

# **Inquiry into Hyponatraemia Related Deaths (IHRD) Implementation Programme**

## **Involvement Strategy**

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**Programme** IHRD Implementation Programme

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## 1 Background and the importance of Involvement

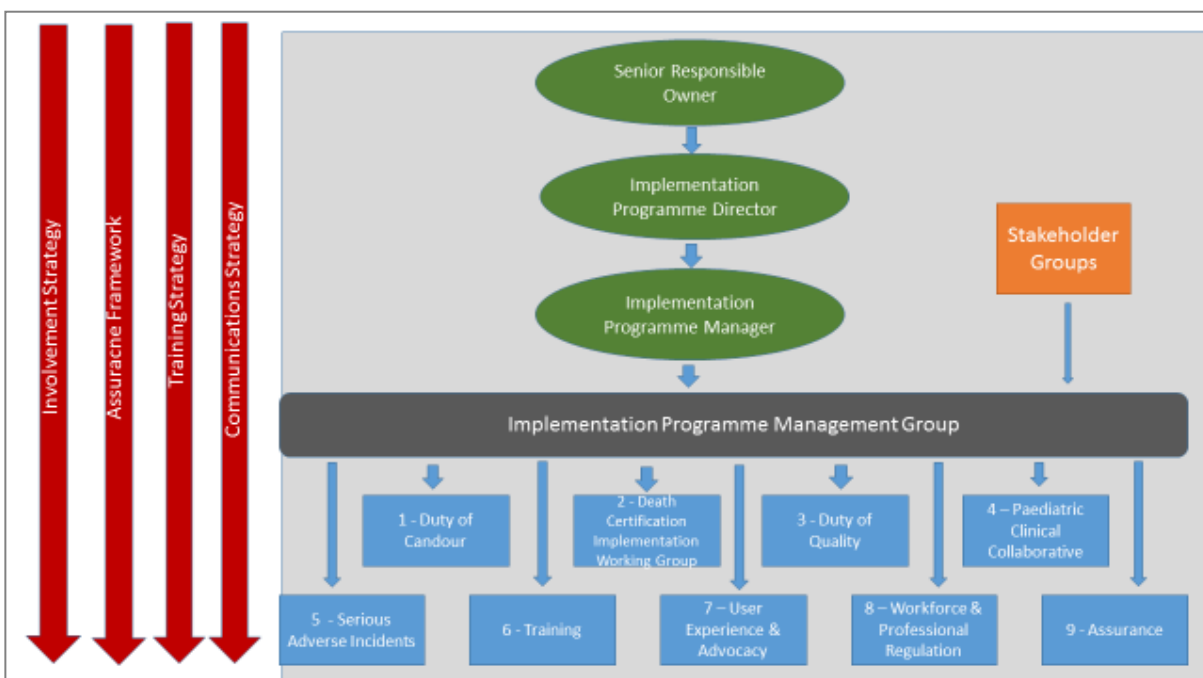
On 31 January 2018 the report of the Inquiry into Hyponatraemia Related Deaths (IHRD) was published following an extensive investigation into the deaths of five children in hospitals in Northern Ireland. From that report, some 96 recommendations emerged, with 120 associated actions.

The Department of Health (DoH) on behalf of the Health and Social Care (HSC) System in Northern Ireland committed itself to putting in place a programme of work, to ensure that systematic practice and cultural changes required to address those recommendations and actions, would be put in place.

In order to do so, a programme delivery structure was established, with a clear commitment to genuine and meaningful involvement of the affected families, service users, carers, the public, staff, HSC organisations, professional and regulatory bodies and other pertinent stakeholders.

### 1.1. Programme structure

The programme structure established (below) includes an Involvement Strategy to integrate stakeholder involvement into the programme of work.



## 2. Centrality of Involvement and partnership working

The critical role of meaningful involvement and partnership working is increasingly recognised when trying to address the system need for improvement and change in health and social care.

Involvement is a statutory duty in Northern Ireland as set down under the HSC Reform Act (NI) 2009. Under this legislation, the HSC system is required to involve and consult with service users and carers in the planning, development and delivery of care.

There have also been a range of strategy and policy drivers taking the HSC in this direction, both before the legislation was enacted and since. Most prominent of these in recent times, has been the Bengoa Report ‘Systems Not Structures’<sup>1</sup> and the Departmental response, ‘Health and Wellbeing 2026, Delivering Together’<sup>2</sup>. In ‘Delivering Together’ the then HSC Minister, Michelle O’Neill, recognised the value of the effective involvement of all stakeholders and committed the DoH to partnership working through the adoption of a co-production approach. The recently launched Co-production Guide, puts this vision into practice to create the opportunity for people to work in genuine partnership and to take shared responsibility for improving health and social care outcomes<sup>3</sup>.

The IHRD report clearly outlines that the involvement of a wide range of stakeholders is key to the successful implementation of the recommendations. The Permanent Secretary as the Senior Responsible Officer for the implementation of the IHRD report recommendations, has reinforced the importance of the need for meaningful involvement in this process. Involving all the main stakeholders in a

<sup>1</sup> Department of Health, Expert panel (2016) Systems Not Structures, available at <https://www.health-ni.gov.uk/publications/systems-not-structures-changing-health-and-social-care-full-report>

<sup>2</sup> Department of Health (2016) Delivering Together, available at <https://www.health-ni.gov.uk/publications/health-and-wellbeing-2026-delivering-together>

<sup>3</sup> Department of Health (2018) Co-production Guide – Connecting realising value through people, available at <https://www.health-ni.gov.uk/publications/co-production-guide-northern-ireland-connecting-and-realising-value-through-people>

partnership based approach, is essential if we are to truly achieve a person centred service, where the culture and practice is such, that the failings identified through this Inquiry are not repeated.

The Involvement Strategy outlines the framework for the involvement of a wide range of stakeholders to work together to help, inform, shape and implement the recommendations. This will be taken forward by the development of individual Workstream Involvement Plans to augment the Strategy. It has been developed and shaped by Involvement Leads, service user and carer representatives, key officials in DoH and workstream members.

Central to the Involvement Strategy, is the involvement and integration of service user and carer participation from the outset. This makes it explicitly clear, that partnership working between those who design, deliver and use HSC services, is integral to the success of this work. It is recognised that where service users, carers and the public are involved in decisions regarding HSC, this will help improve quality, effectiveness and outcomes. It utilizes the knowledge, expertise and skills of people from a diverse range of backgrounds. It gives life to the concept of real partnership working. It helps to ensure that the implementation of the Inquiry recommendations, are agreed upon by the relevant stakeholders and have an increased chance of being successfully adhered to, for the benefit of future users of HSC services.

The implementation of the recommendations will require leadership at all levels both for HSC staff and also the service users, carers and other representatives who are engaged to take forward this work. This is supported by the direction of travel outlined in the HSC Leadership Strategy, which seeks to establish a collective leadership culture to create the conditions for change<sup>4</sup>.

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<sup>4</sup> Department of Health (2017) HSC Collective Leadership Strategy, available at <https://www.health-ni.gov.uk/publications/hsc-collective-leadership-strategy>

## 2.1 Principles of involvement

Key principles of genuine involvement and co-production have been adopted to inform how we will take forward the work associated with recommendation implementation. The programme seeks to operate in a manner that embraces the following principles:

- ***Open and transparent*** – with each person having a responsibility to be open and honest in their interactions and relationships with others.
- ***Dignity, respect and equality*** – valuing the expertise, knowledge, time and commitment, people have made to progress the implementation of the recommendations.
- ***Inclusivity, equity and diversity*** – facilitating the inclusion of all those who need to be involved and who chose to do so. Recognising that one-size does not fit all, a range of methods/approaches will be utilised to ensure we engage in ways appropriate to stakeholder needs.
- ***Collaboration and partnership*** – building constructive relationships with others.
- ***Communication*** – regular up-dates to ensure relevant people are up-dated with feedback provided to all stakeholders to outline how their involvement has contributed to the work.

In following these principles, we hope to co-design and co-deliver meaningful change for HSC safety, quality and practice.

## 2.2 Aims and objectives

The overall aim of the Involvement Strategy is to provide a framework and commitment for the effective involvement and engagement with stakeholders to co-produce the implementation of IHRD recommendations. The strategy seeks to provide a consensus, consistency and collaboration of approach of good practice for co-production and involvement.

Through the development of the Involvement Strategy, the objectives will be to:



- Involve people to make use of their diversity of knowledge, expertise and experience for the most effective implementation of the recommendations;
- Ensure a wide range of stakeholders are involved at key stages of the implementation of recommendations;
- Adopt a variety of approaches to ensure we are responsive to the needs of stakeholders;
- Evaluate the effectiveness of involvement;
- Complement the Communications Strategy.

### **3. Stakeholder identification and mapping**

In order to ensure that the implementation of the recommendations is delivered in the most effective and efficient manner and that the learning is truly embedded into practice, it is essential that all stakeholders are appropriately engaged. Building representative networks is a core element of co-designing solutions for change and to that end, an exercise was undertaken to identify representatives to include people using the 'ARE IN' principles:

- **Authority** to influence change;
- **Resources** ie finance/access/influence;
- **Expertise** from a social, technical and professional perspective;
- **Information** ie access to data;
- **Need** – engaging people who will be affected by the outcome alongside having an experience of using and engaging with HSC services.

A stakeholder mapping exercise was undertaken to identify people who should be involved in the programme of work. The stakeholders were then indicatively mapped to determine their potential interest and influence in the implementation of the recommendations. This was to ensure the stakeholders were identified and also support the identification of the most appropriate mechanism to engage (Figure 1).

**Figure 1 Stakeholder mapping**

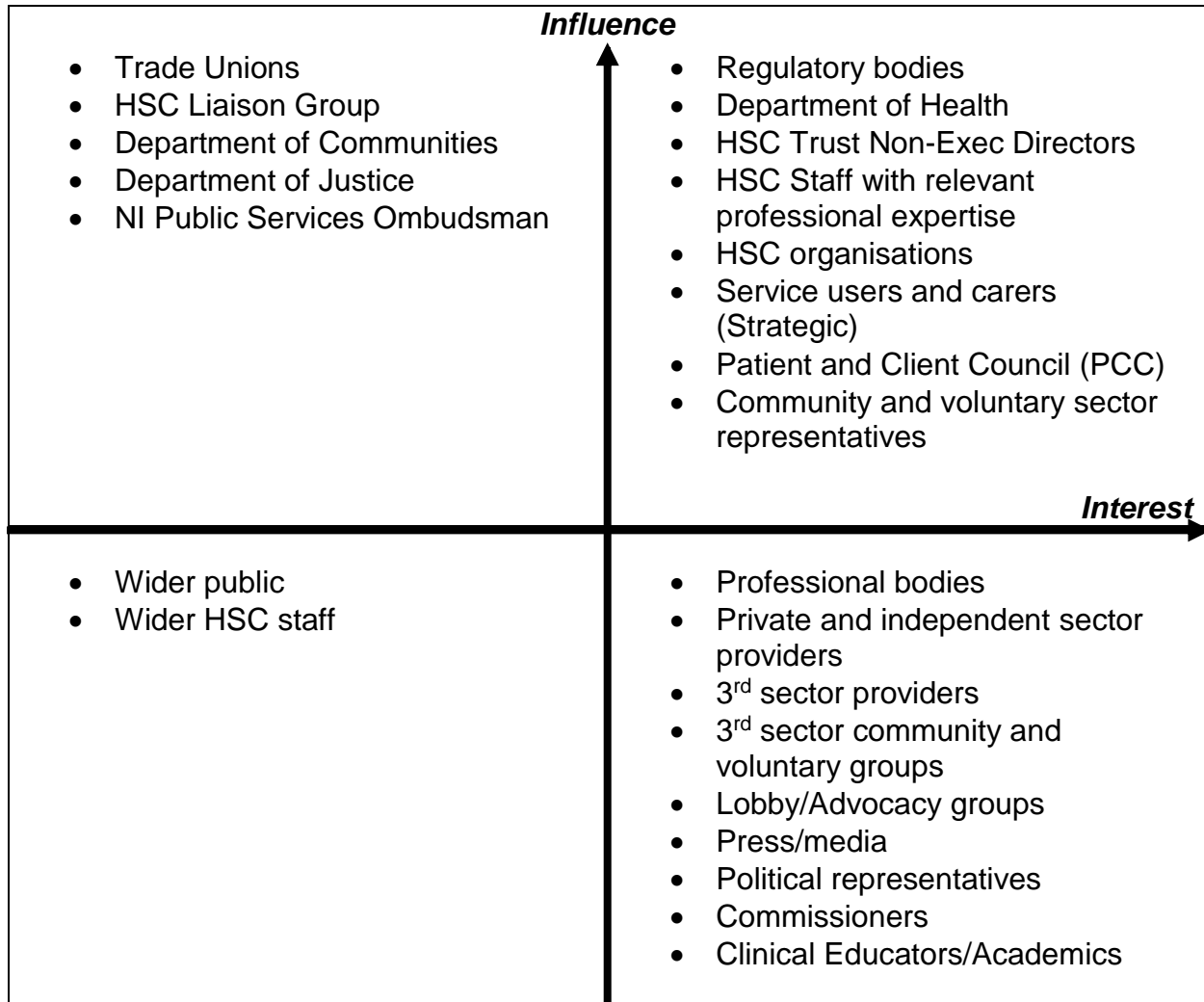


Figure 1 has been undertaken for the IHRD Programme as a whole and this may look quite different for individual workstreams. It should be noted that the figure is subjective and the position of each stakeholder could be argued differently. This is a fluid process and will change with stakeholders moving to different quadrants and the approaches to the involvement of all identified groups will adjust accordingly. The individual workstreams will also utilise this model to help shape and inform their individual involvement plan.

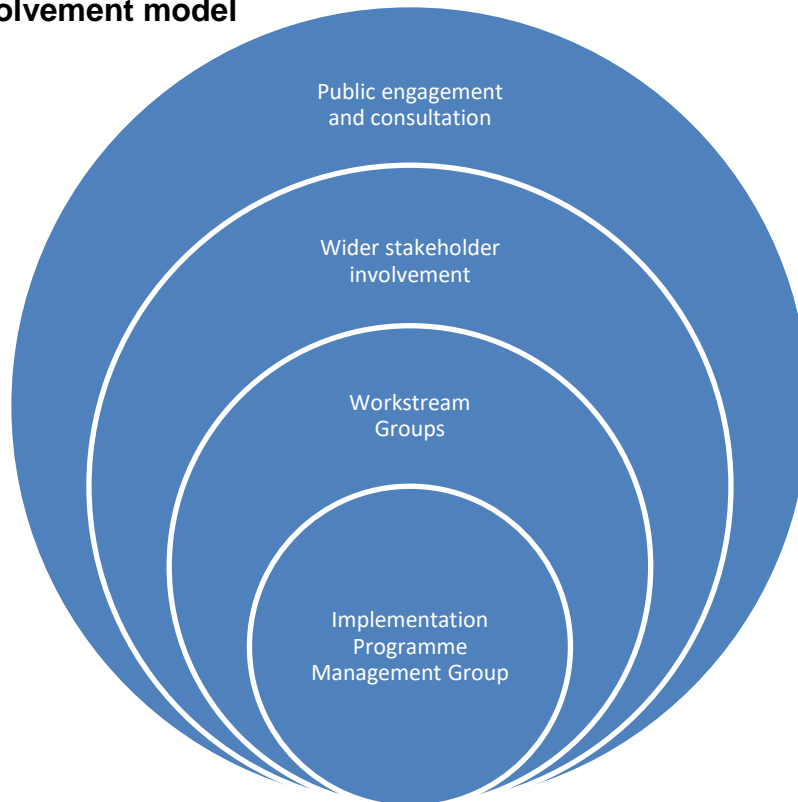
A separate process is in place to ensure the meaningful involvement and communication with the families involved in the IHRD.

#### 4 Involvement model

The involvement model envisaged for this programme of work is one that is co-designed by the workstreams.

The model sets out as a series of interconnected concentric circles to identify different groups and the interconnectedness. At its core is the concept that all individuals and partners identified through the stakeholder analysis will have a part to play and will be invited to engage in the process in different ways (Figure 2).

**Figure 2 Involvement model**



##### 4.1 Implementation Programme Management Group

The Implementation Programme Management Group (IPMG) has overall oversight and approval function for the delivery of the recommendations arising from the IHRD. This group is comprised of the Chairs from each of the workstreams and sub groups alongside, key officials in DoH. The Patient and Client Council (PCC) will participate in the group in an observer capacity.

## 4.2 Workstream groups

The driving force/building block of the Involvement Strategy will be the establishment of nine workstreams, who have the responsibility to progress the recommendations arising from the Inquiry. This will be undertaken in a partnership based approach with representative networks bringing together individual expertise, knowledge, and skills of a range of people from across the sectors, including DoH, HSC staff, HSC Non-Executive Directors, Educators, 3<sup>rd</sup> sector organisations and service users and carer representatives.

It was deemed critical that workstream members were drawn in substantive numbers from across all sections of stakeholders to build a representative network using the 'ARE IN' principles. In addition, the ability to and experience of being involved in system wide change and operating at a strategic level were understood to be essential pre-requisites for workstream members. This combined with the urgent need for progress in regards to the establishment of the workstreams resulted in people being recruited in a targeted manner to help expedite progress.

Each workstream will design an approach via an Involvement Plan most suited to the nature of the work they are engaged in. This will provide a structure to ensure that the involvement and engagement of a range of stakeholders is targeted. Common to all the individual workstreams however, will be the core involvement principles outlined previously and the identification of who the recommendations will impact on. It is essential that each workstream Involvement Plan connects into the wider Involvement Strategy to ensure efficiency of engagement and an avoidance of duplication or consultation fatigue.

Workstream members will also facilitate a process to engage the wider involvement of the networks and partnerships that members bring with them. This will necessitate two way engagement with the constituency from which they are drawn.

#### 4.2.1 Building people's capacity

Support mechanisms have been built in to ensure members are empowered and equipped to undertake this work including:

- **Promoting understanding:**
  - Orientation sessions to provide background information as to the objectives of the work, programme structure, operating arrangements and requirements of each member. Recognising the important contribution which all workstream members bring, to co-produce the implementation programme.
  - Workstream induction/briefing sessions to provide background information to increase understanding and equip participants with the necessary evidence to take forward recommendations.
- **Sharing information:**
  - The full Inquiry report to provide an understanding of the rationale for the recommendations attributed to the respective workstreams, workstream briefings, research etc.
  - Programme Initiation Document (PID) to outline the programme of work.
- **Developing skills and knowledge:**
  - Implementing best practice involvement guides and materials to embed good practice for involvement and includes role description to ensure clarity of engagement, workstream terms of reference, good meeting etiquette, implementing out of pocket expenses etc.
  - Undertaking training needs analysis to identify further knowledge or skills development required. This may include participation at courses, conferences and seminars etc.

#### **4.2.2 Support for involvement**

It is recognised that there are a number of stakeholders from many different sectors and professions involved in the workstreams. There is a need to ensure that both organisations and also individuals are investing their time and resources to bring about change for HSC.

On an individual level, each member of the workstream will have an identified person whom they can link in with to clarify matters, discuss issues, seek guidance to help foster a sense of inclusion and encourage full and active participation.

At a wider level, sector support will be provided through the establishment of Liaison Groups. These groups will provide a support mechanism to:

- Support participation and identify areas of concern;
- Promote shared learning;
- Act as a communication channel;
- Provide a consistency of approach.

Liaison groups will be co-ordinated for the following sectors:

- Service user and carers;
- HSC (made up of Medical Directors, Heads of Nursing and others);
- Trust Oversight Group;
- Non-executive Board members;
- Community and voluntary.

#### **4.3 Wider stakeholder involvement**

Alongside the work streams, it is recognised that there are stakeholders who have valuable knowledge, experience and skills which can contribute to the implementation of the recommendations. It is recognised that a tiered approach is

required for the range of stakeholders to get involved which will include the co-ordination of other stakeholder groups for the following sectors (but not restricted to):

- Professional and Regulatory Bodies
- Organisations representing staff
- Education and training bodies

Appendix 1 seeks to identify how stakeholders will be impacted and their involvement on an on-going basis to support the effective implementation of the IHRD recommendations. This will run in parallel to the individual workstream Involvement Plans.

Each workstream will develop and implement an Involvement Plan (appendix 2) to take forward the specific outworkings from the group. This will require an identification of who will be affected to ensure this work is targeted to specific sectors and groupings who may be affected by the implementation of the recommendations.

The Involvement Strategy will be closely aligned to the Communication Strategy to ensure there is a consistency of message, alongside ensuring it is appropriate and targeted to the identified audience. The Communication Strategy will also support the engagement of a range of stakeholders to implement the Involvement Plan which will be generated by each workstream.

There is a recognition that a wide and diverse range of people will need to be involved. A variety of involvement approaches and tools will be utilised to engage with the stakeholders. This will be dependent on the nature of the work and who we are seeking to involve. Specific support and expertise from the Participation Network in Children in Northern Ireland (CiNI) will be availed of to ensure the voice of children and young people is included. A range of involvement methods for wider engagement are available at the Engage website (<http://engage.hscni.net>) and may include:

- **Regular up-dates** to keep stakeholder groupings up-dated on progress.
- **Task and Finish Groups** to progress time or subject bound discussions.
- **Focus Groups or Workshops** to obtain input from identified groups.
- **Formal Consultation** to hear and engage with a range of people on particular options for change.

There is recognition, specifically in regards to the service user and carer component of the workstreams, that in order to foster the ethos of transparency and openness that opportunities for much wider input amongst this constituency needs to be secured. The initially identified service user and carer members of the workstreams will be integral in advising how best to achieve that aim, whilst ensuring that peoples time and effort are most effectively used. This will include working in partnership with already established networks and membership schemes including the Patient and Client Council (PCC) and also the Northern Ireland Council for Voluntary Action (NICVA) to engage a wide range of individuals. Alongside this, we will also seek to link with existing mechanisms to engage wider stakeholder involvement as appropriate. This will include a wide range of stakeholders as identified in figure 1 and also in the Communication Strategy.

#### **4.4 Public engagement and consultation**

The implementation of a number of the recommendations arising from the IHRD will impact on the population as a whole. Linking closely with the communication plan, it is essential that the IHRD is not solely associated with a particular population group or condition. The recommendations will potentially have a far and wide reaching impact, which will change how we do things on a wide variety of fronts, from health and social care to long standing societal traditions or timescales for burials.

A core element of the Involvement Strategy, will be to ensure that people are kept up-to-date at all stages of the programme of work. On-going information exchange will be provided through:



- The development and implementation of the Communication Strategy to provide regular up-dates at key stages throughout the programme lifespan.
- Establishing an internet presence via DoH website, to allow individuals and groups to register their interest to keep up-dated on the work of the programme but also to register their interest to get involved in specific areas.
- Agreements with the PCC and also NICVA to engage a wide range of community and voluntary groups. This will support the reach out to increase awareness and engage interested groups and the public in a conversation about the impact of the recommendations on the public.
- Use of formal Public Consultations where appropriate. These will be undertaken to obtain the views of a wide range of people to inform and support the relevant workstream, to refine and assess the options available. All formal consultation will be undertaken in line with the Department of Health Consultation Scheme<sup>5</sup>.

There needs to be genuine opportunities for the public to take part and have their views heard. It is essential that targeted approaches are made to communicate with these groups on an ongoing basis and to obtain their views and engage as appropriate to their level/area of interest. This will include groups who are identified as hard to reach or easy to ignore and the involvement of these groups must be targeted to ensure the appropriate approaches are utilised.

## **5 Delivery**

The implementation of the Involvement Strategy is the responsibility of IPMG, key officials in DoH, Involvement Team, with support from workstream members, the wider HSC family, including HSC Board and Trusts, Third Sector organisations and other stakeholder groups.

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<sup>5</sup> Department of Health (2015) DoH Personal and Public Involvement Consultation Scheme, available at <https://www.health-ni.gov.uk/publications/personal-and-public-involvement-ppi-doh-consultation-scheme>

To support implementation, DoH has invested in the development and outworkings of the Involvement Strategy through the engagement of Involvement Leads. Their role will be to advise and support the overarching Involvement Strategy and individual Involvement Plans.

A critical success factor of this Strategy is the alignment with the Communication Strategy. This will ensure the effective communication of information to the wide range of stakeholders which will support the implementation of the recommendations.

### **5.1 Timeframe**

Timescales will be included in each workstream involvement plan. These are subject to a continuous process of alignment across the IHRD programme and therefore may be adjusted as circumstances change.

## **6 Assurance and monitoring**

This is a comprehensive programme of work where a range of stakeholders will be involved at various levels. A programme of evaluation will be established to ensure we are meeting our objectives and targets and engaging with the right stakeholders which may be found in appendix 5. This also presents an opportunity to learn from both what went well and what we could differently in future.

## Appendices

### Appendix 1 Wider stakeholder involvement

This table seeks to identify who will be impacted, the purpose of their involvement and an overview of the action which is required to support the implementation of the IHRD recommendations. The DoH and Workstream Chairs will have overall responsibility for the involvement of these groups. This will link closely with the Communications Strategy and in particular the message board.

Who will be impacted?	Who will we engage to involve these groups?	What needs to be undertaken?	How will we engage with the identified stakeholder groups? *	Outcome
HSC Staff	<ul style="list-style-type: none"> <li>• Professional Bodies</li> <li>• Organisations representing staff</li> <li>• HSC Liaison Group</li> <li>• Trust Oversight Group</li> <li>• Regulatory Bodies</li> <li>• Education and training bodies</li> </ul>	<ul style="list-style-type: none"> <li>• Be informed about programme of work.</li> <li>• Input into discussions for programmes of work which may impact on members.</li> <li>• Engage with members in relation to identifying potential options for changes to practice.</li> <li>• Consult with members.</li> <li>• Up-date and review guidance.</li> <li>• Identify education and training needs.</li> </ul>	<ul style="list-style-type: none"> <li>• Briefing meetings/regular up-dates.</li> <li>• Consultation</li> </ul>	Staff have opportunity to input into development of options and are fully consulted in relation to potential changes to practice.

Who will be impacted?	Who will we engage to involve these groups?	What needs to be undertaken?	How will we engage with the identified stakeholder groups? *	Outcome
HSC Governance responsible Directors/Officers	<ul style="list-style-type: none"> <li>• Non-Executive Directors</li> <li>• HSC Liaison Group</li> <li>• RQIA</li> </ul>	<ul style="list-style-type: none"> <li>• Up-date and review governance processes and guidance.</li> <li>• Identify education and training needs and implement.</li> </ul>	<ul style="list-style-type: none"> <li>• Presentation to Liaison Group meetings.</li> </ul>	HSC senior officials have the opportunity to contribute to the improvements in governance arrangements
Service users and carers	<ul style="list-style-type: none"> <li>• PCC</li> <li>• NICVA</li> <li>• Community and voluntary sector</li> <li>• Other identified networks</li> </ul>	<ul style="list-style-type: none"> <li>• Support the integration of the service user and carer voice into decision-making.</li> <li>• Raise awareness of opportunities to get involved.</li> <li>• Provide regular up-dates.</li> </ul>	<ul style="list-style-type: none"> <li>• IHRD website</li> <li>• Involvement opportunities presented by each workstream Involvement plan.</li> <li>• Consultation</li> </ul>	Service users, carers and the public are facilitated to be involved in service re-design.
General public	<ul style="list-style-type: none"> <li>• Commissioners</li> <li>• Political representatives</li> <li>• Media/press</li> </ul>	<ul style="list-style-type: none"> <li>• Keep informed about the outworkings of the recommendations.</li> <li>• Support the engagement and involvement of identified communities (geographical or sector).</li> <li>• Support active involvement into the</li> </ul>	<ul style="list-style-type: none"> <li>• Briefing meetings</li> <li>• IHRD Website</li> <li>• PCC Membership Scheme</li> <li>• NICVA</li> <li>• Consultation</li> </ul>	Awareness raising. Public are fully informed about potential changes to services.

Who will be impacted?	Who will we engage to involve these groups?	What needs to be undertaken?	How will we engage with the identified stakeholder groups? *	Outcome
Wider Government	<ul style="list-style-type: none"> <li>DoH</li> </ul>	<p>decision-making process</p> <ul style="list-style-type: none"> <li>Engagement on potential legislative changes and their impact</li> </ul>	<ul style="list-style-type: none"> <li>As part of Impact Assessments</li> </ul>	<p>Wider government agencies are involved to support the development of cross-departmental public policy. Wider government are involved to support the development implementation of legislation.</p>

\*specific involvement activity will be outlined in the individual workstream involvement plans. This table outlines the strategic interactions which will be undertaken.

## Appendix 2 Workstream Involvement plan

Each workstream will be required to develop an involvement plan. This will shape the engagement and involvement of a wide range of stakeholders and likely to be used at different stages of the workstream work when looking at different recommendations/actions.

<b>Consider:</b>	<b>Detail</b>	<b>Who</b>	<b>When</b>
<ul style="list-style-type: none"> <li>Why are we involving stakeholders? Consider stage of proposal</li> </ul>			
<ul style="list-style-type: none"> <li>Who do we need to involve? Identify what networks are available in the workstream?</li> </ul>			
<ul style="list-style-type: none"> <li>How are we going to involve the identified stakeholders?</li> </ul>			
<ul style="list-style-type: none"> <li>What information will support this?</li> </ul>			
<ul style="list-style-type: none"> <li>What help or support</li> </ul>			

<p>do we require to achieve this?</p>			
<p>After involvement implementation, consider:</p> <ul style="list-style-type: none"> <li>• Were there other stakeholders who should have been involved?</li> <li>• Were stakeholders engaged at the right stage of the process to influence decisions?</li> <li>• The impact of involvement ie changes made, identified wider options etc?</li> </ul>			





## **Appendix 3                      Engagement log**

To link with the Communication Strategy

## Appendix 4 Involvement guidance

As part of your involvement plan, you will use a variety of different ways to engage and involve a wide group of people. It is important that the information that is disseminated is consistent and also that it is clear what we are asking people to get involved in.

The following template provides a framework to help you reach out to involve stakeholders to engage in your programme of work. Develop the information and share it with service users and carers in the workstream to get their input.

A range of different methods are available on the [Engage website](#) which provides a search tool to help you identify a suitable method for your target audience.

### Template Programme of work title

Introductory text to outline IHRD programme of work.

We are seeking your input into:

[Project name]

Include an overview of the following information to support understanding and help outline what you are asking representatives to do:

- Background/context
  - Provide a brief overview about the project.
- What has happened to date?
  - Outline action to date eg – workstream has developed a draft overview or options have been generated by engaging with specific groups and we want to further refine these.
- How can you get involved?
  - What are you asking the group or person to do? Include some questions to stimulate people’s thinking.
- Who and when to respond to?

- Contact details – both on-line and hard copy and a date to return by
- Further information
  - Always include the IHRD website
  - Include further information as appropriate
  - Include contact details for queries

## Appendix 5 Assurance and monitoring template

	<b>Objective</b>	<b>How will we measure involvement?</b>	<b>Action</b>
1	Involve people to make use of their diversity of knowledge, expertise and experience for the most effective implementation of the recommendations.	<ul style="list-style-type: none"> <li>- Engagement log</li> <li>- Engagement monitoring for workstream members</li> </ul>	
2	Ensure a wide range of stakeholders are involved at key stages of the implementation of recommendations.	<ul style="list-style-type: none"> <li>- Stakeholder mapping</li> <li>- Engagement log</li> </ul>	
3	Adopt a variety of approaches to ensure we are responsive to the needs of stakeholders.	<ul style="list-style-type: none"> <li>- Map approaches adopted using the worksteam Involvement plans</li> <li>- NICVA</li> <li>- PCC</li> <li>- Others</li> </ul>	
4	Evaluate the effectiveness of involvement.	<ul style="list-style-type: none"> <li>- Evaluate involvement practices</li> <li>- Liaison Groups</li> </ul>	
5	Complement the Communications Strategy.	<ul style="list-style-type: none"> <li>- Press releases</li> <li>- Social media</li> </ul>	