for Evaluation Templates)

Resources:

Examples/ Templates

Sharing expectations questionnaire (Appendix no.13)

Adverts (Appendix no 14)

Invitations (Appendix no 15)

Application form (Appendix no 16)

Terms of Reference (Appendix no 17)

Evaluation templates (Appendix no 18)

Close-the-loop template (Appendix no 19)

Cost analysis (Appendix 20)



2. Checklist for organisational requirements for embedding meaningful Patient Engagement as part of how we work.

This checklist is relevant for healthcare organisation, service, department or team leaders. Complete the checklist, identify the gaps and create an action plan for improvement.

	Yes	No	Some	N/A
Commitment and Leadership				
Do you have one or more people who are responsible for Patient Engagement in your hospital/ CHO/ service/team?				
Do you have an overarching commitment to engagement in your service?				
Is this commitment shared across all: <ul style="list-style-type: none"> • Frontline staff • Managers • Governance • Volunteers 				
Do you have shared aims, values and guiding principles for engagement?				
Are patients and staff familiar with HSE values and guiding principles for engagement?				
Do you have a strategy for Patient Engagement?				
Is Patient Engagement a standing item on meeting agendas? Do you dedicate time at meetings to discuss patient feedback and recommendations?				
Do you include Patient Engagement in induction training?				
Do you include Patient Engagement in staff appraisals?				
Do you include Patient Engagement in governance?				
Do you use patients' input to help shape strategic goals and priorities?				
Assessing readiness:				
Do you have readiness assessment templates for Patient Engagement and for change available for all staff?				
Have you conducted an "as is" assessment of Patient Engagement?				
Effective communication				
Do you have a health literacy policy that all staff are aware of and using?				
Does your health literacy policy include: <ul style="list-style-type: none"> • Communicating Clearly guidelines? • Plain English guidelines? • Avoidance of the use of acronyms in written and spoken communication? • Use of jargon busters where jargon needs to be used? 				
Do you have an interpreter service readily accessible in your service?				
Is there a question included on pre-admission/appointment information to ask if patients have any literacy needs?				
Have you /your team completed the National Healthcare Communication Programme modules / effective communication training?				
Do you record the number of staff who have completed the NHCP programme?				
Communication pathways				
Do you have a communication plan that includes Patient Engagement? (See appendix 6.8)				
Do you have consistent messaging regarding the benefits of Patient Engagement and its importance?				



	Yes	No	Some	N/A
Do you have messaging to inform patients and the wider community of the opportunities to partner in your decision-making processes and how to get involved?				
Do you have a communication pathway within your team and across other teams who may be involved in your patients care?				
Building in evaluation				
Do you have a Patient Engagement evaluation process in place?				
Training and education				
Have you an education/training programme for all staff which include the following?:				
What Patient Engagement is, why it is important, what the benefits are.				
Cultural competence, attitudinal awareness.				
Effective Communication skills as above.				
How to select and conduct meaningful PE activity/activities including: <ul style="list-style-type: none"> the context and aim of the engagement activity for patients invited to engage. Clarity around roles and responsibilities of staff and patients involved in PE activities. How to evaluate PE. 				
Do you have a number of trained or experienced facilitators in group work in your organisation?				
Have you conducted a needs analysis regarding capacity building for Patient Engagement for your staff?				
Policies and Procedures				
Has your organisation developed messaging to inform patients and the wider community of the opportunities to engage in service design delivery and evaluation?				
Do you have an application process to respond to expressions of interest from patients and the wider community to engage/partner?				
Do you have a recruitment/interview process in place that can help identify patients/public to partner with a healthcare organisation?				
Do you have named mentors to support patients/wider community in partnering with a healthcare organisation outside meetings?				
Is there a process in place to act upon information /feedback you receive?				
Does your service/hospital/CHO have a process for “close- the -loop” feedback to inform those involved (patients and staff) in the engagement activity about the outcome of their input including if there is no impact?				
Do you have a process to invite patients to be active members of QI teams or other decision making committees?				
Do you have a patient forum/ patient experience advisory councils/boards?				
Are you adhering to the HSE expenses policy?				
Have you considered rewards for participation in Patient Engagement activities?				

(See appendix 11)



Part D: Policy making level.

At **Policy making level** engagement is about:

- healthcare organisations and government partnering with patients to identify and create more accountable healthcare priorities, policies and governance structures.
- involving patients in decision-making about future plans for health policy¹⁶.
- focusing on developing, implementing and evaluating national, state and local health care policy and programmes¹².
- ensuring that the health care system goals, focus and resource allocation is oriented around and responsive to patients' perspectives, values, expertise and priorities.
- It is a way for healthcare organisations to demonstrate accountability, promote transparency, utilise patient's expertise and respond to patient's needs.



1. Essential Steps for conducting meaningful Patient Engagement activities in healthcare policy development or review.

For Essential Steps checklists refer to page 57 - 69 of this book highlighted with these icons





1. Checklist for processes and policies to support meaningful engagement with patients at the Policy Making level of Healthcare.

This checklist is relevant for healthcare organisation, service, department or team leaders. Complete the checklist, identify the gaps and create an action plan for improvement.

Processes and policies to support patients to engage in policy making processes locally, regionally or nationally.	Yes	No	Some	N/A
Do you have consistent messaging regarding the benefits of Patient Engagement and its importance?				
Has your policy group developed messaging to inform patients and the wider community of the opportunities to partner in your decision-making process and how to get involved?				
Does your policy group have a process for sharing information & materials with patients regarding policy development?				
Do you have an application process to respond to expressions of interest from patients and the wider community to engage/partner?				
Do you have a process to match the skills of the patient with opportunities that may be available?				
Do you have a recruitment/interview process in place that can help identify patients/public to partner with a healthcare organisation?				
Do you have easy to understand, unbiased information regarding the context and aim of the engagement activity?				
Do you have training programmes regarding the context and aim of the engagement activity?				
Do you provide guidance to enable patients/wider community to participate actively in public deliberation?				
Do you have a named mentor to support patients/wider community in partnering with a healthcare organisation outside meetings?				
Are patients/public invited to be active members of QI teams or other decision making committees?				
Do you have a patient forum/ patient experience advisory councils/boards?				
Are you adhering to the HSE expenses policy?				
Do you have patient representation in the design of clinical quality standards? (e.g NCEC)				
Do you have patient representation on national committees that have oversight authority in healthcare e.g HSE Board, HSE Executive Management Team?				
Do you conduct town hall meetings to discuss healthcare issues of importance at local, regional and national level?				
Do you have a public forum in place to provide insights from patients that influence decisions made about healthcare?				
Do you have a process for “close-the- loop” feedback to inform those involved in the engagement activity about the outcome of their input?				

(See appendix 12)

HE



IN THIS SECTION



Section 4

Some examples of good patient engagement practice in Healthcare services



Better Together
Health Services Patient Engagement Roadmap

“

Governance structure within Mental Health Services

to formally involve people with direct lived and supporter experience to be involved in the design, delivery and evaluation of Mental Health Services.

”

Example 1:

Governance structure for Mental Health Engagement

The concept for the need for people with direct lived and supporter experience to be involved in a formal way in the design delivery and evaluation of services has been well established and accepted in Mental Health services for some time now. In an Irish context this has been a key policy theme since ‘A Vision for Change 2006(chapter 3) and is further enhanced in our current national policy ‘Sharing the Vision’. Much progress has been made in recent years in progressing this policy aim, in mental health with a number of initiatives to engage and involve people with personal lived experience and their family and supporters in service improvement approaches to help develop more recovery orientated and person centred mental health services.






To ensure that this collaboration and co-production with service users, Family members, Carer’s and supporters was achieved in a consistent and quality assured way across all parts of the service, was one of the challenges that emerged during implementation. In response to this the National Mental Health Office initiated a number of programmes to address this issues including advancing Recovery in Ireland (ARI) 2014 and mental Health Engagement (MHE) 2016. These functions were aligned under the office of Mental Health engagement and Recovery (MHER) in 2019.

The Mental health Engagement function established in 2016 set out a structure to capture the experience of SUFMC’s to inform the design, delivery and evaluation of services. The establishment of the MHE structure was based on the recommendations of the ‘Partnership for Change’ document which was co-produced by a reference group of SUFMC’s on behalf of the HSE. (https://www.drugsandalcohol.ie/25702/1/HSE_Partnership_for_change.pdf)

The partnership for change recognised the need to integrate lived mental health and recovery expertise and experience into the heart of service provision from both a therapeutic and service improvement perspective.

When we use the term “*patient*” we are referring to people who use, or are supported by healthcare services, their personal support network, communities and anyone who may use healthcare services in the future.

The HSE national Mental Health Operations team signed off on the following Engagement structures

National Head of Mental Health Engagement and Recovery (GM Member of national MH Operations team)	
	Inputs into a number of national strategic, planning and policy groups to ensure they are informed by lived experience perspective
National office of Mental Health Engagement and Recovery HSE	
	Oversees implementation of national service and corporate plan objectives for engagement and recovery
Mental Health Engagement Lead CHO Area (member CHO Area Management Team)	
	Leads on implementation of local service plan priorities for engagement
	Lead on key engagement activity
	Facilitate local and Area for a
	Provide lived experience expertise to key strategic programmes and policy's
CHO Area Engagement forum	
	Strategic Service Improvement structure based on Engagement feedback and co-production principles
	MH Staff & Management, NGO's SUFMC's Public, MH Local Forums
Mental Health Engagement Local Forum	
	Regional or county based
	Open to all people who would like to share experience or perspective on Mental Health issues
	Facilitated by Area Lead for Engagement supported by volunteer chair and secretary
	Issues raised recorded in MHER action log and brought to attention of appropriate level of service for response
	Forum tool of service improvement.

The introduction of the mental Health Engagement structures facilitated a range of service improvement initiatives across CHO's directly as a result of having a service user perspective available. Below are some examples.

Exemplars of Service Improvement Initiatives developed through Mental Health Engagement.

Development of Community Café:

In CHO 2 Mental Health Engagement feedback identified the lack of appropriate supports for Service users out of hours. A service user led co-production group was set up to come up with an out of hour's service to address this need. The community café model was developed where people could visit after hours and receive peer and other supports. The cafe is now being funded by the HSE.

Social phone calling support:

During the Covid 19 pandemic Forums identified the severe impact of the lack of social interaction and face to face appointments for service users. The CHO 3 forums came up with a social phone calling initiative where vulnerable people could receive a social support phone call from trained volunteers and mental health staff.

User friendly communications:

A forum in CHO 1 highlighted that correspondence was often very clinical in its tone and used a lot of jargon. A Service user led co-production group drafted some sample texts for some of the more common correspondences issued by services to people that used a clearer and more simplified language and this has now been adopted by services for their correspondence with service users.

Right to wear your own clothes:

A Forum in the west identified the practice of inpatients having to wear pyjamas while in an acute unit which they found very disempowering and disrespectful to service users. The issues was brought to the local area Management team and it was agreed that the practice would be stopped and people allowed to wear their own clothes.

Development of local information Directory

Local forums in the East identified that although they were a lot of useful services and supports available to MH service users, these were not widely known about even by staff. They set about developing a directory of local services and this is being replicated nationally now.

Input into design of new psychiatric acute unit

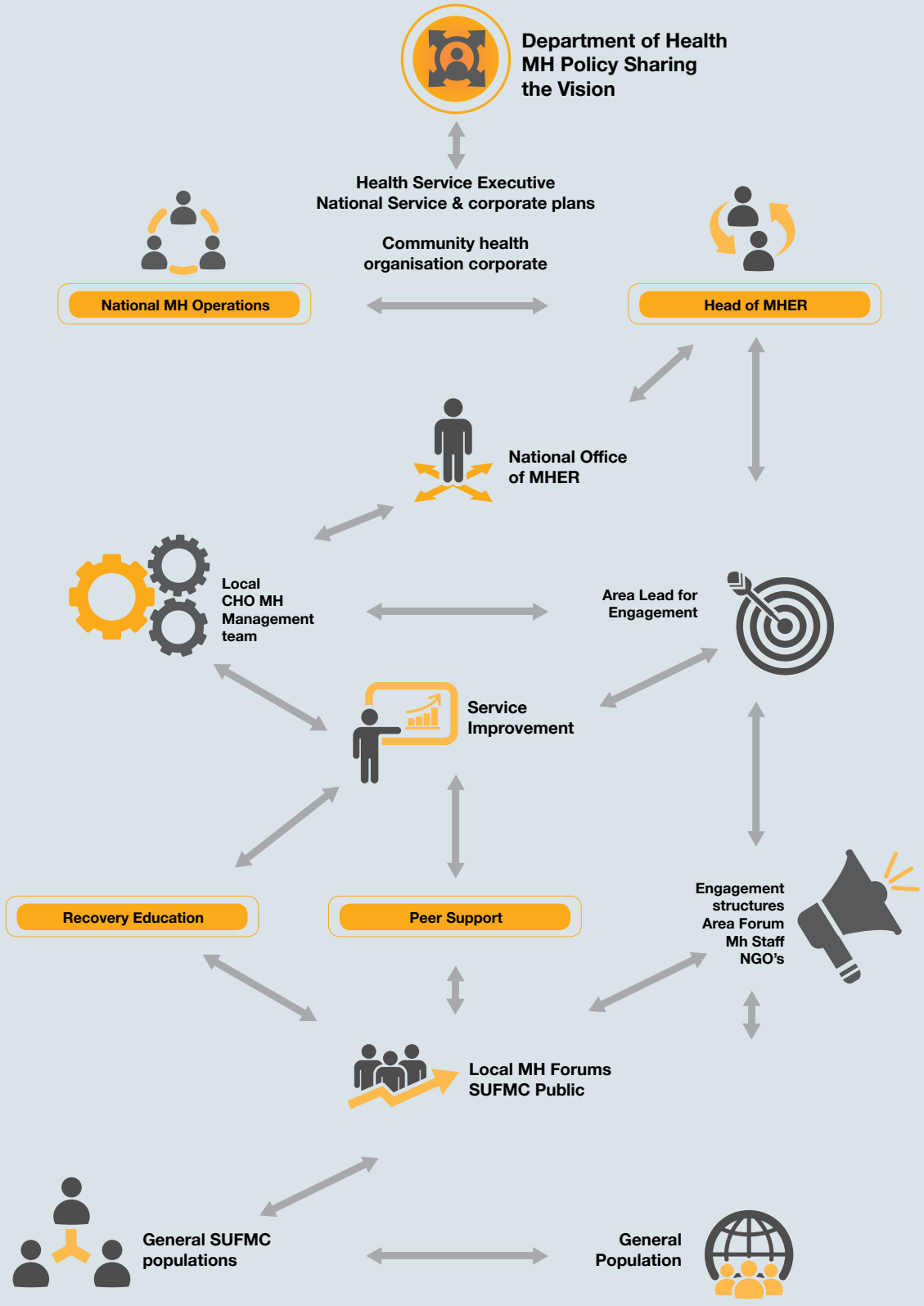
A forum in the east engaged with HSE estates on the design of a new psychiatric inpatient acute unit. They were able to ensure that the designers took into consideration service user perspective in relation to areas including dignity and privacy of residents, family visitation, recreational and seclusion facilities.



The community café model was developed where people could visit after hours and receive peer and other supports.

The café is now being funded by the HSE.

Organisational Governance Map containing MHE structures



Example 2:

Patients as Partners in Tallaght University Hospital: Patient Community and Advisory Council

Patient Community & Advisory Council (PCAC)

Established in 2012 with the support of the Executive Management Team in an effort to Increase the participation of the community in Tallaght University Hospital. PCAC is the patient and community element working in partnership with the organisation that is Tallaght University Hospital.

Mission Statement

A process by which people are enabled to become actively and genuinely involved in defining the issues of concern to them, in making decisions about factors that affect their lives, in formulating and implementing policies, in planning, developing and delivering services and in taking action to achieve change (HeBE 2002).

Aims of the Council

- To engage with the Hospital on service delivery, planning, design and evaluation
- PCAC will partake in hospital projects in partnership with the hospital
- Work in partnership with the Hospital to plan and action key deliverables on an annual basis
- Develop additional community links in partnership with the Hospital
- Develop, implement and monitor the effectiveness of the PCAC with the Hospital

Projects Undertaken by PCAC

- ED Workshop
- End of Life Workshop
- Hospital Awareness two Day Event
- Critique of Patient Information Leaflets
- Hospital Map
- Zero Harm Leaflet “My Medicines
- Development in Atrium – Community Involvement
- Logo for PCAC
- Adult Ed Department Inforgram
- Tour of Hospital
- Community Health Talks
- NALA signage Audit commissioned by the PCAC and funded by TUH
- Statement of Support for Carers
- Patient Information Booklet





TUH Patient Surveys

TUH carried out a paper based survey in 2015 to 1000 in-patients, post discharge, who had spent time in TUH. Since then TUH have continued to carry out local surveys in areas such as radiology, outpatients, inpatients etc. We have also participated in the National Inpatient Experience Survey since 2017.



Volunteer Programme

TUH has a robust Volunteering Programme since we opened our doors in 1998. Our Volunteers are predominantly patients or families of patients of our services. We have over 150 Volunteers participating in programmes such as coffee shop / pastoral care/ arts programme. When the COVID-19 pandemic hit in 2020 many of our volunteers had to cocoon for their safety. However, we introduced other volunteer programmes to ensure the comfort of our patients i.e. Patient Care Package Service, Sending Love and Book in a Bag. Our Volunteers feel they are giving back to the hospital and also giving back to their community.



Our Volunteers Rising to the COVID-19 Challenge



Patient Care Package Service (PCPS) Delivered in 2021

11,086 Care Packages Delivered to the wards
2291 Laundry bags delivered to families of patients

Sending Love Delivered 2021:

779 sending loves messages delivered to patients

Book in a Bag continues to be popular with over 3000 books provided.

We are in the process of reviewing and expanding our Volunteer Services.



Our Volunteers feel they are giving back to the hospital and also giving back to their community.

In August 2021 we invited our existing Volunteers back on site as well as recruiting new Volunteers to reform our Meet & Greet service to:



Meet Greet and Guide Service

The new “guide” component of this service offers our patients the opportunity to be shown directly to their out-patient destination. This service will be expanded to cover areas hospital wide.



The aim of the Meet Greet & Guide Service is to take any uncertainty from the patient’s journey to their destination. It also provides an ideal opportunity for the patient to chat with the Volunteer about any concerns or fears they may feel attending the hospital.

All Volunteers went through the Garda Vetting process and completed relevant training modules including Children First, Hygiene, PPE, Manual Handling etc.



Health Talks in the Community

These have been delivered since 2017 and the demand on same has expanded with 33 talks in the community delivered. TUH receives requests for specific health talks and delivers same at various locations in the community.

- 2017 we delivered 8 talks in the community
- 2018 we delivered 8 talks in the community
- 2019 we delivered 17 talks in the community
- 2021 we held 2 virtually in addition to the podcast series referenced below



Due to COVID-19 these talks had to be suspended. In 2021 our Communications Department worked with the Centre for Learning and Development (CLD) in partnership with our clinicians and allied healthcare professionals applied for a grant from the Adelaide Health Foundation and created our first podcast series (6 episodes). It brought our ‘Let’s talk about’ community talks online and to a larger audience as they are available on iTunes, PodBean and YouTube. Funding has been secured for a second series which will focus on brain health.



Fettercairn Annual Health Care FAIR

There is also the support the Hospital provide through the Communications Office to the organising of the Fettercairn Health Fair each year. Our Communications Co-ordinator represents the Hospital on the organisation Committee and various departments across the hospital provide information stands at the FAIR.

COVID-19 obviously had an impact on the fair taking place last year so we took it virtual in 2021 and had a number of events in the open air, making it a Health Awareness Month...see across for details:



Quality Care Boards – Patients as Partners in their Care



These quality care boards are located on each ward. The top three are permanent and the bottom three change as to what is being promoted throughout the hospital in any given month e.g. Sepsis week / Medication safety etc.

Example 3:

Mayo University Hospital: Patient Experience Advisory Council

“Nothing about me without me“

Roadmap for Organisational Excellence, from the bedside to management team (PowerPoint Presentation)
Mayo University Hospital is leading the way on Patient Engagement and has Patient and Family Experience Advisors working with the hospital. The ultimate goal is bringing the perspectives and lived experiences of patients and families directly into the planning, delivery and evaluation of care. This is part of an overall hospital plan to establish an on-going culture of Quality Improvement and to enhance Safety and Quality for patients and their families.

There is a Patient and Family Experience Advisory council in place that meets monthly and reports into the Hospital Management Team. Patient Experience advisors sit on the Nutrition Steering Committee, MUH Wellness Walkway project, Medication Safety and an Emergency Department Quality Improvement project. The hospital is one of the first in the country to undertake this venture and work collaboratively with Patient Experience Advisors who share first hand their experience of being a patient/family member. The patient is the expert on the quality of the service they received, and on how their illness impacts on their daily life and that of their family. This expertise provides the hospital with a wealth of information.

The Patient Experience Advisors have provided input to the Patient Information booklet and will assist the hospital with the development of a ‘purposeful visiting - partner in care’ initiative which will transform the hospital visiting policy. Prior to Covid the advisors shared their experiences of care with hospital staff, student doctors and nurses in a number of Patient Engagement education sessions enhancing the quality of health professional education.

To learn more about the Patient and Family Engagement initiative please download our Patient and Family Engagement Information leaflet.

<https://www.saolta.ie/sites/default/files/publications/Information%20Leaflet%20-%20Patient%20Engagement.pdf>

Example 4:

Youth Advisory Council CHI

<https://www.cuh.ie/youth-advisory-council-yac/>

Example 5:

The HSE National Patient & Service User Forum

<https://www.hse.ie/eng/about/who/qid/person-family-engagement/national-patient-forum/>

Example 6:

National Screening Service Patient and Public Partnership Strategy 2019-2023

<https://www.hse.ie/eng/about/who/qid/person-family-engagement/patient-and-public-partnership/patient-and-public-partnership-strategy-2019-2023.pdf>

Example 7:

Saolta University Health Care Group Patient and Public Engagement Strategy 2020-2023

<https://saolta.ie/sites/default/files/publications/Saolta%20Patient%20and%20Public%20Engagement%20Strategy%202020->

Example 8:

A National Framework for Person-centred Planning in Services for Persons with a Disability

<https://www.hse.ie/eng/services/list/4/disability/newdirections/person-centred-planning-framework-summary-report.pdf>

References

1. deBronkart, Dave. Let Patients Help
<https://www.amazon.co.uk/Patients-Help-Patient-Dave-deBronkart/dp/1466306491>
2. WHO 1978, Declaration of the Alma-Ata.
https://cdn.who.int/media/docs/default-source/documents/almaata-declaration-en.pdf?sfvrsn=7b3c2167_2
3. Roseman, D., Osborne-Stafnsnes, J., Amy, C.H., Boslaugh, S., Slate-Miller, K. (2013). Early Lessons From Four 'Aligning Forces for Quality' Communities Bolster The Case For Patient-Centered Care. *Health Affairs* 32, NO 2. (2013);232-241. DOI:10.1377/hlthaff.2012.1085
4. Rivoire, Eleanor. Masterclass "Patient Engagement, the "Game Changer" in Healthcare. Dublin October 2019.
5. Fancott, C., Baker, G.R., Judd, M., Humphrey, A., Morin, A. (2018) Supporting Patient and Family Engagement for Healthcare Improvement: Reflections on "Engagement-Capable Environments" in Pan-Canadian Learning Collaboratives. *Healthcare Quarterly* VI 21 Special Issue 2018
6. Baker, G.R. and J.-L. Denis 2011. "Patient Engagement and System transformation" Presentation to Patient Engagement Workshop, Edmonton, AB, November 2011.
7. Fitzgerald, L., E. Ferlie, G. McGivern and D. Buchanan 2013. "Distributed leadership patterns and service improvement: Evidence and Argument from English Healthcare". *Leadership Quarterly* 24(1)227-39. Doi:10.1016/j.leaqua.2012.10.012
8. Health and Social Care Regulatory Forum: Framework for Public and Service User Involvement in Health and Social Care Regulation in Ireland, 2009
9. Healthwatch UK (2018) Public Engagement in Health: A Literature Review October 2018.
<https://www.healthwatch.co.uk/sites/healthwatch.co.uk/sites/Healthwatch%20England%20literature%20review.pdf>
10. Bombard, Y., Baker, G.R., Orlando, E., Fancott, C., Bhatia, P., Casalino, S., Onate, K., Denis, J.-L., Pomey, M.-P. (2018) Engaging patients to improve quality of care: A systematic review. *Implementation Science* (2018) 13:98 <https://doi.org/10.1186/s13012-018-0784-z>
11. Higgins, T., Elaine Larson, E., Schnall, R. (2017). Unraveling the meaning of Patient Engagement: A concept analysis. *Patient Education and Counseling* 100 (2017) 30-36
12. Carman, K.L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., Sweeney, J. (2013). Patient and Family Engagement: A Framework For Understanding The Elements and Developing Interventions and Policies. *Health Affairs* 32 No.2 (2013):223-231 DOI:10.1377/hlthaff.2012.1133
13. Institute for Patient and Family Centred Care. 2017
14. Grande, S.W., Faber, M.J., Durand, M.-A., Thompson, R., Elwyn, G. (2014). A Classification model of patient engagement methods and assessment of their feasibility in real-world settings.
15. Hibbard, J.H., Greene, J. (2013). What the evidence shows about patient activation: Better health outcomes and care experiences; fewer data on costs. *Health Affairs* 32 No 2 (2013): 207-214
16. Whiston, L., Barry, J.M., Darker, C.D. (2017). Participation of patients and family members in healthcare services at the service and national levels: A lesson learned in Dublin, Ireland. *Patient Education and Counseling* 100 (2017) 583-591 <http://dx.doi.org/10.1016/j.pec.2016.10.025>
17. Ocloo, J., Matthews, R. (2016). From tokenism to empowerment: progressing patient and public involvement in healthcare improvement. *BMJ Qual Saf* 2016;25:626-632.
18. Coulter, Angela PhD Patient Engagement—What Works?, *Journal of Ambulatory Care Management: April/June 2012 - Volume 35 - Issue 2 - p 80-89* doi: 10.1097/JAC.0b013e318249e0fd
19. Bulhama, N and Lee, T. 2019. *Harvard Business Review* 8th Amy 2019.
20. West, M and Dawson, J. 2012 from "Employee engagement and NHS performance"
21. Lyubovnikova, J., West, M.A., Dawson, J.F. orcid.org/0000-0002-9365-8586 et al. (1 more author) (2015) 24-Karat or fool's gold? Consequences of real team and co-acting group membership in healthcare organizations. *European Journal of Work and Organizational Psychology*, 24 (6), pp. 929-950. ISSN 1359-432X <https://doi.org/10.1080/1359432X.2014.992421>
22. Borrill, C., West, M.A., Dawson, J., Shapiro, D., Rees, A., Richards A., Garrod, S., Carletta, J., Carter, A. (2000). Team Working and Effectiveness in Health Care: Findings from the Health Care Team Effectiveness Project. Birmingham. Aston University.
23. Batalden, M., Batalden, P., Margolis, P., Seid, M., Armstrong, G., Opipari-Arrigan, L., Hartung, H. (2016) *BMJ Qual Saf* 2016;25:509-517. Doi:10.1136/bmjqs-2015-004315
24. Cole-King, A and Gilbert, P. 2011. "Compassionate Care: the theory and the reality". *Journal of Holistic Healthcare*. Vol8; Issue 3 Dec 2011
25. Halpern J. What is clinical empathy?. *J Gen Intern Med.* 2003;18(8):670-674. doi:10.1046/j.1525-1497.2003.21017.x
26. Bryant, L. (2009) The Art of Active Listening. *Practice Nurse*, 37, 49-52. <https://doi.org/10.1080/09540120600578409>
27. Sherry R. Arnstein (1969) A Ladder Of Citizen Participation, *Journal of the American Institute of Planners*, 35:4, 216-224, DOI: 10.1080/01944366908977225
28. Hahn, D.L., Hoffman, A.E., Felzien, M., LeMaster, J.W., Xu, J., and Fagnan, L.J. (2017) Tokenism in Patient Engagement. *Family practice*, 2017, vol.34, No.3, 290-295 doi:10.1093/fampra/cmw097
29. Dent, M., Pahor, M. (2015). Patient involvement in Europe- a comparative framework. *Journal of Health Organisation and Management* Vol 29 No. 5, 2015. DOI 10.1108/JOHM-05-2015-0078
30. Barnes, M., & Cotterell, C. (2012). From margin to mainstream. In M. Barnes, & P. Cotterell (Eds.), *Critical perspectives on user involvement* (pp. xv-xxvi). The Policy Press.

Some further reading is listed in Appendix 21.



Better Together

Health Services Patient Engagement Roadmap

Better Together: The Health Services Patient Engagement Roadmap

Providing the essential guidance and tools for healthcare staff to create a strong culture of meaningful Patient Engagement, where Patient Engagement is encouraged, expected and respected.