

Framework for Public Involvement in Clinical Effectiveness Processes

inclusivity
transparency
sustainability
openness
Public
dignity
fairness
diversity
learning
involvement
responsiveness
collaboration
support
respect
partnership

The National Clinical Effectiveness Committee is a Ministerial committee of stakeholders, including patient representatives, that was established to oversee a National Framework for Clinical Effectiveness. Its Terms of Reference are:

1. Provide strategic leadership for the national clinical effectiveness agenda.
2. Contribute to national patient safety and quality improvement agendas.
3. Publish standards for clinical practice guidance.
4. Publish guidance for National Clinical Guidelines and National Clinical Audit.
5. Prioritise and quality assure National Clinical Guidelines and National Clinical Audit.
6. Commission National Clinical Guidelines and National Clinical Audit.
7. Align National Clinical Guidelines and National Clinical Audit with implementation levers.
8. Report periodically on the implementation and impact of National Clinical Guidelines and the performance of National Clinical Audit.
9. Establish sub-committees for NCEC workstreams.
10. Publish an Annual Report.

This toolkit is published by:

The Department of Health
Hawkins House, House Street, Dublin, D02 VW90, Ireland
Tel: +353 (1) 6354000
www.health.gov.ie

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Introduction

Public Involvement in Clinical Effectiveness Processes strengthens public participation in healthcare decision-making and brings public knowledge and experience to these processes.

For this Framework, Clinical Effectiveness Processes include the development of National Clinical Guidelines (developing good standards) and National Clinical Audits (developing strong review practices) to drive improvements in healthcare outcomes.

Public involvement is a developing area; however, public involvement goals and preferred processes are often articulated in vague terms by organisations [1, 2]. This Framework outlines some practices to follow and/or consider when involving the public in Clinical Effectiveness Processes. This Framework also offers practical tips and tools to assist with its implementation.

The Framework adopts the viewpoint that public involvement can improve clinical guideline and audit quality, implementation, and representativeness and responds to the needs and expectations of the public [1].

Public involvement informs decision-making from a position that really matters, meaning the real world, and often practical, perspective. Issues that the public are really interested in are addressed, not just the decisions of the health care team and researchers who determine best practice for optimal clinical and process outcomes.

The time now seems right to view Clinical Effectiveness Processes in such a way that both professional's perspectives as care providers and the public's preferences are considered equally in the decision-making process [3].

In implementing this Public Involvement Framework, attention should be given to the National Clinical Effectiveness Committee's Criteria for Quality Assurance of National Clinical Guidelines and National Clinical Audit.

What is public involvement?

Public involvement refers to any process that directly engages the public in decision-making and gives full consideration to public input in making that decision. For this Framework, public involvement refers to a series of activities or practices to involve the public in National Clinical Guideline and National Clinical Audit processes.

Good public involvement is as much about human relationships and interactions, as it is about methods. It is about working together with the public to improve health communities [4].

Who are the “public”?

The term “public” includes a wide range and variety of individuals, as well as groups and/or organisations, who may be involved in Clinical Effectiveness Processes. These include: people who use, or have used, healthcare services, carers and family members, parents, organisations who represent patients, patient support groups, charities that represent specific health conditions, individuals with an interest in a topic, and members of the general public. While acknowledging that the public can also include health professionals, in keeping with the NCEC Modus Operandi (i.e.

method of working) for the context of this framework, public members should not have practiced as a registered health professional for a minimum of 5 years.

Why is public involvement in Clinical Effectiveness Processes important?

Public involvement is important as it helps to develop priorities and make improvements based on public identified needs rather than assumptions. Involving the public in National Clinical Guideline and National Clinical Audit processes enhances the legitimacy of the guideline or audit, from a public perspective. The public may also be involved in some clinical practice guidance development (i.e. clinical policies, procedures, protocols, and local guidelines).

Why do the public get involved?

Members of the public may have a number of reasons for getting involved, including wanting to help others, wanting to improve the standard of healthcare in Ireland, as well as possible personal benefits.

What is needed to involve the public?

Successful public involvement in Clinical Effectiveness Processes requires the following three conditions:

- 1) A clear purpose and objective from the outset of the process
- 2) A clear structure of how public involvement will be conducted
- 3) A commitment to the process

This Framework is designed to provide practical guidance to achieve all three of these conditions.

Acknowledgements

The research team would like to acknowledge the valuable contributions of the ***Expert Advisory Panel***.

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We would like to thank all members of the public involved for their valuable feedback, without which this Framework would not be possible.

Permissions

Permission has been granted by the International Association for Participation for adaptation of their Spectrum of Public Participation [5] in this Framework. We also obtained permission for use and adaptation of a number of resources to assist with implementation of this Framework as follows: Armstrong's Framework for continuous patient engagement in clinical practice guideline development [6]; Guidance Document 7 Survey Questionnaire for Public Contributors & Guidance Document 9 Assessment of Meaningful Public Involvement adapted with permission from European Patient's Forum "Value+ Toolkit"; and Guidance Document 10 Record of Public Involvement Practice/Activity Template adapted with permission from Personal and Public Involvement Toolkit of Southern Health and Social Care Trust.

Development of the Framework



Development of the Framework

The development of this Framework was informed by a systematic review of patient engagement in the governance and development of national clinical effectiveness processes [7]; a desktop review of national and international patient and public involvement practices in clinical effectiveness processes [8]; a web-based and hard-copy public consultation [8]; and a consultation with an Expert Advisory Panel [8].

Who is this Framework for?

This Framework is written for the NCEC's National Guideline Development Groups and National Audit Governance Committees. The information will also be useful for other NCEC public involvement activities e.g. clinical guidance development, and to wider interest groups looking to work together with public, such as researchers, educators and regulators.

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Funding: The process for developing this Public Involvement Framework for the NCEC was funded by the Department of Health and overseen by the Clinical Effectiveness Stream of the National Patient Safety Office, Department of Health.

The Framework



The Framework

Introduction

This Framework is designed to outline the practices that may be undertaken to involve the public in Clinical Effectiveness Processes of National Clinical Guideline Development and National Clinical Audit Governance.

Rationale for the Framework

An increase in public involvement policies has been advocated previously as a means of enhancing the responsiveness (i.e. readily react to suggestions) and transparency (i.e. open and honest) of healthcare systems [9, 10]. However, involving the public in Clinical Effectiveness Processes that affect them has widespread benefits, not only for healthcare delivery.

Processes of National Clinical Guideline and National Clinical Audit are generally perceived as tools that will inform healthcare professionals' decisions rather than facilitate public involvement in decision-making [3]. The current move towards actively involving the public from the outset of these processes represents a cultural shift (i.e. change in behaviour, thoughts and beliefs) to one of mutual benefit for the public (patients) and healthcare providers. After all, patients themselves are experts of their own experience and are likely to have greater insight into their own lived experience of various conditions.

A person-centred approach in the context of healthcare delivery values "a person" (the service user) as an active participant of the health service. This person-centred approach gives greater insight into factors related to a condition and facilitates National Clinical Guidelines and National Clinical Audits that are congruent with personal values, beliefs and environmental conditions of the service user [11]. Ensuring such an approach can facilitate healthcare professionals in considering all relevant domains of a person's health.

Specifically, ensuring that issues of priority for the public are appropriately taken into account from the beginning of Clinical Guideline development and/or the Clinical Audit process helps to ensure the guideline and/or audit is relevant and applicable to the public.

Overview of the Framework

Framework Vision and Values

The vision of this Framework is to work with the public to use their knowledge and experience to improve the quality of healthcare. This approach will help to inform all National Clinical Effectiveness Committee processes. These processes include the development of: National Clinical Guidelines (developing good standards); and National Clinical Audit (developing strong review practices).

The Framework is underpinned by the core values of:

Dignity and respect

We will treat everyone involved in national clinical effectiveness processes with dignity and respect. We will treat any shared personal experiences as confidential, unless there are clear legal and professional reasons to do otherwise such as a child protection issue.

Support

We will give the public involved in national clinical effectiveness processes the support and resources they need to be full partners in this work.

Transparency and openness

When we work with the public in national clinical effectiveness processes, we will be open and transparent. We will include the public when we make any decisions and we will clearly show their contribution.

Learning and responsiveness

We will encourage everyone involved in national clinical effectiveness processes to listen openly to each other and speak without using jargon. We will use continuous learning and reflection to thoroughly evaluate and improve public involvement processes.

Inclusivity, fairness, and diversity

In our national clinical effectiveness process, we will include members of the public with different: backgrounds, culture, skills, knowledge, and experience. We will be sensitive to everyone's needs and abilities. We will value, accommodate and respect everyone taking part.

Sustainability

Throughout our work, we will encourage the public to take part so we can support and sustain ongoing quality public engagement.

Collaboration and partnership

We will base public involvement in national clinical effectiveness processes on effective collaboration and partnership. In this context, we view partnership as dialogue and agreement between at least two experts, including the patient as an expert in their own life.

These seven core values are threaded through the following Framework. Additionally, practical resources and guidance documents for the Framework have been developed to help implement these values successfully.

Structure of the Framework

A visual illustration of the **Framework for Public Involvement in Clinical Effectiveness Processes** is presented on the following page of this document.

There are five **Levels of Public Involvement** which may be engaged in. These are:

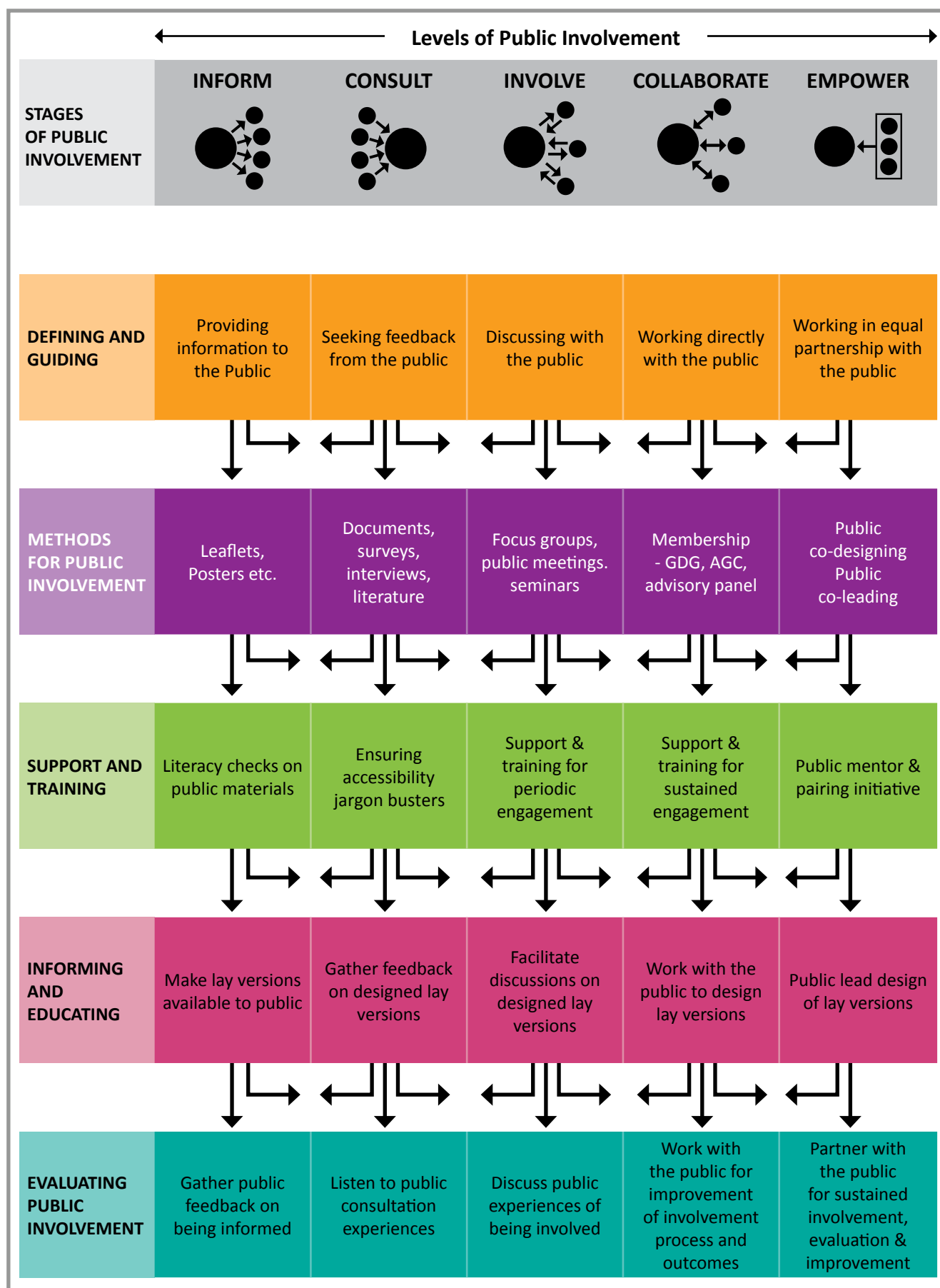
1. Informing the Public
2. Consulting the Public
3. Involving the Public
4. Collaborating with the Public
5. Empowering the Public

There are five stages to consider for Public Involvement. These are:

1. Defining and Guiding Involvement
2. Methods for Public Involvement
3. Support and Training for Involvement
4. Informing and Educating via Involvement
5. Evaluating Public Involvement

These levels and stages are presented in dedicated colour-coded sections throughout this document.

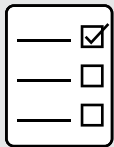
Whilst the Framework illustrates different levels and stages of involvement, including the activities that may be undertaken at these levels and stages, it is important to note that the Framework is **navigable** – i.e. – not all stages must be taken within the same level, and horizontal movement (back and forth) across the Framework is expected. This process will be discussed further in “Section 1”.



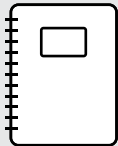
To assist with implementation of this framework a number of practical resources are provided throughout and at the end of this document. These are:

- Checklists
- Worksheets
- Think Points
- Key Messages from the Public
- Templates (at end of document).

Practical resources can be identified by the following icons:

**CHECKLISTS**

To support completion of tasks

**WORKSHEETS**

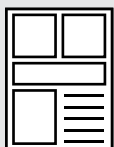
To brainstorm ideas

**THINK POINTS**

To stimulate thinking

**KEY MESSAGES FROM THE PUBLIC**

To relay key messages from the public consulted about this framework

**TEMPLATES: GUIDANCE DOCUMENT**

Section 1:

Defining and guiding involvement



SECTION 1: Defining and Guiding Involvement

From the outset of involving the public in National Clinical Guidelines and National Clinical Audit, it is important to define and guide precisely what public involvement will achieve, and who you will involve.

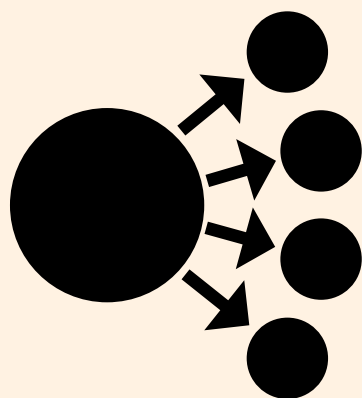
This section of the framework will help you decide:

- (i) the level of public involvement
- (ii) who, from the public, to involve
- (iii) how to invite the public

Defining Public Involvement

This Framework adopts the Public Participation Spectrum [5] developed by the International Association for Public Participation. This spectrum outlines five levels of involvement – **inform, consult, involve, collaborate and empower** - reflective of different public participation goals and increasing level of public impact on decisions. This Public Participation Spectrum acknowledges the legitimacy of different levels of participation depending on goals, time frames, resources and levels of concern in the decision to be made [5]. The desired objective for meaningful involvement, however, should be to work together with the public throughout all steps of National Clinical Guideline and National Clinical Audit processes to improve the quality, safety, efficiency and effectiveness of health service delivery.

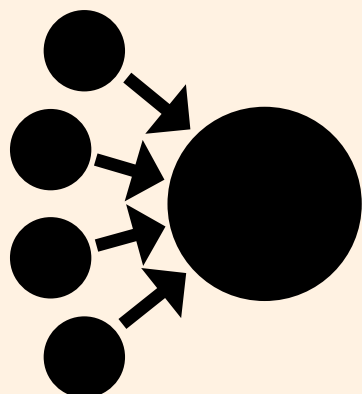
Level 1: Informing the Public



The public involvement goal of level 1 is “to provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions”.

Level 1 informing consists of one-way dialogue to tell the public something about National Clinical Guideline or National Clinical Audit processes, without directly seeking their input into any decisions made.

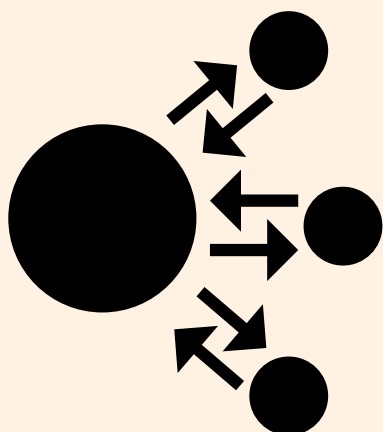
Level 2: Consulting the Public



The public involvement goal of level 2 is “to obtain public feedback on analysis, alternatives and/or decisions”.

Level 2 consulting consists of listening to the public before a decision is made to gain feedback on their experiences and perspectives to inform a particular aspect of a National Clinical Guideline or National Clinical Audit. Interaction would be one-way with limited opportunity for dialogue.

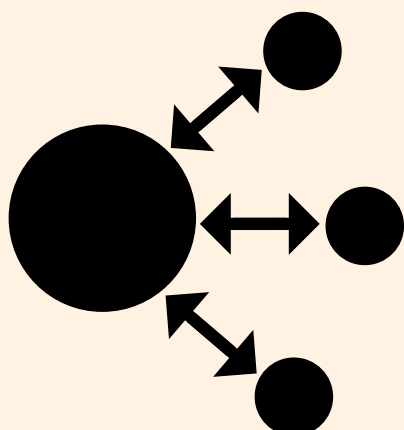
Level 3: Involving the Public



The public involvement goal of level 3 is “to work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered”.

Level 3 involving consists of two-way dialogue with the public to discuss a particular aspect of a National Clinical Guideline or National Clinical Audit. Consideration would be given to public views when making a decision. The final decision on how, or if, public views are taken on board are not influenced by the public.

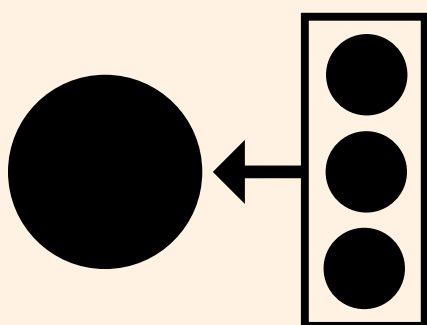
Level 4: Collaborating with the Public



The public involvement goal of level 4 is “to partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution”.

Level 4 collaborating consists of working directly with the public from the outset (ideas stage) of National Clinical Guideline or National Clinical Audit processes, and throughout the process until finalised, for example, public as active members of a National Clinical Guideline Development Group (GDG) or National Clinical Audit Governance Committee (AGC). There would be multi-way dialogue, in-depth relationships and the opportunity for the public to influence decision-making deliberations and group outputs.

Level 5: Empowering the Public



The public involvement goal of level 5 is “to empower the public to lead the decision-making process”.

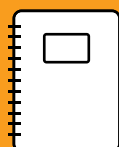
Level 5 empowering consists of working in equal partnership with the public where there would be multi-way dialogue, shared decision-making authority and opportunities for the public to co-lead and co-design throughout all stages (beginning to end) of National Clinical Guideline and National Clinical Audit processes.

Deciding the level of public involvement

Reflecting on the levels of public involvement outlined above you need to decide at what level you want to involve the public throughout the various steps (from beginning to end) of National Clinical Guideline and National Clinical Audit processes. One way to think about this is to consider Arnstein's Ladder of Citizen Participation which focuses on levels of participation, from passive to active with a shift in power to a more equitable relationship as you climb the ladder [12].

To help you to consider the level at which you want to involve the public provide answers to the questions in worksheet 1 below. The think point below should help you think about explanations for your answers.

Here, Armstrong et al.'s [6] framework for public engagement will also help you to think about the steps in the guideline/audit development and/or governance processes that you wish to involve the public in, and the purpose of involving the public at each step (see Appendix 1).



WORKSHEET 1 BRAINSTORMING LEVEL OF PUBLIC INVOLVEMENT

Level 1: Inform Do you want to share information with the public?	Yes/No: Explain your answer
Level 2: Consult Do you want to ask the public about their experience or for their feedback on the clinical guideline/audit?	Yes/No: Explain your answer
Level 3: Involve Do you want to work with the public to discuss and deliberate about the clinical guideline/audit?	Yes/No: Explain your answer
Level 4: Collaborate Do you want to work together with the public in deciding what to do and in doing it?	Yes/No: Explain your answer
Level 5: Empower Do you want to work in equal partnership with the public, where the public can lead the way & take elements of control and responsibility?	Yes/No: Explain your answer



THINK Point! Choosing public involvement level

- What are your goals for public involvement?
- How much influence or decision making power will the public have?
- At what steps of the process do you want to involve the public?
- What resources will you need to achieve this level of public involvement?
- What are your timelines and deadlines?



KEY MESSAGES FROM THE PUBLIC

For levels of public involvement the public recommend:

Avoid tokenism & consider co-design

“To be able to raise the topic is important to me. To have my voice heard. Not to be the token patient”

“Role of patient representative must be clarified within group. Very important that this is not perceived as being token”

“To be offered a more participatory role, perhaps as a co-researcher”

Guiding Public Involvement

It is of crucial importance to always remain aware of the guiding principles of involving the public. This framework adopts the guiding principles for public involvement outlined by the Department of Health in Ireland [13].

Ensuring all voices are heard

The public, especially those whose voices are seldom heard, have a right to be involved in the development of the health and social services that they use and this is a key element in the delivery of patient-centred care.

Central involvement of the public

The public should be centrally involved in their own care.

Open dialogue, trust, mutual respect

Open dialogue, trust and mutual respect are key ingredients of successful public involvement.

Inclusion, diversity, equity

Involvement must be based on inclusion, diversity and equity – health services must engage socially excluded groups including those who are socio-economically disadvantaged, ethnic minorities and Travellers, people with disabilities, lesbian, gay, bisexual and transgendered people, children, young people and older people and users of mental health services.

Clear channels of communication

Clear channels of communication with the health service for members of the public are essential to effective involvement.

Accurate and timely feedback

Accurate and timely feedback and information are key elements of successful public involvement.

Systematic evaluation and learning

Public involvement initiatives must be systematically evaluated and learning from public involvement initiatives must be disseminated across the health and social services.

It is intended that the core values outlined at the outset of this Framework reflect these principles when guiding public involvement.

Inviting the public to be involved

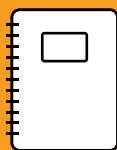
When reaching out to the public to seek involvement you will need to decide i) who, of the public, you will invite to get involved, and ii) what approach you will use to invite the public to be involved.

Deciding which public members to involve

It is important to know from the outset who's input would benefit the clinical guideline and audit process. Use worksheet 2 below to brainstorm ideas about who from the public you might involve.

This worksheet will not only help you decide who to involve but also consider what characteristics, qualities and experience they may need (see table below for some criteria to consider), what you want them to do and how you are going to advertise, where and when. Brainstorming these ideas will also help you develop your public involvement advertisement and role specification.

The think point below should help you explain reasons for your answers.



WORKSHEET 2

IDENTIFYING THE PUBLIC TO INVOLVE

Who from the public might be involved? Think about how you define the public	<i>Answer & Explanation</i>
Why do you want to involve the public? Think about what you want to achieve by involving the public	<i>Answer & Explanation</i>
What do you want the public to do? What level and step in the process do you want to involve the public?	<i>Answer & Explanation</i>
What, if any, public eligibility criteria will you apply? Think about essential and desirable criteria for inclusion in personnel specification for your advertisement	<i>Answer & Explanation</i>
What message do you want to relay to the public? What will motivate the public to get involved?	<i>Answer & Explanation</i>
How will you advertise your public invitation? How will you access (e.g. formats and routes of advertising) the public you want to get involved; and who might you miss/exclude?	<i>Answer & Explanation</i>
What will be the timing of your advertisement? Think about what your public response deadlines are?	<i>Answer & Explanation</i>
How will you monitor the success of your approach to public invitation?	<i>Answer & Explanation</i>



THINK Point! Who, of the public, to involve?

- Who do you want to involve, and why?
- How important is demographic representation (i.e. characteristics of the public involved are similar to those of people they represent)?
- Are wider public interest groups needed?
- How many people do you need to take part for balanced representation?
- How will you reach the public you need?
- Will people need particular skills or experience?

CRITERIA	QUESTIONS TO CONSIDER
PERSONAL EXPERIENCE	Do you need individuals with direct and/or indirect experience of an illness, clinical condition and/or health service experience?
SKILLS AND KNOWLEDGE	Do you need individuals with specific skills or knowledge e.g. topic area, research evidence, medical terminology, literacy, group work processes, good communicator, ability to be objective, to challenge and to influence etc.?
PUBLIC INVOLVEMENT EXPERIENCE	Do you need individuals with any previous experience in public involvement initiatives or clinical effectiveness?
DIVERSITY	Do you need individuals from more than one social, cultural, economic group? Do you need to consider gender balance and geographical spread?
LOGISTICS	Do you need to take account of public time commitment and financial constraints that might impact on individuals getting involved?
CONFLICTS OF INTEREST	Do you need to determine if there are any conflicts of interest?

Approaches to inviting the public to get involved

There are three potential approaches to inviting the public to be involved. These include:

- Open invitation to the general public
- Targeted invitation to specific public members and/or representative organisations,
- Combination of open and targeted public invitations.

All approaches have potential advantages and disadvantages (see Table below adapted from the G-I-N PUBLIC Toolkit [14]).

Whilst undertaking all three approaches to inviting the public to be involved, it is important to be aware of the potential sources of bias that can occur during public selection, response and attrition (i.e. drop-out) processes.

See Tables below (adapted from Haddaway et al, 2017 [15]) for an overview of these bias sources and some approaches to think about to try minimise potential sources of bias.

Approaches to inviting the public to be involved

PUBLIC INVITE APPROACH	POTENTIAL ADVANTAGES	POTENTIAL DISADVANTAGES
OPEN INVITE <i>Advertising invite for public involvement with role & personal specification; consider applications from those who meet role criteria. Also includes making draft documents available online for general public feedback.</i>	Transparency Open to all interested parties & viewpoints	Overwhelmed with volume of feedback Inadequate feedback Personal bias (<i>individuals with very positive or negative experiences respond</i>)
TARGETED INVITE <i>Seeking public involvement from specific representative organisations, or groups and individuals, with specific interests, expertise and responsibility. These could be public members known to, or nominated by, other guideline/audit developers.</i>	Effective in generating responses Plan ahead to find relevant individuals Volume of feedback manageable	Important viewpoints may be overlooked or avoided Invited individuals may not be interested or able to respond in a timely manner
OPEN & TARGETED <i>Advertising for public members <u>and</u> seeking public members already known to guideline/audit developers.</i>	Openness and transparency Reach all relevant organisations and individuals	Overwhelmed with volume of feedback

Potential sources of bias in public invitation process

PUBLIC SELECTION	PUBLIC RESPONSE	PUBLIC ATTRITION
<p>IDENTIFICATION BIAS <i>Purposely identifying & inviting targeted public based on personal/organisational knowledge</i></p> <p>NETWORK BIAS <i>Asking others (e.g. snowballing) to suggest potential public members for involvement</i></p> <p>AWARENESS BIAS <i>Announcing an open call for involvement risks missing public with no access to the advertisement</i></p> <p>SELF-PROMOTION BIAS <i>Systematically searching for public members to involve may miss those without an online presence</i></p>	<p>AWARENESS BIAS <i>Public did not have access to the advertisement</i></p> <p>RESOURCE BIAS <i>Limited public resources (time, money) may hinder involvement</i></p> <p>ACCESS/ TECHNOLOGY BIAS <i>Public may not have ability to respond</i></p> <p>INTIMIDATION BIAS <i>Public less likely to respond if feel their views unlikely to be heard e.g. minority groups</i></p> <p>FAITH BIAS <i>May not respond if believe their views will not be heard due to failures on part of reviewers/methodology</i></p> <p>APATHY BIAS <i>May not respond if feel others will perform the role for them</i></p>	<p>COMMITMENT BIAS <i>Public unable to commit to involvement throughout the full extent of the clinical effectiveness process</i></p> <p>TIMESCALE BIAS <i>Public may leave roles/change jobs especially if there are long timescales for being involved</i></p> <p>RESOURCE BIAS <i>Limited public resources (time, money) may hinder involvement</i></p> <p>ACCESS/ TECHNOLOGY BIAS <i>Public may not have ability to respond</i></p> <p>INTIMIDATION BIAS <i>Public less likely to respond if feel their views unlikely to be heard e.g. minority groups</i></p> <p>FAITH BIAS <i>May not respond if believe their views will not be heard due to failures on part of reviewers/methods</i></p>

Some ways to reduce bias in public invitation process

PUBLIC SELECTION	PUBLIC RESPONSE	PUBLIC ATTRITION
Use several selection methods i.e. purposive, snowball, open & systematic*	Use several methods of advertisement & response modes	Avoid overtasking by phasing contact at appropriate stages
	Offer financial support	Provide multiple methods of interaction
	Be open and contactable to facilitate response from less vocal/ minority groups	Provide a supportive encouraging environment for involvement
	Emphasise that all views are valid	Provide resources to aid travel to meetings

***Purposive** = use of known contacts; **Snowball** = suggestions made by known key stakeholders; **Open** = need for stakeholder participation advertised publicly; **Systematic** = a structured/ methodical search for relevant stakeholders

Advertising involvement opportunities

When advertising public involvement opportunities consideration needs to be given to the information that is made available to the public such as:

- An involvement role and person specification
- Clarity of expectations from the public
- A structured application form for the public involvement role to enable assessment of applications according to eligibility criteria
- An outline of supports and training available to the public if they do decide to get involved.

A sample template for advertising public involvement opportunities is shown in Guidance Document 1: “Public Involvement Advertisement Template” and Guidance Document 2: “Public Involvement Application Form” at the end of this document



TEMPLATES

A sample template for advertising public involvement opportunities is shown in Guidance Document 1: “Public Involvement Advertisement Template” and Guidance Document 2: “Public Involvement Application Form” at the end of this document.



KEY MESSAGES FROM THE PUBLIC

In relation to inviting the public to be involved, the public recommend:

- **Diverse and inclusive public representation**

"Feedback should be sought on a wide scale."

"Ask more people! If one recruitment strategy doesn't work, think of another. Don't proceed until you have decent representation."

- **Clear information about getting involved i.e. – clear role description and outline of what supports and/or training is available**

"It would have been good to know what my role was, to have some training linked to my role on the guideline group and to know that I was not going to be the only PPI rep on the committee."

- **Ensure advertisements are accessible**

"Requests for feedback should possibly be advertised via forums such as social media."

"Make use of major social media mainly facebook, youtube short videos, instagram (communicate through photos or graphs, etc.)."

- **The public proofread advertisements pre-release**

"That patient participants are involved BEFORE the advertisements are made public. That all information is 'proof-read' by a lay person before going to print."

Section 2:

Methods for public involvement



SECTION 2: METHODS FOR PUBLIC INVOLVEMENT

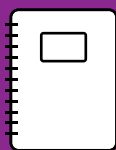
This section of the Framework presents examples of public involvement methods that may be used to involve the public in Clinical Effectiveness Processes of National Clinical Guidelines and National Clinical Audit.

The methods you select to involve the public depends on the level at which you want to engage with the public. Factors to consider are: i) your goals for public involvement, ii) the amount of interactive dialogue you want with the public, iii) the profile of the public you are seeking, and iv) your available resources and timelines. Examples of potential methods to consider are illustrated below. These methods can be delivered in different routes e.g. face-to-face, online, and/or paper-based. It is important to remember that all methods have strengths and limits and you need to select the best approach tailored to your specific public involvement goal and desired outcome in any given context. Here again, Armstrong et al's [6] framework may help you to identify public involvement methods according to your purpose for public involvement (see Appendix 1).

A multi-component approach or a *bundle* of methods can be employed to create multiple opportunities for the public to get involved across all steps of National Clinical Guideline and National Clinical Audit processes. It is important that you make the processes of public involvement clear and transparent (open) for everyone involved, especially the public.

GOAL	METHOD
Informing (level 1) <i>i.e. telling the public</i>	Leaflets, posters, etc.
Consulting (level 2) <i>i.e. listening to the public</i>	Documents, surveys, interviews, literature
Involving (level 3) <i>i.e. discussing with public</i>	Focus groups, public meetings, seminars
Collaborating (level 4) <i>i.e. working directly with public</i>	Membership – GDG, AGC, advisory panel
Empowering (level 5) <i>i.e. equal partnership with public</i>	Public co-designing and co-leading

In section I (worksheet 1) you decided your level(s) and goals of public involvement. Use worksheet 3 below to decide how you will involve the public to meet that goal. i.e. what methods of consultation and participation will you use. Use the accompanying think point to reflect on the practicality of employing the method(s) you selected.



WORKSHEET 3

DECIDING ON PUBLIC INVOLVEMENT METHODS

Informing the Public If your goal is to inform the public by sharing information with them what methods will you use to achieve this?	Answer & Explanation
Consulting the Public If your goal is to ask the public about their experience or gather their feedback on the clinical guideline/audit what methods will you use to achieve this?	Answer & Explanation
Involving the Public If your goal is to discuss and deliberate about the clinical guideline/audit with the public, what methods will you use to achieve this?	Answer & Explanation
Collaborating with the Public If your goal is to work together with the public in deciding what to do and in doing it, what methods will you use to achieve this?	Answer & Explanation
Empowering the Public If your goal is to work in equal partnership with the public, where the public can lead the way & take elements of control and responsibility, what methods will you use to achieve this?	Answer & Explanation



THINK Point!

Involvement Method

- What are your timelines for involvement, including time to invite and select public contributors?
- Will you be able to provide the support and/or training that the public might need to participate in the activity?
- What are the costs of implementing this method (e.g., costs relating to the venue, catering, travel needs, etc.)?
- What are the resource implications (e.g., availability of staff/facilitators etc.) for using this method?



KEY MESSAGES FROM THE PUBLIC

When selecting involvement methods, the public recommend:

- Considering accessibility of the method
- Using a variety of alternative methods
- Being flexible
- Making it easy for the public to be involved.

Informing the Public (Level 1)

At the lowest level of public involvement, information about National Clinical Guidelines and/or National Clinical Audit may be made available to the public, for example, through **public leaflets or posters**. Materials (leaflets and posters) designed for the public should undergo literacy checks prior to publication to ensure information is free of jargon and easily understood. The National Adult Literacy Agency (NALA) may be consulted to achieve these checks. NALA Plain English guidelines [16] at a glance recommend to:

- Think of the person reading the information
- Be direct and use the active voice
- Avoid unnecessary jargon
- Define unfamiliar abbreviations and acronyms
- Avoid Latin and French expressions
- Have an average of 15-20 words per sentence
- Remove unnecessary words and phrases
- Avoid using nouns made from verbs
- Be consistent with terms
- Break up dense text
- Use colour and images appropriately
- Use space to help text stand out
- Use a clear readable font
- Emphasise text carefully.

Consulting the Public (Level 2)

Listening to the public can involve seeking feedback on written documents, conducting research and/or reviewing research. For **feedback on written documents** the public could be asked to submit their views on publicly available draft versions of guidelines/audits. If using this method consider:

- What will be the time period for public feedback (e.g. 30 days)?
- How will draft guideline/audit documents be made publicly available (e.g. online)?
- How will the public be invited to feedback (e.g. social media, email, website, etc.)?
- What will be the response format for public feedback (e.g. open responses, structured survey, etc.)?
- How will you manage and incorporate public feedback into the clinical guideline/audit?
- What will be your process for responding to public queries/comments, if relevant?

For the **conduct and/or review of research** you could explore public experiences through hard-copy surveys, telephone consultations, or web-based consultations (such as Skype or dedicated online platforms for providing feedback), individual interviews, and/or examine systematic literature reviews and/or primary research studies to identify information gaps on public experiences to inform the National Clinical Guideline or National Clinical Audit. If developing or adapting a *survey questionnaire* consider the following [4]:

- Is the title is short and meaningful?
- Are questions short and succinct?
- Is it's colour and design visually attractive?
- Will you offer incentives for completion?
- Is return of the questionnaire easy?
- Are completion instructions clear and unambiguous?
- Do you want to use open or closed questions?
- Are the most important questions asked first?
- What are the pros and cons of electronic or had copy distribution?
- Do you need to pilot the questionnaire before distribution?

For *interviews* consider the following [4]:

- Where will interviews take place and when?
- How will you create the right interview atmosphere?
- Who are the interviewees – do you need to consider any reasonable accommodations for specific physical, cognitive, audio and visual impairments or psychosocial needs?
- How will you capture the interview data?
- What questions will you ask?
- What will you do with the interview data?
- Will any follow-up after the interview be required?

It is important to be aware of potential advantages and disadvantages of level 2 consultation methods as outlined in the table below.

POTENTIAL ADVANTAGES	POTENTIAL DISADVANTAGES
<ul style="list-style-type: none"> • Ability to effectively gather the views of a large number of public members regarding their needs, experiences, and expectations • Helps to assess public relevance of National Clinical Guidelines and National Clinical Audit and identify topics most important to the public • Method can be adapted to suit the public member e.g. when, where, how completed 	<ul style="list-style-type: none"> • One-to-one feedback between a public member and those wishing to hear their views is limited • No identification of recurring ideas that may become apparent in group discussions • Gathers individual viewpoints, rather than collective ideas



KEY MESSAGES FROM THE PUBLIC

For public consultations, the public recommend:

- Factoring in adequate time
- Providing advance notice
- Sending reminder notices when deadlines are approaching
- Planning for late submissions

Below is a **checklist** for implementing successful public consultation (level 2).



CHECKLIST for Public Consultation

PLANNING

Establish transparent consultation process	
Identify and involve the public at all consultation stages	
Determine the purpose of the consultation	
Allocate time and resources for consultation	
Devise a consultation plan with a project lead	

TIMESCALES

Consider the optimum time period for consultation	
Set up efficient administrative systems for alerting people to consultations & managing responses in a timely manner	
Provide advance notice of consultation dates	

METHOD

Identify method most appropriate for information needed	
Ensure method addresses purpose of the consultation	
Ensure method reaches those with an interest in the topic	
Ensure method allows input from range of public members, including vulnerable or under-represented groups	

GUIDANCE

Be clear on what information is being sought from the public & what questions need to be answered	
Provide guidance on what respondents might comment on	

FINDINGS & DISSEMINATION

Decide plan for analysis of data & how this will be managed	
Make comments and responses publicly available	
Document the consultation process and make it publicly available	

Involving the Public (Level 3)

Encouraging the public's active participation in Clinical Effectiveness Processes ensures the ability to foster deliberation and discussion between members of the public. **Focus groups, public meetings and seminars** have the advantage of allowing for deliberation and group consensus over clinical guideline or clinical audit content. This is particularly helpful when seeking to reach a compromise between individuals in relation to aspects of the process.

These events generally involve guided discussions of a small group of individuals, with a designated chair leading the activity. Focus groups, public meetings or seminars can be facilitated as either *once-off* sessions or several *sequential* (with the same group of individuals) or *concurrent* (with different groups of individuals) sessions in the same location. Focus groups are a popular activity for involving the public, as they are a way to facilitate group discussions about National Clinical Guidelines and National Clinical Audit. Engaging in group discussions not only ensures a greater number of views are heard, but also highlights any recurring ideas raised amongst the group.

It is important to be aware of potential advantages and disadvantages of focus groups, public meetings and seminars as outlined below.

POTENTIAL ADVANTAGES	POTENTIAL DISADVANTAGES
<ul style="list-style-type: none"> • High level of interaction • Greater understanding of how people think about issues • Accessing views of people who would not be prepared, or able, to provide written submissions • Allows the public have a greater understanding of clinical effectiveness processes 	<ul style="list-style-type: none"> • Necessary to have a skilled facilitator/ chair • Over-representation of some people • Some people may feel inhibited to speak



KEY MESSAGES FROM THE PUBLIC

For focus groups, the public recommend:

Thinking about group composition

"Separated focus groups, one group of patients and one group of health care professionals, alternatively a more balanced group."

"Focus groups should contain similar groups or equal mixtures of people from one particular background to avoid group think."



CHECKLIST for Group Discussion

GETTING STARTED

Decide whether group discussions are the right choice

Determine objectives of the group discussions

SCOPE YOUR INVOLVEMENT

Set parameters

Build a discussion group plan

Determine the number of sessions needed

Identify dates and locations

Consider virtual versus face-to-face groups

PLAN AND PREPARE

Advertise for involvement

Select representatives for discussion groups

Invite participants

Draft the discussion guide

Determine interactive exercises (if any)

Review and pilot the discussion guide

CONDUCT THE GROUPS/MEETINGS

Select and prepare chairs/moderators

Coordinate room logistics

Gather materials

Coordinate with a transcriptionist (if needed)

Chair/moderate the sessions

Debrief with chairs/moderators

Transcribe recordings (if required)

ANALYSE AND REPORT FINDINGS

Review transcripts

Determine key findings

Draft report

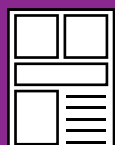
Communicate results (& planned actions) to the public

Collaborating with the Public (Level 4)

Another way to involve the public is to collaborate with them from the outset of the clinical guideline development and clinical audit process as **active members of National Clinical Guideline Development Groups (GDG), National Clinical Audit Governance Committees (AGC) or associated Public Advisory Panels**. An advantage of adopting this method is the inclusion of the public at the ideas stage of development. This method is also valuable to ensure that a feedback loop exists (i.e. between guideline/audit personnel and the public) in relation to documents developed and recommendations made. Engaging with the public collaboratively ensures they feel a valued contributor to Clinical Effectiveness Processes. Feeling valued is important for fostering lasting

partnerships into the future. It is important to be understand everyone's expectations and concerns at the outset of involvement in GDG and AGC.

A practical way to ensure that the public are involved as active members of GDG and AGC is by **mapping the expectations and concerns of all members of the GDG/AGC** at the outset of group formation. By doing so, a greater awareness of all party expectations and motivations for involvement would be clear.



TEMPLATES

A sample template for mapping everyone's expectations and concerns, and setting clear ground rules for the group, is shown in Guidance Document 3: "Template for Mapping Expectations and Concerns" at the end of this document.



KEY MESSAGES FROM THE PUBLIC

For membership on guideline groups or audit committees, the public recommend:

- Having more than one patient on the group
- Establishing clear group ground rules at the outset of the group
- Being clear on expectations
- Facilitator to ban jargon, or make sure it is explained every time.

Empowering the Public (Level 5)

At the highest level of public involvement, the public should be empowered to **co-design and co-lead** on various aspects of National Clinical Guideline and National Clinical Audit processes, for example:

- co-chairing guideline development group/audit governance committee meetings
- getting involved in co-consultation processes with the general public
- co-dissemination of guideline/audit process and impact outcomes
- designing and facilitating training/mentoring for the public
- actively involved in, or co-lead, writing guideline/audit documents or lay summaries
- acting as lay reviewers for draft clinical guidelines/audit documents.

Built on the principle that those who use a service are best placed to design it, **co-production** is a term used to refer to a way of working together where everyone works with each other on an equal basis to create a service or come to a decision that works for all (<https://www.thinklocalactpersonal.org.uk/>).

TLAP's (Think Local Act Personal) top tips for co-production, which you should consider when working in equal partnership with the public, include:

- Everyone involved should have an equal say
- The public should be involved from the very beginning
- The public should be involved in all stages of the process from planning to implementation and evaluation
- Everyone involved should have the same vision and hopes for public involvement
- Start small and build up to bigger projects, let the public lead not professionals
- Acknowledge that a range of skills are needed for working in equal partnership
- Get the right people involved, including professionals, who support working in equal partnership with the public
- The public should be clear about their expectations and be fully engaged in the process
- The public know what works so you can't get it right without them
- Allow the group to find collective solutions.

Reflecting on the points above, use the think point below to determine how you are going to support working together in equal partnership with the public.



THINK Point! **Working in Equal Partnership**

- What resources are required for the public and/or other group members (e.g. participation fees, expenses, time, flexibility)?
- What specific skills will all parties need to work in equal partnership (e.g. facilitation, listening, reflecting)?
- How will what the public say be acknowledged and respected?
- How will it be ensured that everything in the process is accessible to the public?
- How will power be shared to ensure everyone has an equal say?
- How will it be ensured that everyone's expectations are clear?

Interpersonal Communication

When collaborating with, and empowering, the public conflicting opinions and constructive challenging of decisions is expected. At such times it is important to remember the underpinning values of this Framework and ensure that dignity, respect and equality of voice are adhered to. Key messages from our public consultation in relation to managing such communication challenges are presented overleaf.



KEY MESSAGES FROM THE PUBLIC

When differences in opinion occur (and consensus on a decision is not forthcoming), the public recommend:

- Having pre-set criteria around managing different opinions or dispute resolution especially when decisions cannot be agreed
- Developing these pre-set criteria in partnership with the public, incorporating them into the group ground rules and using them as appropriate
- Having an experienced chair/facilitator to coordinate discussions
- Giving equal attention to listening to, and respecting the perspective of the public
- Having peer support available on the group for the public
- Explaining and exploring the evidence, rationale and consequences of different opinions of all parties
- Reviewing any alternatives that take account of the daily lives, and quality of life, of the public
- Once all views and options are reviewed consider the best compromise, based on the best available evidence
- Seek additional public and/or clinical input, as appropriate to help reach consensus.

Section 3:

Support and training for
involvement



Section 3: Support and Training for Involvement

Supporting the public to become involved in National Clinical Guidelines and National Clinical Audit is an essential element of this Framework. Training for the public, and guideline developers/audit personnel seeking to involve the public, is also essential for maintaining good engagement practices for involvement.

The support and training needs required by the public, and the guideline/audit developers, will depend on the goal of public involvement, what you expect the public to get involved in and the knowledge and experience of the public who get involved, and the guideline/audit developers.

At the outset of public involvement processes you need to think about, and conduct a *training and support needs assessment* (if relevant), to determine what the specific support and/or training needs of all those involved are.

This section of the Framework offers some suggestions of potential support and training needs, according to the level and method of public involvement, however these are not meant to be prescriptive. These are categorised as follows:

1. Literacy checks on public materials (level 1)
2. Ensuring accessibility (level 2)
3. Support & training for periodic involvement (level 3)
4. Support & training for sustained involvement (level 4)
5. Public Mentor/ Pairing Initiative (level 5)

Literacy checks on public materials

For level 1 - inform, all National Clinical Guideline and National Clinical Audit materials should be public friendly. For example, there should be a glossary of terms in the actual National Clinical Guideline and National Clinical Audit documents. Plain English Information should be available for the public. The National Adult Literacy Agency may be liaised with to gain Plain English Language edits on any publicised materials [16].

Ensuring accessibility

For level 2 – consult, where information is obtained from the public on draft documents, it should be ensured that all materials are accessible to the public (i.e. - easily understood). One way to do this is to create **lay versions** of documents. Lay versions are summaries of more lengthy documents or articles that are used to explain complex information to people who have no prior knowledge of the area. Examples of lay version documents could include production of plain language versions of guidelines/audits, or development of patient decision aids or education materials.

Another way to make information accessible and understood by the public is by using **jargon busters** in your documents. Jargon busters are plain language descriptions of commonly used words and phrases in a document and what they mean. These descriptions help the public navigate documents that are laden with medical terminology and complex/rare terms. Involving the public in the design of these jargon-busting materials may enhance the level of relevance and accessibility to the public.

See below for an example of a “jargon buster”.

Say what?

5 × 3 simple ways to say it better



Best practice

- The best treatment
- The safest choice
- The advice of experts



Evidence-based

- Proven
- Tried-and-true
- With a good track record



Multidisciplinary team

- Team of specialists
- Team of experts
- Doctors and nurses from many fields



Continuum of care

- Every stage of care
- The care you need over your lifetime
- The care you get from the moment you come in to the time you go home



Core measures

- Services they ranked
- Skills they tested
- Improvements we're making

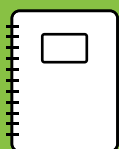
#CountOnCoffey

Support and training for periodic and/or sustained involvement

For level 3 – involve, public members may only be engaged in **periodic** involvement (e.g. as part of a focus group once a month for three months, or attending one public meeting). For level 4 – collaborate, public members may be engaged in more **sustained** (i.e. – continuous) involvement (e.g. as part of a guideline/audit development group that meet once a month for twelve months). Though public members require supports and training at both these levels of involvement, their needs may differ in terms of the level of support or training required.

To help you to determine the supports and training of the public, complete **worksheet 4** below with the public. A similar worksheet can be completed to aid support and training needs for involving the public.

The following sections of this Framework will help you consider what the support and training needs of the public are.



WORKSHEET 4 SUPPORT AND TRAINING NEEDS ANALYSIS

<p>What skills, knowledge and/or experience do the public need for their involvement role?</p>	<p style="text-align: right;"><u>YOUR ANSWER</u></p> <p><i>Skills:</i></p> <p><i>Knowledge:</i></p> <p><i>Experience:</i></p>
<p>What skills, knowledge and experience do the public have that will help them fulfil their defined involvement role?</p>	<p style="text-align: right;"><u>PUBLIC'S ANSWER</u></p> <p><i>Skills:</i></p> <p><i>Knowledge:</i></p> <p><i>Experience:</i></p>
<p>Are there any aspects of this role that the public have concerns about, or that they may find challenging?</p>	<p style="text-align: right;"><u>PUBLIC'S ANSWER</u></p> <p><i>Concerns:</i></p> <p><i>Anticipated challenges:</i></p>
<p>What is the public's preferred support and/or training method?</p>	<p style="text-align: right;"><u>PUBLIC'S ANSWER</u></p> <p><input type="checkbox"/> <i>face-to-face seminar</i></p> <p><input type="checkbox"/> <i>online based training/support</i></p> <p><input type="checkbox"/> <i>e-learning</i></p> <p><input type="checkbox"/> <i>telephone support</i></p>

Providing tailored support

Some potential different forms of support that the public might need are described below. Supports to consider for all public to be involved effectively include; practical, financial, and informal support.

Practical Support

Practical supports involve giving consideration to making reasonable adjustments to the physical environment of meetings that the public will be attending. Some examples of practical considerations, as outlined in the G-I-N PUBLIC Toolkit [14], are listed below:

- Adjustments for people with sensory impairments e.g. provide large print documents or microphones in meetings
- Booking meeting rooms large enough for an electric wheelchair to maneuver, and with stair-free access
- Adjustments for people who experience fatigue e.g. longer breaks or have a rest room
- Adjustments to lighting for people who have lupus
- Ensuring any food provided meets people's dietary needs

Use the **think point** below to consider other practical supports that may be required to ensure communication is inclusive.



THINK Point! Supports for Communication

Think about the diverse communication abilities of the public who are involved.

What additional, if any, practical supports will be needed to support communication e.g. interpreters, signers, augmentative and alternative communication tools and/or technologies such as video or tele conferences?

Financial Support

At the outset of the public involvement process, it must be decided if you will:

- I. **reimburse public members** (i.e. – payments will compensate for travel expenses and any other out-of-pocket costs), or
- II. **compensate public members** for their involvement (i.e. – payment for not only the expenses they have incurred but also for their time and effort).

Compensation may encourage more public members to become involved. The G-I-N Public Working Group [14] recommends that cost incurred by public members should at the very least be reimbursed.

You may pay expenses for travel and subsistence to individuals who work for your organisation on a voluntary and unpaid basis. The payments must not be higher than Civil Service rates for repayment of travel and subsistence expenses.

According to information from Revenue.ie, these expenses are tax-free provided:

- The organisation's functions and aims are both altruistic and non-commercial (for example registered charities)
- The expenses are needed only to allow the unpaid person to carry out his or her work
- The expenses paid are only to reimburse the person for expenses they actually incur.

If a person receives a wage, bonus or honorarium for work for a charity, they cannot receive travel and subsistence tax-free.

Reference: <https://www.revenue.ie/en/employing-people/employee-expenses/travel-and-subsistence/voluntary-work.aspx> (published 31 May 2017).



TEMPLATES

A sample template for calculating the cost of public involvement is shown in Guidance Document 4: "Template for Calculating the Cost of Public Involvement" at the end of this document adapted from INVOLVE, UK, Involvement Cost Calculator.

Informal Support

Consideration should be given to providing informal support to public members during their involvement throughout Clinical Effectiveness Processes. Public needs will vary widely from individual to individual. For example, one person may have participated in Clinical Effectiveness Processes previously, whereas another person may be entering this experience for the first time and be naturally apprehensive about the process.

Supports may change and fluctuate over time (e.g. – a public member may be in need of greater emotional and/or psychosocial support following a particular guideline/audit group meeting in which sensitive issues were discussed). Tailoring support to the needs of each individual can help people to make valuable contributions. Some strategies for providing informal support to the public are outlined below.

Private meeting with public member(s): Aim to talk with each public member separately at the initial meeting of the guideline development or clinical audit group. This will provide an opportunity to understand what additional supports they may need.

Dedicated public liaison contact point: Appoint a dedicated public liaison contact point who the public member(s) can contact with any queries or concerns. The liaison point responsible for providing tailored support for public members should be in contact with them before the first meeting of the group, and may consider attending the first meeting. Following this, this person should aim to phone or to email each member periodically to make sure that their experience is favourable and no problems have arisen. Make this contact point clear to all public members so that they feel fully supported in their involvement.

External support organisations: Link all public members to appropriate support organisations outside of the public involvement process, as relevant.



KEY MESSAGES FROM THE PUBLIC

For support, the public recommend:

“Have plain English information.”

“Version of guideline for lay community.”

“Provide jargon busters if some technical terms are hard to avoid” and/or “a glossary of terms appended [to the guideline].”

“Make sure they have met the facilitator before so they feel comfortable asking questions.”

“A link person to run through information, expectations etc.”

Providing tailored training

Both members of the public, and guideline developers/audit personnel seeking to facilitate public involvement in Clinical Effectiveness Processes, could benefit from tailored training.

This training could pertain to different areas for each group. For example, for public members, training could be in technical areas such as how to understand clinical terminology (such as the processes of National Clinical Guideline or National Clinical Audit development) or around how to assert one's voice within a group effectively. On the other hand, tailored training for public involvement facilitators could include how to design lay descriptions of materials, and how to effectively chair a group session (ensuring that all voices are heard). Further examples of training areas may include:

- Training to understand clinical guidelines
- Training to understand clinical audit
- Training in communication/facilitation skills
- Training in public-speaking
- Training in presentation skills.

Training could be delivered in various formats, e.g. - face to face workshops/seminars, online based support/webinars, e-learning, telephone support, etc.



TEMPLATES

A sample template for a Public Involvement Training Workshop is shown in Guidance Document 5: “Template for Public Involvement Training Workshops” at the end of this document.

Use the **think point** below to brainstorm some things you need to consider prior to developing tailored training for your group.



THINK Point! Providing tailored training

Location of training

In-house, out-of-house, or self-directed (e.g. web-based)

Timing of training

Once-off, periodic or ongoing

Facilitator of training

Internal or external facilitator

Cost-effectiveness and time-consumption

Logistics of delivering various training approaches

Public Mentor/Pairing Initiative

In addition to training, or as an alternative to training (if this is not deemed feasible), it may be possible to provide a public involvement mentorship for public members who are new to the processes of National Clinical Guideline and National Clinical Audit. This initiative can be organised before public members start on a group and continue to provide a source of support whilst groups are ongoing. Public members may be willing to support each other, and having someone who has been through the process previously to talk to could be a valuable source of help and support. This mentorship would involve providing people with contact details for other public members involved in Clinical Guideline and/or Clinical Audit processes. Check what details people are willing to share with strangers and never give out personal details without explicit permission.

Below is a **checklist** for potential supports and training for public involvement. Use this to keep track of each step as it is completed and/or considered.



CHECKLIST

Support and Training

LITERACY CHECKS	
Include glossary of terms in guideline/audit documents	
Make Plain English information available to the public	
Liaise with NALA for Plain English edits, as required	
ENSURING ACCESSIBILITY	
Ensure all materials are easily understood	
Create lay versions of guideline/audit documents	
Use jargon busters in documents	
SUPPORT & TRAINING FOR PERIODIC & SUSTAINED INVOLVEMENT	
Complete needs analysis to determine support & training needs of public and guideline/audit personnel	
<i>Practical Supports</i>	
Provide fact sheets & large-print documents as needed	
Make reasonable adjustments to physical environment of meetings, as required	
Ensure wheelchair access	
Incorporate long breaks & access to a rest room	
Assess dietary requirements	
Provide support for inclusive communication as needed	
<i>Financial Supports</i>	
Reimburse the public for expenses	
Compensate the public for time & effort, as appropriate	
<i>Informal Supports</i>	
Consider need for emotional/psychosocial support	
Hold a private meeting with public member	
Appoint a dedicated public liaison contact point	
Link to independent external support organisations	
<i>Training</i>	
Host a training workshop or seminar	
Pair the public with a public mentor	

Section 4:

Informing and educating via
involvement



Section 4: Informing and educating via involvement

This section outlines how the public might be informed and educated about the outcomes and recommendations of National Clinical Guideline and National Clinical Audit processes; including how the public might be involved in such dissemination.

The most common approach to inform and educate the public about National Clinical Guideline and National Clinical Audit outcomes and recommendations is through the ***design of lay versions of guidelines/audits***.

To develop lay versions you need to think about how you are going to design and disseminate the lay version of the guideline/audit.

In line with this Framework's five levels of public involvement, you need to consider, if and, how the public will be involved in this design and dissemination process.

For instance:

- Make lay versions of the guideline/audit available to the public (level 1)
- Gather feedback from the public on designed lay versions of guideline/audit (level 2)
- Discuss designed lay versions of guideline/audit with the public (level 3)
- Design lay versions of guideline/audit with the public (level 4)
- Facilitate public to co-design lay versions of guideline/audit, and co-disseminate public involvement outcomes (level 5)

Ideally, lay versions of National Clinical Guideline and National Clinical Audit for the public should be developed with and/or by the public (*i.e. level 4 collaborate & level 5 empower*) in order to ensure understanding, focus, relevance, and acceptability of the documents prior to dissemination.

When considering dissemination of the National Clinical Guideline or National Clinical Audit outcomes to members of the public, it may be beneficial to use media releases (e.g. – via online resources, such as the Department of Health Website). The Guideline International network (G-I-N) PUBLIC Working Group and the Scottish Intercollegiate Guideline Network (SIGN) advocate for directly involving the public in media releases [14, 18]. This provides a platform for personal stories to be told and can help to raise awareness of guideline and/or audit recommendations.

Guidance for Designing Lay Versions

Lay versions of National Clinical Guideline and National Clinical Audit should reflect precisely what is contained in the finalised documents, in a comprehensible format.

Since National Clinical Guideline and National Clinical Audit include recommendations about what should or should not be provided or done, the precise recommendations should not be lost when producing lay versions.

Additional information may be included if it helps to foster an understanding of the recommendations.

Some important items to include in lay versions are outlined in the table below.

Context	Who is the information for?
Background information about the condition	What are the risk factors? How will the condition progress? How long will the condition last? What is the risk of other problems arising from the condition?
Information about treatment interventions	What are the treatments, including the alternatives? What are the risks associated with treatments? What can I do for myself (i.e. self-management)?
Sources of further information	For example, providing phone numbers and website for sources of support
Information on how materials were produced	A major challenge when producing versions of guidelines/audits for the public is presenting information on benefits and harms in a way that is easy to read and not too complex. Although the public may not want too much information about the research evidence, it must be presented in a way that is easily understood and can enable people to make informed choices.

Below is a **checklist** for developing lay versions of materials.



CHECKLIST for Lay Versions

Is the lay version transparent? Have you declared any financial and intellectual conflicts of interest?	
Has the lay version been developed with the public?	
Is this lay version based upon an assessment of the available evidence?	
Are the levels of evidence and strength for recommendations in the lay version appropriately communicated?	
Is a realistic idea of the condition conveyed?	
Are all options (with benefits and risks) described?	
Does the lay version ensure a person-centred outcome? (Will the public be able to make informed decisions on the basis of information in this version?)	
Considering the communication of any potential risks – Are the benefits and harms described with absolute numbers rather than with percentages?	
Has the lay version been deemed understandable by members of the public?	
Has the lay version been approved by NALA?	
Will the lay version be accessible to all members of the public?	

Hosting a Public Event

Another option for disseminating the outcomes of development groups and/or consultations is hosting a dedicated public event. Whilst this is a more time-consuming option, it will foster a greater level of discussion around the newly available materials, and may raise a greater level of awareness surrounding their use.

Considerations for hosting a public dissemination event include:

- The location of the event
(*In-house or external location*)
- Recruitment of a discussion panel for the event
- Who to invite to the event
(*Solely members involved in the relevant guideline/audit groups or members of relevant public organisations*)
- Reimbursing public members for attendance.

Below is a **checklist** to help you plan a public event.



CHECKLIST for Public Event

BEFORE THE EVENT	
Involve public member/s in planning the event	
Determine objectives for the event	
Develop advert & decide how to reach a diverse audience	
Decide on what methods and visuals to use for the event	
Create an agenda, event outline & facilitator materials	
Develop briefing materials for event attendees	
Consider logistics e.g. budget, venue, catering, accessibility, facilitators, timelines	
Have a key contact person for the event	
Develop event evaluation (attendees) and debriefing (facilitators) forms	
DURING THE EVENT	
Attend to room layout for interactive discussion	
Set up refreshments/catering as appropriate	
Prepare registration desk	
Set up visual materials/presentations (check IT working)	
Display signs to venue/room	
Have an event outline – timing, facilitator(s), activities, breaks	
Hand-out any briefing materials	
Distribute event evaluation forms to attendees	
AFTER THE EVENT	
Analyse attendees feedback from event evaluation forms	
Ask facilitators to complete event debriefing form	
Process any expenses or payment recognition	
Send post event thank you email/letter to attendees, summarise key points from the day, acknowledge feedback and signpost other involvement opportunities	



KEY MESSAGES FROM THE PUBLIC

The public recommend:

- Fully involving the public in a participatory role in all dissemination processes

"I would like to help with preparing a speech for the event."

"I think they [public representatives] should have a more concrete role in the dissemination of the group findings and not just in delivering their own personal story."

- Giving the public an opportunity to discuss their involvement in National Clinical Guideline and National Clinical Audit processes

"I think they [public representatives] should also have been given the opportunity to discuss their involvement in the national clinical audit strategy process. This is an ideal opportunity to explain to other PPI participants what is involved, how they found the experience, and why they would (or would not) encourage others to participate in a similar way."

Section 5:

Evaluating Public Involvement



Section 5: Evaluating Public Involvement

It is important to evaluate the impact of public involvement in order to embed public involvement in National Clinical Effectiveness Processes and contribute to sustained improvement ensuring that the public have a real influence in the decision-making process. To be meaningful, public involvement in National Clinical Effectiveness Processes should make a difference.

The Irish Health Service Executive highlight a need to ensure a ‘*process*’ and ‘*outcome*’ evaluation of how public involvement practices are carried out.

- **Process** evaluation (i.e. effectiveness or success of the involvement process) will help improve public involvement practices.
- **Outcome** evaluation (i.e. evidence of change or improvement) will help determine the degree to which involving the public impacts on the guideline/audit and wider health services.

This includes reporting back to the public to highlight how their involvement was incorporated into the decision-making process, and to show the wider public community how public involvement shaped the guideline and/or audit process.

It is important to include all perspectives in the evaluation of public involvement, not just the public themselves.

You will need to decide when to evaluate public involvement impact. Ideally, evaluation occurs as soon as the clinical guideline development or clinical audit process starts to establish baseline data from which impacts can be assessed. Some impacts can be assessed throughout the involvement process and others at the end.

In evaluating public involvement you need to consider what your intended goals and outcomes were for public involvement, and you will need to have a clearly documented map of your involvement practices to enable you to evaluate them.

You will need to think about what is the purpose of your evaluation, what it is that you want to evaluate and what information you will need to collect.

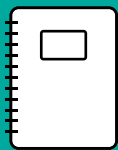
Deciding what public involvement impact(s) to evaluate

Use **worksheet 5** below, from the Public Involvement Impact Assessment Framework (PiiAF) [19] (guidance for research) to help formulate the specific question(s) you want your impact evaluation to answer.

An illustrated example is provided in the first row where researchers wanted to assess whether:

- Involving young people (WHO?)
- In advisory group discussions to help develop outcome measures (HOW?)
- Produced evidence seen as more credible and relevant by young people (WHAT?).

Use the questions in the accompanying **think point** to consider what to evaluate e.g. value, public representativeness, success of methods, impact and learning for the future.



WORKSHEET 5
WHAT QUESTIONS DO YOU WANT YOUR IMPACT EVALUATION TO ANSWER?

WHO? <i>(e.g. engaging with young people)</i>	HOW? <i>(e.g. via an advisory group helping to select appropriate outcome measures)</i>	WHAT? <i>(e.g. lead to evidence that is perceived to be more credible and relevant by a range of stakeholders)</i>



THINK Point! Public Involvement – What to evaluate

Value

- How did the public feel about their contribution?
- Did the public feel valued as part of the team?
- How did everyone feel about the process of public involvement?

Public Representativeness

- Were the public who got involved representative of those affected by the guideline/audit?
- Were there any public groups or interests not represented?

Success of methods

- Were the public involvement methods successful?
- How clear was the public role in the process?
- How do the public rate the support and training they received for their involvement?

Impact

- Was information collected from the public used to inform the guideline/audit?
- What actual difference(s) did the public make to the guideline/audit process, activities and/or end result?
- What difference did involvement of the public make beyond the guideline/audit process and activities itself?

Learning for the Future

- What challenges were encountered to involving the public, and how were these overcome?
- What advice would you give to others for involving the public in the future?

Deciding what approach to use to evaluate public involvement impact

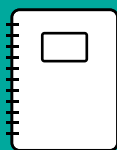
Once you decide what it is you want to evaluate you need to decide how you will gather information taking account of resources and timelines.

Use **worksheet 6** below, from the PiiAF [19] to help you move from your evaluation question(s) to decisions on evaluation design and methods.

These decisions will be determined by the purpose of your evaluation and the questions you want to answer.

PiiAF recommends that you should ideally aim to identify particular impacts, quantify them where appropriate and explore the processes leading to them. To do this a mixture of qualitative and quantitative methods and data would be required.

The next section of this *Evaluation Framework* offers some suggestions of potential methods, measures and indicators for evaluating public involvement at different levels, these are not meant to be prescriptive.



WORKSHEET 6

WHAT APPROACH WILL YOU USE TO EVALUATE PUBLIC INVOLVEMENT?

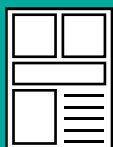
What is your public involvement goal(s)? <i>(What is your public involvement intended to achieve?)</i>	What is your Impact Evaluation Question(s)? <i>(Think about: 'Who', 'What' and 'How')</i>	What design will you use? <i>(What design is required to address your impact question(s), e.g. qualitative, quantitative, or mixed methods?)</i>	What data collection methods will you use? <i>Where will you collect the data from and how will you collect it, e.g. interviews, or questionnaires?</i>	What impact measures or indicators will you use? <i>How will you assess whether an impact has been achieved?</i>

Feedback on Public Involvement Experiences

One approach you might employ to evaluate public involvement experiences is to gather accounts of the experiences of the public who were consulted and involved.

You could explore experiences qualitatively and/or quantitatively by gathering data through interviews or survey questionnaires about how the public felt about level of involvement, what they thought about the involvement process (both positive and negative), the difference their involvement made and recommendations for making things better for consulting and involving the public in the future.

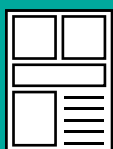
Public feedback could be gathered using an open-ended evaluation template which would allow the public to tell their involvement story. The public will often have innovative recommendations for effective involvement that guideline developers and audit personnel may not have previously thought of.



TEMPLATES

A sample template for gathering public involvement experiences is shown in Guidance Document 6: “Template for Public Feedback on Involvement Experience” at the end of this document.

Alternatively, a survey questionnaire with a series of both open- and close- ended questions could be employed. “How did we do when we involved you” [20] is an example of a survey questionnaire that can be applied to gather feedback about public experiences of being involved in Clinical Effectiveness Processes. This questionnaire assesses how the public felt about being informed, listened to, taking part and what difference their involvement made.



TEMPLATES

Adapted with permission [20], a sample template for the “how did we do when we involved you” public involvement evaluation is shown in Guidance Document 7: “Template for Survey Questionnaire for Public Contributors” at the end of this document.

Discussing Public Experiences of Involvement

Rather than simply gathering information from the public about their involvement experiences; guideline developers and audit personnel may wish to organize a dedicated feedback event, or workshop, in which the public can discuss their experiences of being involved.

This interactive event/workshop could act as a “thank you” to the public for their valuable contributions and could act as a catalyst for evaluating the impact that public involvement practices had on not only the public who took part but also the GDG/AGC members.

This would enable exploration and discussion about the benefits for the public, and for the organisations involved and wider health services, of working together, alongside discussions about what worked well within the public involvement approach used, and what did not (i.e. – what could have been done differently, and what could have been improved upon).

Use the **think point** below to help you develop a semi-structured topic guide for your discussions with the public about involvement practices.



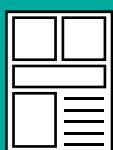
THINK Point! Discussing public involvement practices

- What are the main lessons we have learnt about public involvement/working together?
- What were the most successful aspects of (working together) our public involvement practices, and why?
- What were the least successful aspects of (working together) our public involvement practices, and why?
- What should we never do again, and why?
- What were the most significant changes, improvements or impacts of (working together) our public involvement practices, and why?
- What can we do to make (working together) our public involvement practices better/more successful?

Partnering with the Public for Improvement

It is important to view the evaluation of public involvement practices as essential for making lasting improvements in public involvement. Effective evaluation also allows for the **establishment of public member** panels for future involvement opportunities, thus encourages partnership between organisations and public contributors.

Those seeking to engage in public involvement activities are encouraged to evaluate the approach undertaken, paying particular attention to feedback received from the public, but also their self-evaluation of the process. Identifying the strong points of an approach and what could be done better in the future allows for **continued improvement**. By publishing such materials, other stakeholders and organisations can also learn what may be deemed as best practice in the area.



TEMPLATES

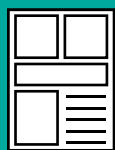
A sample template for identifying areas of improvement is shown in Guidance Document 8: "Identifying Areas for Improvement" at the end of this document.

Using **indicators** to measure public involvement practices can help identify areas for improvement. The European Patient's Forum [20] outlines key indicators for meaningful patient involvement which can be adapted to evaluate public involvement in CEPs.

These key areas are:

- Public involvement at the beginning and throughout the process in planning and decision making
- Co-operative working with other parties, supported by a clear understanding of each other's roles
- Providing information and support for public involvement, including clear communication about the process itself
- Monitoring and evaluation of public involvement from the perspective of all the partners
- Evaluation of the process results and impact, identifying how public involvement has enhanced the results/outcomes.

The European Patient's Forum [20] developed these indicators into a detailed Assessment Grid to assess meaningful public involvement practices. This evaluation should include the perspective of everyone involved, not just the public. While acknowledging that some indicators will be unable to be assessed until process completion, the European Patient's Forum recommends that evaluation takes place throughout the involvement process so ongoing adjustments can be made if necessary.



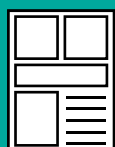
TEMPLATES

Adapted with permission [20], a sample template for assessing meaningful public involvement is provided in Guidance Document 9: “Template for Assessment of Indicators of Meaningful Public Involvement for all Parties” at the end of this document.

Reporting Public Involvement Practices

An important part of this Evaluation Framework is for you think about how you will report and disseminate your public involvement practices including your evaluation of those practices.

This might involve completion of a report at the end of a public involvement activity and/or at the end of a completed process such as completion of the National Clinical Guideline/ National Clinical Audit process.



TEMPLATES

Adapted with permission [21], a sample template for reporting on public involvement is provided in Guidance Document 10: “Record of Public Involvement Practice/Activity Template” at the end of this document.

All reports on public involvement activities and practices could be collated into an NCEC Annual Report on Public Involvement Practices. This would provide a transparent overview of public involvement practices and activities with overall learning highlighted, and recommendations for future practices outlined. To assist with recording public involvement practices and/or activities a database or register could be set up which would enable the NCEC to measure improvements over time.

The public contributors might also want to record and keep track of their involvement practices and activities. The NHS Research and Development Forum Service User and Carer Working Group [22] have developed an Involvement Portfolio that could be used by the public to record, provide evidence of, and reflect on their level of involvement experiences, training events attended, skills acquired, committee membership etc. Its use is voluntary and it is up to the public how they use the portfolio and what they record.

The Involvement Portfolio is available from: www.rdforum.nhs.uk/content/working-groups/service-user-carer-working-group/involvement-portfolio.



CHECKLIST for Evaluation

PUBLIC INVOLVEMENT IMPACT(S)	
Decide on what public involvement impacts to evaluate	
Consider process evaluation impacts	
Consider outcome evaluation impacts	
Decide on the specific questions you want your impact evaluation to answer	
EVALUATION DESIGN & METHOD(S)	
Decide on what design you will use (e.g. qualitative)	
Decide on what method/s you will use (e.g. interviews)	
Consider resources & timelines for evaluation	
Decide on impact measures, indicators to use (see below)	
EVALUATION MEASURES & INDICATORS	
Feedback on public involvement experience	
Open-ended evaluation to hear public involvement story	
Survey questionnaire for public contributors	
Discussing public experience of involvement	
Open public feedback event or workshop	
Develop semi-structured topic guide for public event	
Partnering with the public for improvement	
Identifying areas for improvement	
Indicators of meaningful public involvement for all parties	
REPORTING & DISSEMINATION IMPACT(S)	
Complete record of public involvement practices	
Invite the public to maintain involvement portfolios	
Disseminate involvement process & outcome impacts	



KEY MESSAGES FROM THE PUBLIC

The public recommend:

- Contact early for feedback
"Feedback should be sought as soon as possible....close to the time of involvement."
- Tell the public beforehand about feedback
"To be told at the start of the process that feedback will be sought and the Guideline Development Group is keen to learn from experiences."
- Highlight the value of feedback
"The importance of the feedback needs to be strongly outlined."
- Use different feedback mediums
"Variety of different options to provide feedback."
- Show the impact of public involvement
"I would like to know how my participation in the focus group influenced the guideline."

Final thoughts



Final thoughts

This Framework is a resource for you to think about, plan, implement and evaluate involvement of the public throughout the Clinical Effectiveness Processes of National Clinical Guideline and National Clinical Audit.

For the final **think point** of this Framework we draw on the **4Pi Standards for Involvement** developed by the National Involvement Partnership (NIP) project, a partnership of organisations hosted by the UK National Survivor User Network [23].

These 4Pi standards reflect the stages of this framework. After navigating through this Framework you should be able to answer the questions: in the following **think point**.



THINK Point! Standards for Involvement

Principles: Is everyone clear on and committed to shared principles and values for involving the public? (*Section I*)

Purpose: Is everyone clear on why the public are being involved, clear on the purpose and outcomes of involvement that you are aiming for? (*Section I*)

Presence: Is everyone clear on who (public) needs to be involved and what role they will play? (*Section I*)

Process: Does everyone know how the public will be involved, including what supports and training will be required? (*Section II, III, IV*)

Impact: Is everyone clear on what the intended outcomes of involvement are, what difference do you hope involvement will make and how the success of public involvement will be evaluated? (*Section V*)

Additional resources

For information about service user involvement in the HSE please view the web page “You and your Health Service” www.hse.ie/eng/services/yourhealthservice/Documentation

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Appendices



Appendix 1: Steps, purpose & methods for public involvement in CEPs (adapted from Armstrong 2016)

Step in process	Purpose of public involvement	Methods of public involvement
1. Nominating topics for guidelines or audit	<p>Identify topics that are important to the public</p> <p>Propose topics to be investigated</p>	<p>Directly solicit topic nominations from the public</p> <p>Solicit topic nominations from patient advocacy groups</p> <p>Review priorities published by patient advocacy groups</p> <p>Review research on patients' priorities and needs</p>
2. Prioritizing topic nominations for guidelines or audit	<p>Solicit feedback on relevance and priority of topics</p> <p>Discuss the urgency of addressing topics</p>	<p>Survey patient groups</p> <p>Review research on patients' priorities and needs</p> <p>Engage patients on committees determining priorities*</p>
3. Selecting group members for guideline or audit development or governance	<p>Help ensure that the composition is both representative and trustworthy</p> <p>Assess conflicts of interest of panel members from public perspective</p>	<p>Review proposed panel members' conflicts of interest</p> <p>Approve proposed panel with ability to suggest changes</p> <p>Directly engage the public on selection of guideline development group and audit governance committee members*</p>

Step in process	Purpose of public involvement	Methods of public involvement
4. Framing the questions or standards (including selection of comparators and outcomes for guidelines; and selection of target measures for audit)	<p>Ascertain questions' relevance and usefulness</p> <p>Assess 'real-world' applicability</p> <p>Identify outcomes of relevance to patients, caregivers, and the community</p> <p>Incorporate other aspects of treatment</p>	<p>Perform focus groups on identified prioritised topics</p> <p>Review existing research on patients' priorities and opinions</p> <p>Solicit public comment on topics prior to formalization of questions or standards</p> <p>Ask stakeholders to suggest materials about patient preferences that are not formally published ('grey literature')</p> <p>Survey patients to rate importance of proposed processes or outcomes</p> <p>Post draft guideline/audit plan for public comment/review</p> <p>Directly engage the public on guideline/audit groups*</p>
5. Creating the plan for the guideline development / audit process	<p>Clarify the context for the guideline and audit in relation to national priorities</p> <p>Help refine or expand scope of the guideline / audit</p> <p>Verify or supplement topics with additional factors not documented in literature related to burden of the clinical topic, variability in practice, the potential for health improvements and / or feasibility of implementation of the guideline/audit</p>	<p>Review existing research on patients' priorities and opinions</p> <p>Survey patients to rate importance of elements of proposed guideline/audit</p> <p>Post draft guideline/audit plan for public comment/review</p> <p>Perform focus groups</p> <p>Directly engage patients, caregivers and advocates on GDGs*</p>

Step in process	Purpose of public involvement	Methods of public involvement
6. Developing systematic review and forming conclusions on quality of evidence for guideline or audit standard	<p>Assist with critical appraisal of studies and evidence synthesis</p> <p>Assess believability of results</p> <p>Suggest alternative interpretations of evidence</p>	<p>Solicit feedback on draft evidence review from guideline development group</p> <p>lay participants even if they did not participate in analysis of evidence</p> <p>Post draft evidence review for public comment</p> <p>Directly engage public on guideline/audit groups*</p>
7. Developing recommendations or standards for guidelines and audit	<p>Assist in translating evidence-based conclusions into meaningful, clear, and respectful recommendations or measureable standards</p> <p>Assist in ensuring that recommendations or standards foster partnership between physicians, patients and families</p> <p>Describe variability in patient/public preferences</p> <p>Help make recommendations or standards easy to understand</p> <p>Provide input when there are gaps in the evidence</p> <p>Indicate which recommendations or standards are counterintuitive (e.g. so that additional explanation can be provided)</p>	<p>Review existing research on patients' preferences</p> <p>Post draft recommendation statements or standards for public comment</p> <p>Perform focus groups</p> <p>Directly engage public on guideline/audit groups*</p>

Step in process	Purpose of public involvement	Methods of public involvement
8. Disseminating and implementing recommendations or standards for guidelines and audit	<p>Endorse guidelines or audit from the public perspective</p> <p>Assist in developing lay summaries of systematic review findings, guideline recommendations and audit standards and findings</p> <p>Assist in developing patient decision aids</p> <p>Identify barriers to implementation of guideline or audit recommendations or standards and suggest possible solutions</p> <p>Facilitate involvement of other public members in Dissemination</p> <p>Improve legitimacy and trustworthiness of guideline or audit process such that recommendations or standards are more likely to be implemented</p>	<p>Consult the public regarding barriers to dissemination and implementation and identifying solutions</p> <p>Directly involve the public in developing lay summaries and patient decision aides*</p> <p>Engage the public in dissemination strategies</p>
9. Updating	<p>Identify when public or other stakeholder views have changed such that a guideline or audit requires update or reaffirmation</p>	<p>Solicit public views regarding when guidelines or audit need updating (e.g. on websites)</p> <p>Include public in formal review of evidence regarding guideline or audit currency*</p>
10. Evaluating methods and impact of involvement	<p>Identify if public were engaged in a meaningful way</p> <p>Suggest options for improvement in future involvement strategies</p>	<p>Provide feedback regarding involvement experience</p> <p>Discuss feedback from the involved public (e.g. verbal, survey)</p>

*May require additional training

Guidance Documents



GUIDANCE DOCUMENTS

Guidance Document 1: Public Involvement Advertisement Template

Become a Public Representative

Is being a public representative right for you?

Being a public representative maybe a good match with your skills and experiences if you can:

- Speak up and share suggestions and potential solutions to help improve healthcare services for others
- Talk about your experiences as a member of the public – but also think beyond your own personal experiences
- Talk about both positive and negative healthcare experiences and share your thoughts on what went well and how things could have been done differently
- Work with people who may be different than you
- Listen to and think about what others say, even when you disagree
- Bring a positive attitude to discussions
- Keep any information you may hear as an advisor private and confidential

What is the role of a public representative?

A public representative is someone who:

- Wants to help improve the quality of our healthcare for all members of the public
- Gives feedback based on their own experiences as a member of the public
- Helps us plan changes to improve how we take care of people
- Volunteers their time typically (usually at least 1 hour and not more than 4 hours per month)
- Public representatives provide a voice that represents all members of the public, who receive care
- They partner with hospital doctors, nurses, and administrators to help improve the quality of our healthcare delivery for everyone

Why should you become a public representative?

- Do you have ideas about how to make sure the public get the best care possible?
- Public representatives give feedback and ideas to help improve the quality and safety of health care

Who can be a public representative?

- You do not need any special qualifications to be a public representative.
- What's most important is your experience as a member of the public. We will provide you with any other training you need and you will be reimbursed for any travel expenses.

For more information about being a patient/public representative:

To get more information or to find out how to apply:

Call: [Insert contact name and phone number]

Email: [Insert contact name and email address]

Join us! Together we can work to make our healthcare service the best it can be.

Guidance Document 2: Public Involvement Application Form

Public Representative Application Form

Name (First and last):

Street Address:

City/County: _____

Home phone: _____

Mobile phone: _____

Email address: _____

Preferred contact (Tick one):

Home phone

Mobile phone

Email

The following questions will help us get to know you better.

1. Are you a ... (Tick all that apply)

Patient

Family member of a patient

Member of the public

2. What language(s) do you speak?

3. We recognise that our public representatives have busy lives. How much time are you able to commit to being a public representative? (Tick one)

Less than 1 hour per month

1 to 2 hours per month

3 to 4 hours per month

More than 4 hours per month

4. Why do you want to become a public representative?

5. Please briefly describe any experience you may have as an active volunteer or as a public speaker.

6. Our public representatives reflect the diversity of the members of the public we serve. Please share anything about yourself that you think would add to the diversity of our team of representatives.

Please return this form to: [insert public representative liaison name and contact information]

Guidance Document 3: Template for Mapping Expectations and Concerns

Mapping Expectations and Concerns

For completion by all members of National Guideline Development Groups and National Clinical Audit Governance Committees at the outset of group formation

Please answer the following questions in relation to your expectations of being involved in the Clinical Guideline/Audit group.

What would the group look like if everything went as you hoped?

What would the group look like if it went pear-shaped?

What issues/concerns have you got about being a member of this group?

What actions do you need to take to ensure a positive outcome?

Our Ground Rules are:

✓
✓
✓
✓
✓

Guidance Document 4: Template for Calculating the Cost of Public Involvement

Public Involvement Cost Calculator

Use this template to calculate the approximate cost of the level of public involvement (and associated supports) you wish to implement.

<http://www.invo.org.uk/resource-centre/payment-and-recognition-for-public-involvement/involvement-cost-calculator/>

**Quantity is the number of each item you need and cost (each) is the cost of a single item.*

PAYMENT AND REWARD			
<i>Payments and rewards for members of the public in recognition of time skills and expertise.</i>			
Fees to individuals <i>It is good practice to offer a fee to individuals for their involvement. What rate is most suitable for the role they will have?</i>	Quantity:	Cost (each): €	Total: €
Vouchers or tokens for individuals <i>Do you want to offer people vouchers or tokens for their involvement? These are sometimes used for one off activities and for children and young people.</i>	Quantity:	Cost (each): €	Total: €
Other rewards for individuals (e.g. prize draw) <i>Would an incentive such as a prize draw be appropriate?</i>	Quantity:	Cost (each): €	Total: €
Fee or donation to a group or network <i>If you are working with a partner or service user group, can you offer a financial reward to the group?</i>	Quantity:	Cost (each): €	Total: €
Funding for additional training and learning <i>Can you fund additional training or learning for the people getting involved as a reward? This would be in addition to any training or learning required for their role.</i>	Quantity:	Cost (each): €	Total: €
TOTAL FOR PAYMENT AND REWARD:			€
EXPENSES			
<i>Out of pocket expenses that the public will incur by getting involved.</i>			
Travel <i>What travel costs will you need to cover to ensure people can get involved?</i>	Quantity:	Cost (each): €	Total: €
Subsistence <i>Do you need to cover the costs of any meals, snacks and refreshments if people will be away from home for a half day or more?</i>	Quantity:	Cost (each): €	Total: €

Childcare <i>Do you need to budget for covering the costs of childcare for the people getting involved?</i>	Quantity:	Cost (each): €	Total: €
Carer costs <i>Do you need to budget for any replacement carers for the people getting involved? This will be especially important if involving people with caring responsibilities</i>	Quantity:	Cost (each): €	Total: €
Personal assistants <i>Do you need to budget for the costs of personal assistants or support workers for any people with disabilities getting involved?</i>	Quantity:	Cost (each): €	Total: €
Overnight accommodation <i>If people are traveling a distance or involved over a number of days, will you need to budget for the costs of their overnight accommodation?</i>	Quantity:	Cost (each): €	Total: €
Administrative costs e.g. printing and postage <i>Will you need to think about any home office costs, such as telephone calls, postage or printing for the people getting involved?</i>	Quantity:	Cost (each): €	Total: €
TOTAL FOR EXPENSES:			€
INVOLVEMENT ACTIVITY <i>The cost of the specific activities for involving members of the public.</i>			
Finding people <i>How are you going to find people to get involved? Will there be any costs to cover, such as advertising or interviews?</i>	Quantity:	Cost (each): €	Total: €
Training and learning costs <i>What training and support will you need to offer to enable members of the public to be well prepared and effective in their role?</i>	Quantity:	Cost (each): €	Total: €
Venues and catering <i>If you have events or meetings planned, what are the costs of an accessible venue?</i>	Quantity:	Cost (each): €	Total: €
Equipment and books <i>Do you need to provide any equipment or books for the involvement?</i>	Quantity:	Cost (each): €	Total: €
Access to facilities (e.g. seminar rooms, teleconference phones, training course access) <i>Will there be any costs for members of the public to have access to you organisational facilities?</i>	Quantity:	Cost (each): €	Total: €

Conferences fees <i>How much will it cost for the involved members of the public to help with dissemination at any events/conferences?</i>	Quantity:	Cost (each): €	Total: €
TOTAL FOR INVOLVEMENT ACTIVITY			€
INVOLVEMENT STAFFING <i>Costs of any staff required to carry out involvement in clinical effectiveness processes</i>			
Administrative support <i>Do you need to think about additional administrative support? This can be useful for managing payments and expenses for members of the public.</i>	Quantity:	Cost (each): €	Total: €
Involvement coordinator <i>Do need a dedicated Public Involvement Coordinator for your project?</i>	Quantity:	Cost (each): €	Total: €
Independent facilitator <i>Do you need an independent facilitator or other person with specialist expertise in engaging with the public?</i>	Quantity:	Cost (each): €	Total: €
Peer interviewers <i>If you are working with peer interviewers, how are you going to cost for their time – on a sessional basis or as contracted employee?</i>	Quantity:	Cost (each): €	Total: €
TOTAL FOR INVOLVEMENT STAFFING			€
OTHER COSTS <i>Any other costs of the involvement.</i>	Quantity:	Cost (each): €	Total: €
Language translation and interpretation costs <i>Will you be working with groups and people who speak a different language?</i>	Quantity:	Cost (each): €	Total: €
Support for people with impairments <i>Will you need to provide support for people with impairments to enable them to get involved?</i>	Quantity:	Cost (each): €	Total: €
TOTAL FOR OTHERS COSTS			€
TOTAL FOR PUBLIC INVOLVEMENT APPROACH			€

Guidance Document 5: Template for Public Involvement Training Workshop

Public Involvement Public Representative Training Day <i>[Insert date]</i> <i>Programme</i>	
10am	Registration (tea /coffee/refreshments available)
10:15am	Welcome and introductions (Appointed Public Involvement Liaison Officer)
10:30am	Expectations of the day
10:45am	Overview of National Clinical Guideline and National Clinical Audit development (1) (Appointed Public Involvement Liaison Officer)
11am	Q&A
11:05am	Becoming involved as a public representative
11:20am	Public representative involvement in Clinical Effectiveness Processes (Appointed Public Involvement Liaison Officer)
11:35am	My experience of becoming involved in Clinical Effectiveness Processes (Public Representative)
11:45am	Q&A
11:50am	Effective public representative participation
12:35pm	Lunch
1:25pm	Overview of National Clinical Guideline and National Clinical Audit development (2) (Appointed Public Involvement Liaison Officer)
1:35pm	Q&A
1:40pm	Group Activity (Table Quiz)
2:20pm	Discussion of Public Representative Scenarios
3pm	Evaluation and close

Guidance Document 6: Template for Public Feedback on Involvement Experiences

Sharing My Story: A Feedback Worksheet

Use this worksheet to help share feedback about your involvement
in the development of:

[insert National Clinical Guideline or National Clinical Audit name here]

Key points about your experience:

When you were involved as a public representative, what things went well? What things did people say or do that was helpful?

When you were involved as a public representative, what things didn't go well? What things did people say or do that were not helpful?

What improvements would you suggest to make things better for other public representatives?

Guidance Document 7: Template for Survey Questionnaire for Public Contributors

PUBLIC INVOLVEMENT IN NATIONAL CLINICAL EFFECTIVENESS PROCESSES

SURVEY QUESTIONNAIRE FOR PUBLIC CONTRIBUTORS

HOW DID WE DO WHEN WE INVOLVED YOU?*

**This evaluation questionnaire was adopted with permission from the European Patients Forum "Value+ Toolkit".*

You were recently involved in:

That took place at:

On:

Please tell us what you think by answering the following questions:

BEING INFORMED	Yes	No	Sometimes
1. Were you told enough for you to be able to take part?			
2. Did we keep you informed and tell you what was going on?			
3. Did you understand what we said?			
4. Were you told who to ask to get more information?			
How could we have informed you more?			

LISTENING TO YOU	Yes	No	Sometimes
1. Whilst you were taking part did we treat you with courtesy & respect?			
2. Did you feel your views and opinions were listened too?			
3. Did you feel your views and opinions were taken seriously?			
How could we have listened to you better?			

TAKING PART	Yes	No	Sometimes
1. Were you clear about why you were taking part?			
2. Did we tell you what you could change?			
3. Did we tell you what you could not change?			
4. Did you feel able to take part?			
How could we have involved you more?			

WHAT DIFFERENCE HAS YOUR INVOLVEMENT MADE?	Yes	No	Sometimes
1. Did you feel you were able to influence decisions that were made?			
2. Did you get a chance to say what you wanted to say?			
3. Did anything happen as a result of you taking part?			
4. Did we tell you what, if anything has happened			
5. Overall, did you feel it was worthwhile taking part?			

Is there anything else you want to tell us?

Would you want to be involved with us again?

Have you recognised any training needs?
(Please use an additional sheet if necessary)

THANK YOU!

Please return to:

(Insert address)

Your comments are anonymous.

Guidance Document 8: Identifying Areas for Improvement

Identifying Areas for Improvement in Public Involvement
How are we doing with regard to involving the public?
<div></div>
What are our strengths, what do we need to do better?
<div></div>
What actions do we need to take to bring about improvement?
<div></div>
How will we know if improvements are being made?
<div></div>

Guidance Document 9: Template for Assessment of Indicators of Meaningful Public Involvement for all Parties

PUBLIC INVOLVEMENT IN NATIONAL CLINICAL EFFECTIVENESS PROCESSES

ASSESSMENT OF INDICATORS OF MEANINGFUL PUBLIC INVOLVEMENT FOR ALL PARTIES*

This indicator assessment was adapted with permission, from the European Patients Forum "Value Toolkit" to evaluate Meaningful Public Involvement in National Clinical Effectiveness Processes.*

Scoring the Grid

Met means that the indicator has been met in full

Partly met means that some effort was made to meet the indicator, but it was not met in full

Not met means that the project did not try to address the topic of the indicator

Please note that this model requires support for public involvement to be planned into the guideline/ audit development process. Much of the support for patient involvement is therefore assessed under that heading.

INDICATOR	Met (2)	Partly met (1)	Not met (0)
<i>Public involvement at the beginning and throughout the project in planning and decision making</i>			
Public identified the guideline/audit topic, or those aspects of the topic of most interest to the public			
All parties were involved in identifying what the public contribution should be, and how and where the public could most effectively be involved			
The public involved represented the type of public who would be affected by the guideline/audit outcomes, taking into account gender, ethnicity, age, etc.			
Meaningful public involvement and its monitoring and evaluation during the clinical effectiveness process were part of the guideline development or audit process design			
The public took part in developing and costing the detailed plans for activities where the public would be involved, taking into account public special requirements, for example, information in different language or formats, needing someone to accompany them to meetings			
The plan included a strategy for communication between all parties, and a strategy for supporting patient involvement			
Maximum Score: 12 Total			

INDICATOR	Met (2)	Partly met (1)	Not met (0)
<i>Co-operative working between the public and other parties, supported by a clear understanding of each other's roles</i>			
There was induction and training for all parties about each other's roles and special expertise			
There was induction and training about the communication methods which would support both public involvement and communication throughout the guideline development or audit process			
There was an agreement about how each party would fully participate in decisions, about what should be presented at full meetings, and which topics were better suited to specialised subgroups (if appropriate)			
There were opportunities to build working relationships through formal and informal activities			
Maximum Score: 8 Total			
<i>Providing information and support for involvement, including clear communication about the guideline development and audit process itself</i>			
There were resources for the recruitment induction, support and expenses of the public, as well as training for specific tasks involved in guideline development or the audit process			
The plan allowed adequate time and resources for appropriate communication with the public			
Mentoring was provided for public individuals			
The public were kept informed about the guideline/audit after their involvement had ended, and about the impact of the guideline/audit results after the developmental process was over			
The contribution made by public involvement to the guideline/audit was acknowledged with appropriate detail in the guideline/ audit results			
Maximum Score: 10 Total			
<i>Monitoring and evaluation of public involvement from the perspective of all parties</i>			
There was a check on how representative the involved public were, in terms of age, gender, disability, ethnicity, sexuality etc. of the public who would be affected by the guideline/ audit outcomes. If it was not possible to involve a particular public members the reasons were recorded			
Perspectives about public involvement in the guideline/ audit process were obtained from all parties			
It was possible to identify the specific contribution made by the public			

INDICATOR	Met (2)	Partly met (1)	Not met (0)
Adjustments could be made during the guideline/ audit developmental process because of the ongoing monitoring of public involvement			
Maximum Score: 8 Total			
<i>Evaluation of the guideline/audit results and impact, identifying how public involvement has enhanced the results/recommendations</i>			
The evaluation described how public involvement shaped the guideline/audit, and achieved more than a similar guideline/audit without public involvement could have done			
The evaluation recorded the reasons for not involving the public in particular tasks or work areas			
The evaluation recorded the reasons for including a patient representative rather than a patient and for not including patients who were representative of a particular patient group			
The evaluation included the impact of the involvement on the public, and on the other parties			
The evaluation identified the impact of the guideline/audit results on health policy			
Maximum Score: 10 Total			

INDICATOR	Met (2)	Partly met (1)	Not met (0)
Planning and decision making			
Co-operative working			
Support for involvement			
Evaluation of involvement			
Maximum Score: 10 Total			

Guidance Document 10: Record of Public Involvement Practices/Activity Template

PUBLIC INVOLVEMENT IN NATIONAL CLINICAL EFFECTIVENESS PROCESSES

RECORD OF PUBLIC INVOLVEMENT PRACTICE*

**This record template was adapted, with permission, from the Personal and Public Involvement Toolkit for staff of the Southern Health and Social Care Trust, Northern Ireland.*

Please answer the following questions in relation to the public involvement practice you have engaged in, or plan on engaging in.

To be completed for all NCEC public involvement practices/activities

To be completed by the NCCDG/NCAGC Chair

Name of National Clinical Guideline/Audit Process	
Name of Chair	
Start & End Date	

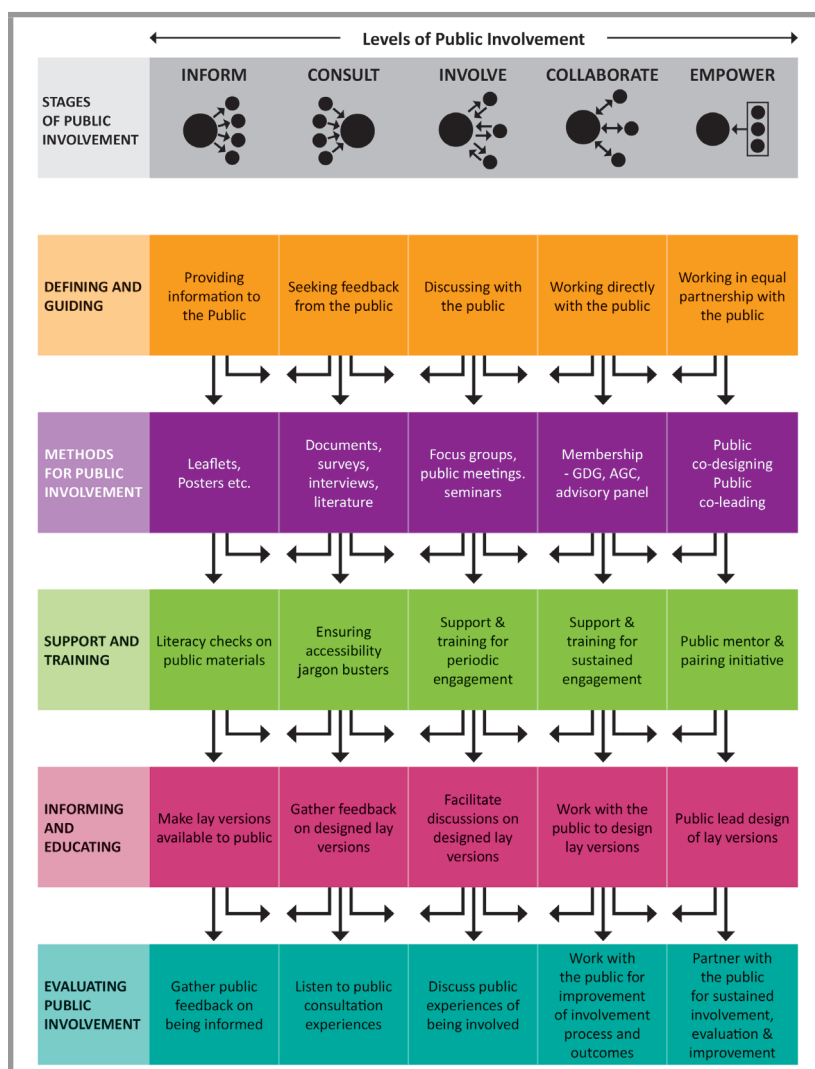
What was the context/background to this public involvement practice/ activity?	
What was the purpose of this public involvement practice/activity?	
Drawing on the Framework, at what level did you involve the public i.e. inform, consult, involve, collaborate, empower?	
How did you recruit and select the public to be involved?	
What method(s) did you employ to involve the public (attach relevant documents such as questionnaires etc.)?	
How did you measure the process and outcome/impact of public involvement (attach relevant documents such as measurement tools)?	

RESULTS AND OUTCOMES

<p>What was the impact of the public involvement practice/ activity?</p> <p>For the public, for the NCGDG/NCAGC, for the actual Guideline/Audit, for the NCEC, for wider health services etc.</p>	
<p>What did the public say about being involved (include quotations/other evidence if available)?</p>	
<p>How did you or are you going to, ensure that the public contributors, and the wider public community, are informed of the results and outcomes of their involvement (e.g. newsletter, website, press release, launch event etc.)?</p>	
<p>How did you evaluate the process of public involvement?</p>	
<p>How did you alter, or will you alter (or recommend to others), any future practices for public involvement?</p>	
<p>Any other comments?</p>	

REFLECTION ON LEVEL OF PUBLIC INVOLVEMENT

Drawing on the Framework for Public Involvement in Clinical Effectiveness Processes, reflect on each stage of involvement and use the figure below to highlight/circle the public involvement practices implemented by the GDG/AGC.



In the box below, provide explanation for the public involvement practices implemented.

Signed (NCGDG/NCAGC Chair): _____

Date: _____

Return Form to: _____

