

“Better Together”: The Health Services Patient Engagement Roadmap.

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Introduction

Right of all people

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}.

**Rightful role
Expertise
Important contribution**

“

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:

- Patients
- Healthcare Staff and Services

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

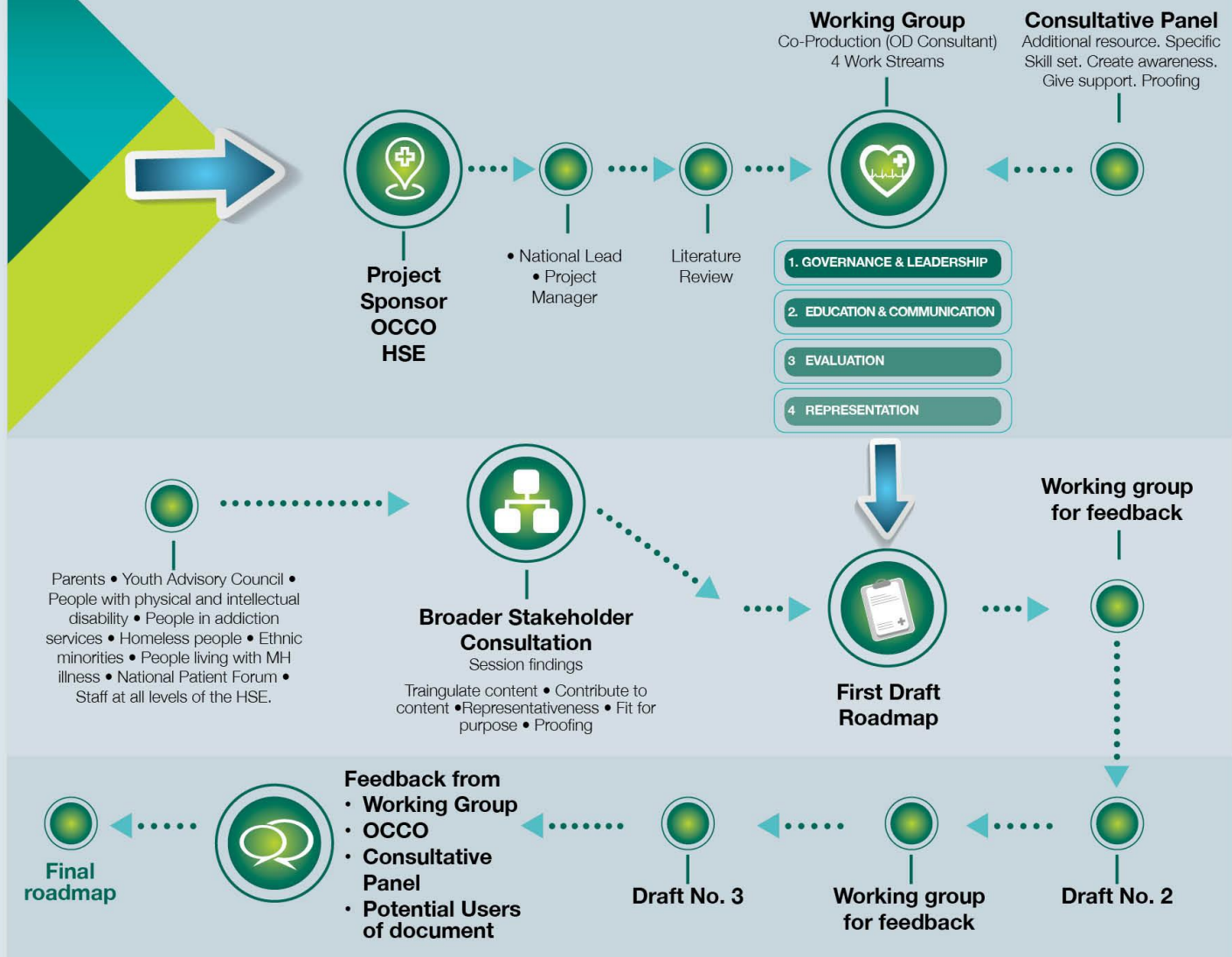
- improvements in patient safety and the quality of healthcare^{3,5,11,12,13,14,15}.
- the design of healthcare services that are fit for purpose and optimally accessible to those who need to avail of them¹⁶.
- developing priorities and making improvements based on needs identified by the patients rather 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.

The purpose of the Roadmap:

- To achieve a consistent, cohesive, considered approach to Patient Engagement.
- Establish a shared understanding of Patient Engagement.
- 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

Development of the Roadmap



The Roadmap Layout

Introduction: context, rationale for and definition of patient engagement, explanation of how to use the Roadmap

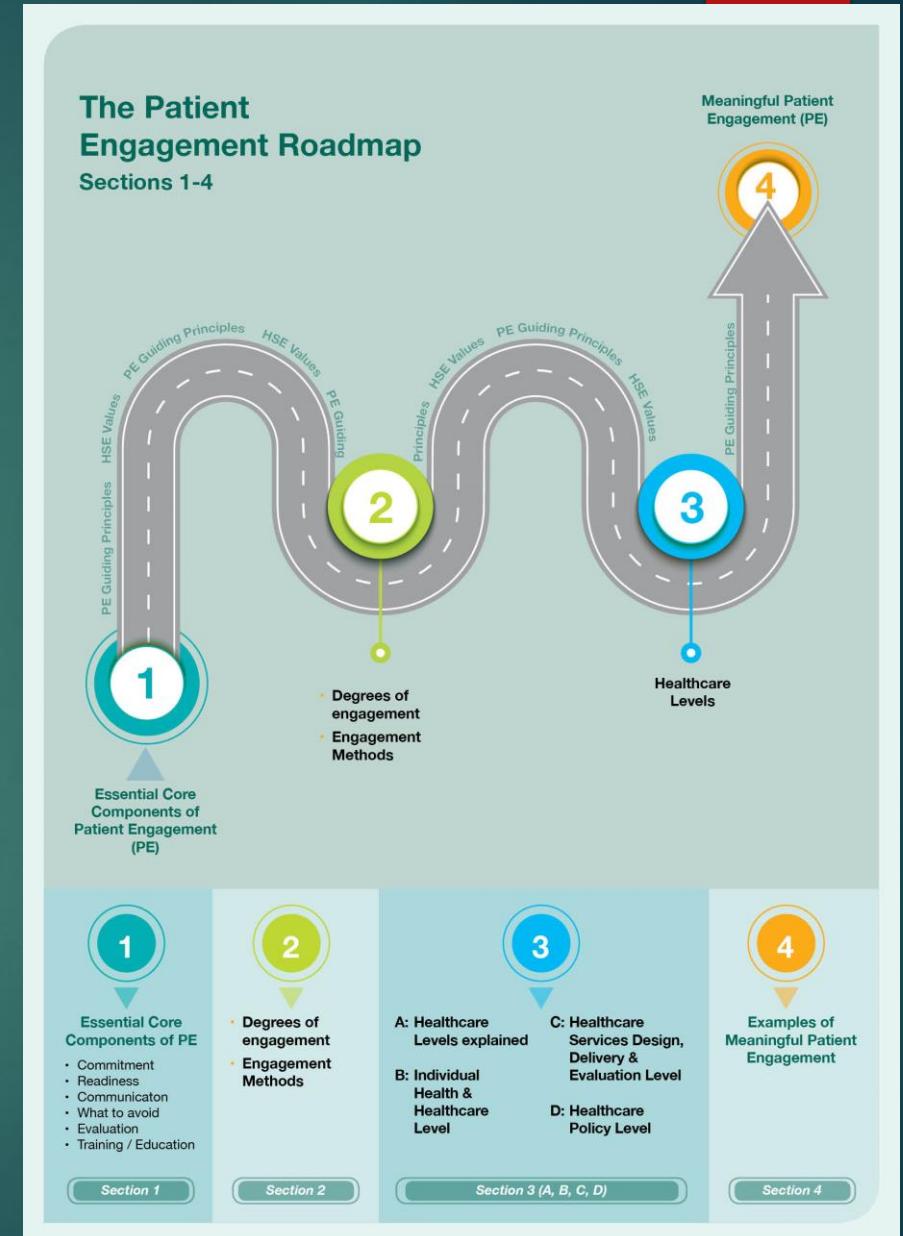
Section 1 : Essential core components for meaningful patient engagement for all staff

Section 2: Four degrees of engagement, and corresponding engagement methods

Section 3: Three healthcare levels at which Patient Engagement occurs

Section 4: Examples of good practice

Appendices: Resources, Templates and Checklists



The Roadmap Key





Not all sections of the Roadmap are relevant for all healthcare staff

Each symbol represents staff working in specific healthcare settings

Find your symbol and follow this throughout the document to guide you to the sections relevant for your healthcare setting

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 symbols 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.



Terms used

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.

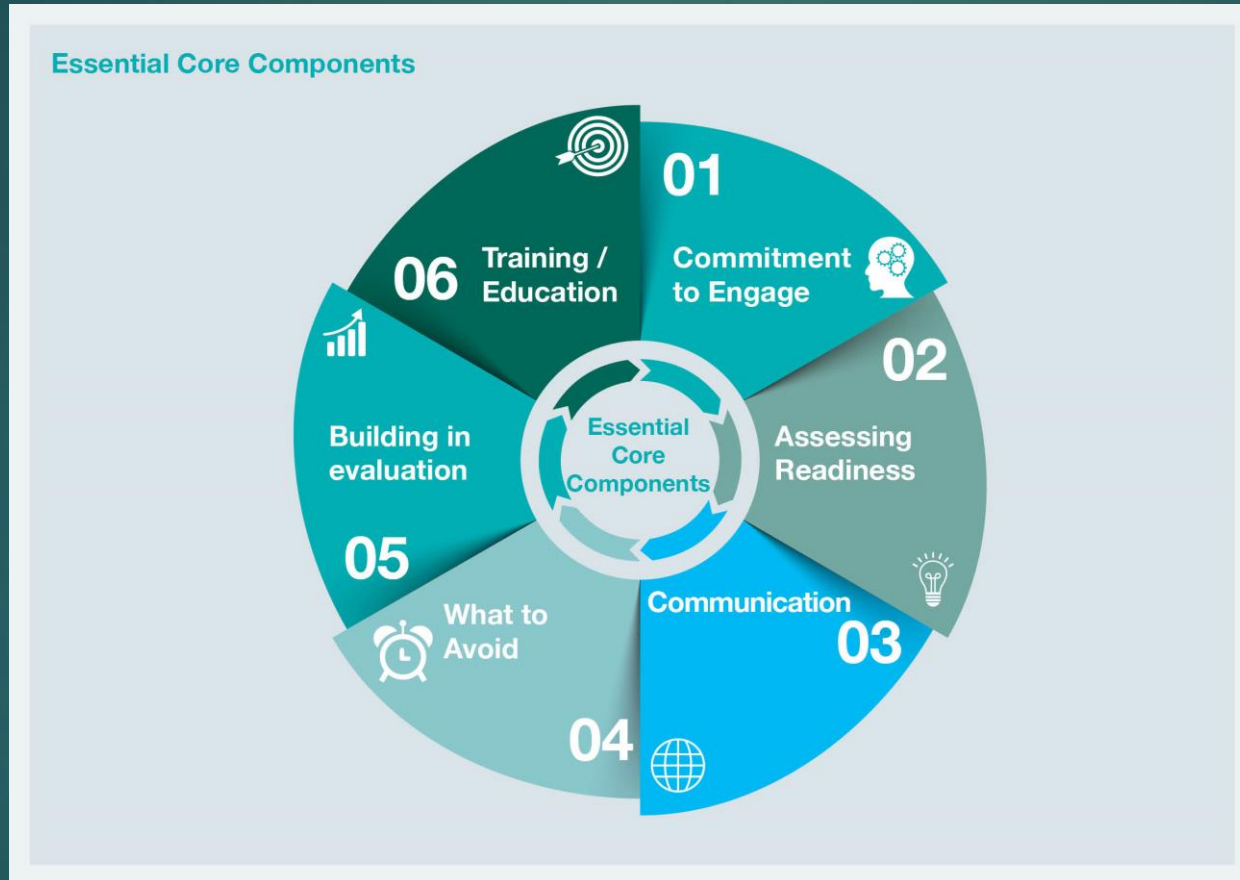


Patient Engagement is a term used to describe the ways in which healthcare staff work together with patients and their personal support network to actively involve them in decisions made about their own health and healthcare; healthcare service design, delivery and evaluation; and healthcare policy.

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.

Section 1:

The Essential Core Components for meaningful Patient Engagement



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.

Assessing Readiness for Patient Engagement

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?		

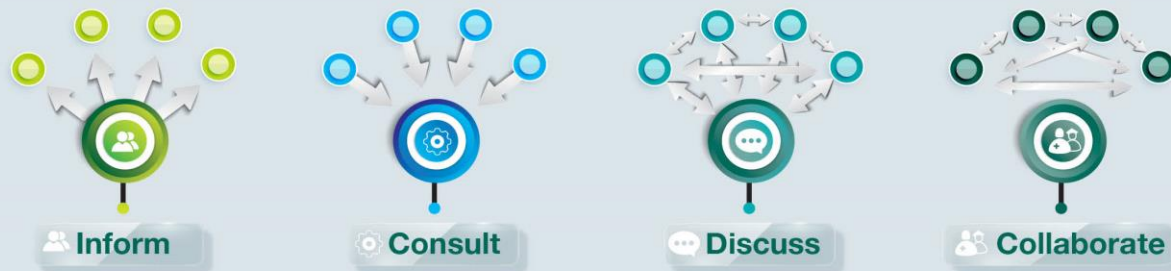
Communication Checklist

	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?			
Have you a system in place to make it easy for patients to ask you to explain terms they do not understand?			
Have you 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)			

Section 2:

Four degrees of engagement explained.

Degrees of Engagement



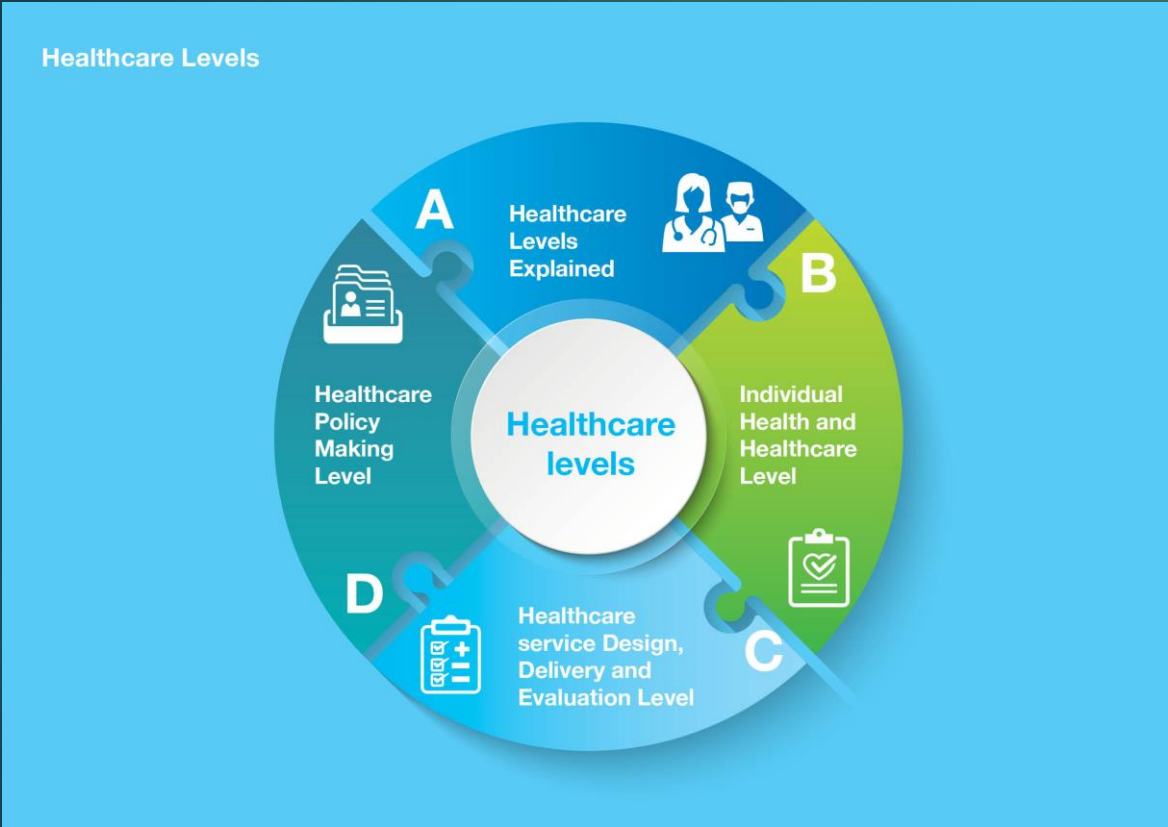
(Adapted from Patterson Kirk Wallace Public Consultation Design)

Under the headings:

- ▶ Goal
- ▶ Direction of information
- ▶ Degree of influence
- ▶ Methods
 - ▶ Corresponding toolkit describing the “How To”.

Section 3:

Three healthcare levels at which Patient Engagement occurs



1. Individual health and healthcare level

- Checklist of actions required for meaningful patient engagement at the individual health and healthcare level

2. Service design, delivery and evaluation level

- Checklist of organisation/service requirements to embed patient engagement as part of how we do our work
- Essential steps to take to select, set up and conduct a meaningful patient engagement method/activity for engaging with patients in service design, delivery and evaluation

3. Policy making level.

- Checklist of actions required for enabling meaningful patient engagement in policy making.
- Essential steps to take to select, set up and conduct a meaningful patient engagement method/activity for engaging with patients in policy making

Corresponding links to resources and templates in appendices

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 involved in their own healthcare Communication is key.				
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 that the patient has understood the information?				
Have you reinforced and reiterated the information you are giving the patient 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				

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?				

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)	
<ul style="list-style-type: none"> 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:	
<ul style="list-style-type: none"> 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	
<ul style="list-style-type: none"> 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	
Invitation approach (see pages 61-65)	
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 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	
<ul style="list-style-type: none"> 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	
<ul style="list-style-type: none"> 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)	
<ul style="list-style-type: none"> 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? 	

C

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.

Commitment and Leadership	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 engagement in your service?				
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/partners?				
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)

D

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)

Section 4:

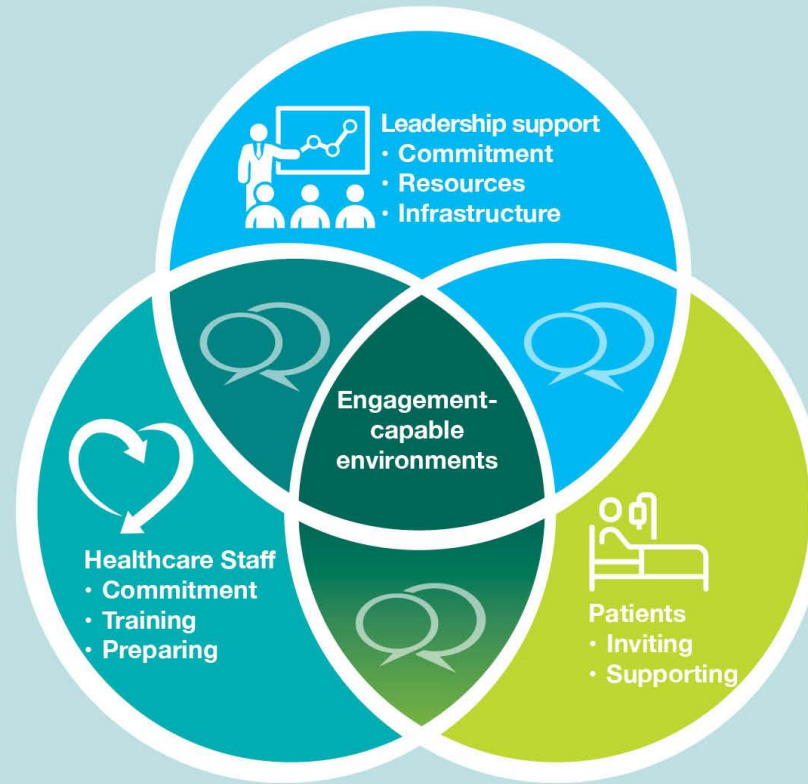
Some examples of good PE throughout the HSE



Engagement capable environments

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.



Thank you for listening

