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An Roinn Sláinte

Mánnystrie O Poustie

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Working Together to Put Things Right – Implementation of Recommendations from the Inquiry into Hyponatraemia-Related Deaths (IHRD) – Update Report

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Overview

There are 96 recommendations in Mr Justice O'Hara's Inquiry into Hyponatraemia-Related Deaths. All are important and all need to be acted upon.

Yet it is not enough for us to work out what needs to be done. We also need to know that what we need to change has been changed and that the evidence is there to back that up and that we have the means to check that this will continue to be the case into the future.

This may sound obvious. But it is a significant challenge in its own right for a system as large as ours.

There are more than 64,000 people employed in health and social care in Northern Ireland across many organisations.

Of these the Department itself, the Health and Social Care Board, the six Trusts (five geographical and the Ambulance Service), the Public Health Agency, the Patient Client Council and the regulator the Regulation & Quality Improvement Authority (RQIA) are perhaps the best known.

The changes need to work across different organisation's boards with different management teams and staff who may also have different ways of working.

So therefore it is vital that the staff of all the organisations involved have a very clear, shared understanding of what needs to be changed and that the new standards apply equally across every organisation.

This is why detailed proposals are in place. These are outlined in the next section and we believe that this will ensure that our work is fully implemented and will continue to be so.

Meanwhile the workstreams are continuing to develop their plans. They are at different stages because some of the recommendations are more complex than others and require considerable research, consultation and reflection. A few also require legislation which will have to await the return of an Executive and Assembly.

However we expect that by our next update in mid-October there will be the beginning of a steady stream of circulars being issued to the sector detailing how individual recommendations should be implemented.

For those recommendations that need Ministerial approval and/or legislation, except for the Independent Medical Examiner (IME), we intend to have developed policy proposals ready for consideration by January of next year. At that point a Minister may decide to issue public consultations on proposals, but we will ensure that by that stage a wide range of stakeholders will have been involved in their development. For the IME we plan to have undertaken a prototype to test how such a system would operate in practice.

Approach to Implementation

All recommendations are going through the same rigorous four part process.

First, the details of what needs to change need to be agreed. Within that there is a requirement to specify everything required to bring the change into effect including existing guidance, legislation, standards and all relevant documentation. Then, for each recommendation, the evidence and measures which will be used to assess that implementation has been successful, need to be clearly set out.

Three levels have been set out for defining successful implementation:

Level One is where it is deemed sufficient for staff to report that the change is in place and being operated – it is not expected that many recommendations will fit into this category;

Level Two is where the relevant organisation will provide evidence of implementation;

Level Three is where assurance will be carried out independently from outside the organisation.

The Assurance workstream has one vital task: making sure that all the recommendations produced by everybody else in the programme can be implemented and sustained and they quality assure this process.

Second, all relevant new materials need to be both developed and tested: new guidance, documentation, training and explanatory material for example. This is to ensure they are fit for purpose and do not result in unintended negative consequences. Where training needs are identified these may need to be discussed and developed with the Education and Training workstream. Where legislation is required it will be necessary to develop a policy for consultation and approval by Ministers. Policy development involves engagement with stakeholders from an early stage and also involves assessing the impact of any change by undertaking equality, regulatory and rural impact assessments if they are applicable.

Third, is the process of implementation itself. Implementation and/or “Go Live” dates will be set. Depending on the nature of the change it may be appropriate for a period of time to be allowed for full implementation. In other cases where it would be confusing to operate old and new processes at the same time a single “Go Live” date for everyone to adhere to will be fixed. These all need to be realistic and set after consulting with whichever parts of the health and social care system will be responsible for implementing them.

Fourth, a circular will be drafted and issued to provide details of the changes and begin the process of reporting on progress with both implementation and monitoring.

Until the implementations are bedded down and are therefore ‘business as usual’, the Department will be responsible for monitoring implementation within the Health and Social Care system.

Stocktake event

Imagine if something went badly wrong with the care of your family member and they came to harm. What would you want to happen next?

This was the first question posed at a gathering of all the people involved in the programme which took place on 28th May to take stock of progress to date and to remind themselves of what their work is all about.

And for many of us the answers are simple:

For someone to tell us as much as possible about what has happened;

To have access to bereavement services if we want them;

To be supported by an independent advocate who knows the system and will help us to have our questions answered;

That the circumstances of what happened will be expertly investigated;

That you will be involved in the investigation if you want;

That the investigation will identify any learnings and they will be acted upon;

That individuals and organisations will behave in a transparent way, explaining what is happening at every stage;

That they will tell the truth about what has happened;

That no-one will withhold, conceal or manipulate information or evidence because of fear of litigation or action by a regulator;

That the entire system from the board to the front line staff prioritises learning, quality and safety.

These are the type of outcomes which the programme is setting out to achieve.

Within that context this was an opportunity for everyone to catch up with the work done by all the other workstreams so that they could see what was going on, make their own comments and share ideas. The individual workstreams are currently drilling into detail around their own recommendations so it is very important that everyone gets the chance to put their work in a wider context. This is even more critical given that some of the recommendations overlap – so therefore workstreams cannot operate in isolation.

Dr Paddy Woods Deputy Chief Medical Officer told the meeting: “Openness is the key both to today and to all of the work we are doing. It is about listening to people, talking to people and telling people the truth.”

“We’re now beginning the next phase where we are moving from developing our ideas to implementing them. We need to take time to do that properly. The solutions need to be owned and taken forward by one and all. It is only right that we pause for thought before implementation and make sure that everybody can contribute to any area of our work.”

Progress reports on work were given and there were detailed discussions on both the challenges and opportunities that lie ahead.

One important priority is to engage as broadly as possible with staff, with service users and carers and with the voluntary and community sector about both the Duty of Candour and improving transparency within the system in order to promote understanding and also help to address concerns.

The Service User and Carer Liaison Group (SU&CLG)

Getting Beyond the Fear Word

How do we support the effective implementation of IHRD recommendations?

Group context

To ensure a strong service user and carer voice in the IHRD Implementation Programme, the Service User and Carer Liaison Group (SUCLG) was set up in September, 2018. Our key functions are to:

- Provide a collective overview of potential service user and carer linkages, involvement opportunities and influence across the programme;
 - Support identification of good practice for involvement;
 - Support the development, implementation and evaluation of the Involvement Strategy and act as a **consultative group to advise** on service user and carer input into wider/workstream involvement plans.
1. Effective and sustainable implementation of the IHRD 96 recommendations, requires at its core, the **effective involvement** of parents, children and young people, service users, carers and the public, and staff at all levels of health and social care systems.
 2. Effective implementation of the 96 recommendations will also only occur, by **creating the conditions** whereby culture change can happen in health and social care workplaces. Put simply, culture is ‘how things are done around here’ – the behaviours, practices and routines in children and young people’s health and social care environments and workplaces in Northern Ireland (FoNS Creating Caring Cultures, 2015; Appendix 2).
 3. Effective implementation requires **culture change** in health and social care environments and workplaces, from a current ‘culture of concealment’(IHRD 2018; RQIA/PcAW Review of Whistleblowing Policy and Procedure in NI; 2015) to individual ward and workplace cultures that are person and family centred (McCormack et al 2013; Shelton et al 1987; Wilson et al 2005/2011).

We must move to a more open and compassionate culture for all because: “A caring culture makes things better for everyone. Parents, children, young people, families and carers feel they have good care. Staff feel valued and supported which helps them to provide the care parents, children and young people want, with compassion and confidence.”(FoNS 2015)

It is important that the implications of implementation are discussed and understood by all HSC staff. When change is imposed, it can be perceived as a threat to personal identity and having not been good enough in the past, which then generates fear. This **genuine concern** can only be dispelled through better information and honest engagement with all staff.

Our SUCL Group want to support this important involvement. However, we are not sure that we ‘in the workstream’ service users, parents and carers – everyone who is involved – have fully recognised our own fears in taking part in the implementation of the recommendations. We must be an integral partner in the implementation process, to ensure that robust mechanisms are put in place. However, these must be realistic agreements that can be put into practice, or they will be filed away as aspirational documents and lessons will not have been learned or attitudes changed.

We need to take individual and collective responsibility to ensure our **voices are loud and clear** in the journey ahead, as part of the ongoing Involvement Strategy development. We must build on the work we have done to date, embedding it as a model for the future. **Implementation is not optional.** If it does not happen, all the work over the past ten months will have been a complete waste of everyone’s time. We have come a long way, but also know how much work there is still to do.

“Now this is not the end. It is not even the beginning of the end. But it is, perhaps, the end of the beginning.”(Winston Churchill)

Workstream 1 - Duty of Candour

Duty of Candour

Earlier this year the Duty of Candour workstream asked for individuals and organisations to submit any evidence or research they have about introducing a statutory Duty of Candour and what it might involve. To date twelve written submissions have been received, predominantly from health and social care representative bodies.

These submissions have been studied by the workstream members, in order to help them with their deliberations. Responses from organisations have been published on the Department of Health website <https://www.health-ni.gov.uk/articles/ihrd-get-involved-duty-candour>. There is still time for others to respond. We are keen to hear from organisations, individuals working within Health and Social Care and also members of the public.

It is essential that the widest range of individuals and organisations have the opportunity to express their views on a Duty of Candour.

As part of this process the workstream held a series of involvement workshops with stakeholders during the month of June. These included:

- two workshops at membership events for the Patient and Client Council. These were designed to assess current knowledge of the Duty of Candour and to inform plans for wider engagement with the general public later this year;
- six workshops with HSC Trust staff, covering each Trust area to assess the knowledge and views of staff working in these Trusts
- an event with the third sector hosted by the NI Council for Voluntary Action (NICVA).

Seamus McAleavey, Chief Executive of NICVA said: "This response to the Inquiry highlights a major shift in thinking in the Department of Health. It will transform the culture in health organisations to the benefit of patients and the public. It will also set the agenda of organisational culture beyond health organisations as the public will expect openness and candour from all, including third sector organisations. That is why it is really important for voluntary and community organisations to engage in this change process and influence its outcome."

A key recommendation of the IHRD was to embed within the health and social care system a 'Being Open' culture alongside a statutory Duty of Candour in Northern Ireland. NICVA believes it is important that the sector is involved as much as possible as the Department implements the recommendations of the IHRD.

As well as the event in Belfast, NICVA will also facilitate one in Derry/Londonderry in the Autumn so that the voluntary and community sector can help input into and inform the workstream.

A number of further events are being planned with other stakeholder groups in the coming months. These will include primary care, independent health care providers, staff working for independent healthcare providers, HSC organisations other (than Trust) including the Patient and Client Council and its membership scheme. There will also be further engagement with third sector organisations, regulators, organisations representing staff and with the general public.

The workstream remains committed to hearing people's views and would like to receive submissions of evidence from anyone who wishes to do so. You can do this by emailing your submission to ihrd.implementation@health-ni.gov.uk

Workstream 2 - Death Certification Implementation Working Group (DCIWG)

This workstream oversees the work of three main sub-groups which are detailed below. In addition the main workstream is itself tasked with delivering on three of the recommendations:

Recommendation 43 - A deceased's family GP should be notified promptly as to the circumstances of death to enable support to be offered in bereavement.

Recommendation 48 - The proceedings of mortality meetings should be digitally recorded, the recording securely archived and an annual audit made of proceedings and procedures.

Recommendation 49 - Where the care and treatment under review at a mortality meeting involves more than one hospital or Trust, video conferencing facilities should be provided and relevant professionals from all relevant organisations should, in so far as is practicable, engage with the meeting.

The workstream has established a task and finish group to take forward these three recommendations. The three existing sub-groups are continuing to progress their respective recommendations.

Independent Medical Examiner (IME) sub-group

One recommendation which will, at one stage or another, impact every citizen in Northern Ireland is that which calls for an Independent Medical Examiner (IME) who would be able to provide robust scrutiny of deaths.

There is a concern around this, however. We have a tradition of burials within three days of death, so it will be important to make sure that the measures we introduce disrupt this as little as possible.

To this end we have been assessing the value of information contained in people's Electronic Care Records. We concluded that this was potentially a very valuable source of information for an IME in order to provide assurance around referrals to the Coroner, the quality and accuracy of the information on the medical certificate of cause of death and the identification of any quality of care issues.

The sub-group is now working on proposals to develop a further prototype IME service to be trialled in real time. This will help to establish what impact an IME service will have for families, doctors and funeral or cremation processes. It is hoped to get this underway by September.

Preparation for Inquests [and Litigation] sub-group

The Preparation for Inquest [and Litigation] sub-group has been examining existing practices in order to develop improved processes for Health and Social Care (HSC) organisations and their legal representatives when dealing with the Coroner, Inquests and Litigation. Some of the recommendations have a natural link and a small working group has been established to take forward the development of guidance and protocols.

HSC Bereavement and Pathology Network sub-group

The HSC Bereavement and Pathology Network sub-group is working to provide support to families through bereavement and to improve the hospital consented post-mortem process. The sub-group have evaluated the existing standard operating procedures, identified the areas that need to be improved in line with the recommendations and are revising procedures as a result. Work is also continuing with HSC Trust Bereavement Co-ordinators to establish what services are currently available to bereaved families and how this could be extended.

Work is currently underway to review the Pathology Standard Operating Procedures (SOPs) to identify those that need to change in line with recommendations in respect of the limiting of a post-mortem (recommendation 44), the exchange of information between the clinician referring for a post-mortem and the pathologist (recommendation 45) and the responsibilities/requirements on a pathologist when providing a post-mortem report (recommendation 47(i), 47(ii), 47(iii), 47(iv) and 47(v)).

Amendment of regional guidance documents and staff training for consent-taking for post-mortems will also be required. The revised documentation will be shared with the various stakeholders for consideration. Testing of the new processes will also need to take place before full implementation can begin to ensure the changes do not have any adverse impact on any other existing protocols or procedures.

We expect that circulars will issue for these recommendations by the end of the year.

Workstream 3 - Duty of Quality

The Duty of Quality workstream as a whole is looking at recommendation 2:

“The highest priority should be accorded (to) the development and improvement of leadership skills at every level of the health service including both executive and non-executive Trust Chairs and Non-Executive Board Members.”

The topic of leadership was featured in the recent stocktake event where those gathered had a presentation from Myra Weir, Director of HR and Corporate Affairs at the SEHSCT, on the HSC Collective Leadership Strategy.¹ Myra set out the Strategy’s aims for a culture that would see collective leadership in action, where leadership was shared and, above all, compassionate.

Arms-Length Body (ALB) Board Effectiveness sub-group

The ALB Board Effectiveness sub-group has set up a number of “task and finish” groups to focus on particular actions.

One of them is looking at recommendation 72. It states: **“All Trust publications, media statements and press releases should comply with the requirement for candour and be monitored for accuracy by a nominated non-executive Director.”**

This recommendation was made after Mr Justice O’Hara found that a press release issued by Altnagelvin Trust about the inquest into the death of Raychel Ferguson “failed to reflect the evidence” and “contradicted Altnagelvin’s own findings.” He concluded: “It is a matter of the gravest concern that a formal public communication issued in the name of an HSC Trust should mislead.”

The group believes that this level of scrutiny would be very difficult to achieve in real time. Therefore it has met with the Trust communications leads to discuss draft principles which media statements and the like could be held up against for scrutiny. The principles will include an authorisation framework for levels of approval, together with accuracy checks, escalation procedures and ALB Board assurance framework arrangements. The group plans to produce a protocol for the sub-group to consider later in the year.

A second group has been looking at developing guidance on the preservation and publication of Board minutes and papers. This is covered by Recommendation 70, which states: **“Effective measures should be taken to ensure that minutes of board and committee meetings are preserved.”**

This followed an occasion at Altnagelvin, when Board minutes were missing.

The group has been looking at the Department of Health’s Good Management, Good Records guidance and is working on an outline publication scheme. It has also met with the Board secretaries from all the HSC Trusts and agreed the scope for the work.

1 <http://www.setrust.hscni.net/pdf/hsc-collective-leadership-strategy.pdf>

A third is working on a handbook for Non-Executive Directors to support them in their ability to scrutinise and challenge the performance of organisations. The group has agreed an outline structure for the handbook and has begun drafting it.

Clinical and Social Care Governance sub-group

This sub-group has 14 recommendations to progress and has split them into three areas, each with its own “task and finish” group to cover: Analysis and Training; Clinical Guidelines and Organisational.

These will be reporting back at the end of July and will consider the best way to consult with those affected by proposed changes.

Maria Somerville sits on both the Board effectiveness and the clinical and social care governance sub-groups.

Hospital has been a very large part of life for her and her 23 year-old son Luke who is severely disabled. At one point he was admitted to hospital 11 times in nine months.

Yet she says that she found it very difficult to communicate her insights and concerns about his condition with professionals.

“I am an expert on my own child but time and again found myself not being listened to, or being dismissed.”

Maria is a social worker and said she was used to being within the system looking out. “I soon discovered what it is like to be outside the system looking in: it was humbling and frustrating.”

But she did not give up. She quietly kept at it. “Once they realised that I did have my own expertise, they started to respect me and to listen to what I had to say.”

Around 17 years ago she became involved in the Wraparound project with the Southern Trust, a pioneering programme that worked with parents in designing services.

She said: “This was way ahead of its time and was well supported by professionals who had the vision to recognise that parents have expertise. It showed me how everything flows from having the right culture. The change required is away from what professionals thought was important for us to what is important to us.”

She has gone on to become involved in several other advocacy projects and was on the Transformation Advisory Board which was set up to progress the Bengoa report into the health system.

She said: “When I was invited to take part in this work I just knew I had to be involved because of the children who had lost their lives and their families. I wanted to do the best for them.

I felt an absolute duty – this could have been my son, your son, any child in Northern Ireland.”

For her the most important thing of all is to get a change in culture. “We need professionals, but they also need us. When they stop listening to service users and carers, that’s when mistakes are made.”

She has been impressed with the work so far – especially the inclusion of Non-Executive Directors. “I’ve learned a lot from them and they have learned from us. It is important to narrow the gap between those at the very top of the system and the people who use it. This is helping to do that.”

“In my experience this is the first time that the Department has engaged in a really meaningful way. This maybe the greatest opportunity they will ever have to put things right. It can’t be wasted.”

But she does see a big challenge ahead: how to make changes work on the ground, day-to-day.

“It will mean professionals relinquishing a wee bit of power. There are people willing to do that and others who will find it very hard.”

There’s also the challenge of bureaucracy. “We need to make sure that we don’t tie ourselves into knots with processes and procedures. What’s most important of all is the values of the people working in the system. They need to have a strong moral compass and to put patients at the centre. What we don’t want to happen is for bureaucracy to take them away from what brought them into public service in the first place.”

Workstream 4 - Paediatric-Clinical Collaborative

This workstream is responsible for 21 recommendations.

Five of them involve the important area of how patients' records are maintained and updated and these have been grouped together. Work is underway to examine how the relevant information on paediatric early warning scores, fluid management, fluid calculation and handover can be included in the Electronic Care Record. If this is a viable option, the IT development of this work will begin in September and aims to be completed by the end of March 2020.

Work is well advanced in relation to Recommendations 10 and 12 with the intention of issuing guidance before the end of this year.

Recommendation 10 - Health and Social Care ('HSC') Trusts should publish policy and procedure for ensuring that children and young people are cared for in age-appropriate hospital settings.

Recommendation 12 - Senior paediatric medical staff should hold overall patient responsibility in children's wards accommodating both medical and surgical patients.

Discussion papers covering all the workstream's recommendations have been prepared. The next phase is to involve parents and children – events are being arranged in September and October to test the proposals set out in a number of the papers.

The Paediatric-Clinical workstream is chaired by **Dr John Simpson**.

John is an associate of the Health and Social Care Leadership Centre. A medical advisor to the RQIA, he was formerly a consultant psychiatrist and medical director with the Southern Trust.

He says: "Our workstream first met in June of last year and what has been really nice is to see how well the group has welded together as a team. We have doctors, nurses, parents, carers and other independent voices as well as people from the Department and the Board. It's a really heterogeneous group and we're making good progress together."

Each of the Trusts has formed its own implementation team and John's workstream has linked in with them to help develop their ideas on what needs to change.

A number of recommendations require IT solutions and John's workstream has formed a sub-group to work with the Electronic Care Record team to put things in place – and he says he's delighted with the level of help that they are receiving to make this possible.

For John these high levels of involvement and co-operation are the keys to success. He said that the health service is sometimes overwhelmed with recommendations and new guidelines which may come from many different sources. In implementing these there can sometimes be a disconnect between the Department, the Board and the Trusts. This project has brought together all of the elements of the healthcare system in Northern Ireland to work in a collaborative manner with users of the service.

“This is a much more coherent way for the Department of Health to be leading change,” he said.

The structure of the health system in Northern Ireland means that individual Trusts operate in different ways, according to their size, geography and needs. In the past John says that this has sometimes inhibited regional co-operation.

But he has been very impressed by how the different organisations are working harmoniously on this project. “Paediatrics is a small speciality and therefore needs a regional drive,” he says.

John’s workstream has come across two recommendations where they believe that the actions proposed will need to be slightly varied. The first is one which recommends that paediatricians should hold overall patient responsibility in a children’s ward. “This is problematic,” he says, “because some patients are in for surgery. We are therefore looking at devising protocols that ensure that surgeons and paediatricians work closely together in such cases to share expertise.”

A second states that foundation doctors should not be employed in children’s wards. The issue here is that although this is reasonable regarding doctors in their first foundation year, foundation year two doctors are being trained in paediatric medicine and work under careful supervision on children’s wards. It is a necessary part of their learning before they go on to become GP’s or indeed consultant paediatricians.

In both cases the workstream has the task of understanding the spirit of the recommendations and then working out the best way of bringing that into effect.

John added: “The bottom line is that our focus must be to improve the quality of care, both now and for the future. We should be constantly trying to do things better, and we must implement measures which make a real impact.”

Orla Watt sits on the Paediatric-Clinical workstream.

She is a community children’s nurse, so has clinical expertise, she is the parent carer of a child with a disability and she also runs the social enterprise Parent Action Community Interest Company (CIC.)

Parent Action seeks to empower the parents of children, young people and adults with disabilities/long-term health conditions and additional needs, so that they can advocate effectively for all their families’ requirements.

Orla is passionate about the need to involve parents in the care of their children when accessing health and social care services, in hospital or in the community, and within the IHRD Implementation Programme. “It is clear from Mr Justice O’Hara’s report that a lack of parental involvement by the system led directly to the tragic and unnecessary deaths of the children. This needs to be properly addressed if the programme is to succeed. It is absolutely crucial.”

“Beyond that we will also need to ensure that the funding and resources are in place to ensure full parental involvement, as well as the involvement of staff on wards, in management and in HR and Directorate of Legal Services roles, not just in the short term but for many years ahead.”

The authorities have a legal responsibility to involve people in decision-making. But Orla says that up until now, parents' experiences of trying to be involved in quality improvement have been of being treated as a tick box exercise by health authorities.

“HSC have devised excellent policies, strategies and programmes for quality improvement, particularly of safety issues and spoken to service users and carers but have not yet effectively involved parents, nor built parents and staff capacity to drive the process, putting people in the lead,” she says.

“What we need is genuine co-production. This requires a big cultural change for what is a very hierarchical system. We need to start it here, with the implementation programme, by recognising staff, parents, children and young people and the public as assets to the programme; and support and build their capacity to work with each other, with staff and with other stakeholders. This takes time, and in my experience, culture change skills from skilled facilitators.”

“I was delighted to be invited to take part in the programme, and the intention is good to work in a more co-produced way. But we need to be facilitated and supported to listen to and actually hear each other, we need to grasp the opportunity and do this well.”

Orla says that there is progress on this front within her own workstream but that capacity building around involving parents, children and young people, staff and other stakeholders is urgently required across the health system in order to ensure that the right principles are applied.

“There is a lot of lived and learned expertise in Northern Ireland and this needs to be used. The point is that parents, service users and carers and staff are great assets because of what they know and their experiences of health care.

Everyone needs to be supported and have their capacity built, to work together, to make the system work better, not only for Raychel, Adam, Lucy, Claire and Conor's families, but all of our children, parents and families, into the future.”

Workstream 5 - Serious Adverse Incidents

The workstream has developed proposals for 17 out of its 18 actions. It is now engaging with stakeholders to test them to make certain that the proposals are practical and can be implemented.

In response to recommendation 37(i) the workstream has developed a draft statement which is entitled “Statement of what you should expect in relation to a Serious Adverse Incident”

Recommendation 37(i) Trusts should publish a statement of patient and family rights in relation to all SAI processes including complaints.

The workstream then launched an online survey to seek views on the draft statement. ²There were approximately 130 responses. A very significant majority of the people and organisations that replied supported the key principles and the establishment of the liaison officer role:

- 94% agreed with the principles;
- 85% of the responses came from health and social care sector staff;
- 94% of the responses came from individuals;
- 78% of responses came from people who had direct experience of the process or who had knowledge of the Serious Adverse incident process;
- 79% or more of the respondents found the various aspects to be clear;
- 60% felt the document was just right in terms of size.

An easy read version will be developed. There will also need to be engagement with health and social care staff as many of them responded to the survey with concerns and queries. A report on the survey results will be published soon. Implementation of the statement will follow further involvement and is planned for November. This will directly deal with seven actions.

There has been good progress with Recommendation 91 and all Trusts are now using the same IT system for recording adverse incidents and using the same framework for coding incidents. This is an essential step to allow analysis of this information on a regional basis to identify patterns and trends. Work is underway to pilot how that might be carried out.

Recommendation 91 - The Department, HBSC, PHA, RQIA and HSC Trusts should synchronise electronic patient safety incident and risk management software systems, codes and classifications to enable effective oversight and analysis of regional information.

It is expected that a circular covering the implementation of three recommendations will be issued by September for implementation. These are:

Recommendation 33 - SAI Reporting: Compliance with investigation procedures should be the personal responsibility of the Trust Chief Executive;

Recommendation 37 (vi) - Trusts should seek to maximise the involvement of families in SAI investigations and in particular: all written Trust communication to parents or family after a SAI related child death should be signed or co-signed by the chief executive. (IHRD Report 2018);

Recommendation 82 - Each Trust should publish policy detailing how it will respond to and learn from SAI related patient death (IHRD Report 2018).

Workstream 6 - Education and Training

The Education and Training workstream is now meeting monthly and has convened on seven occasions. Membership continues to grow as relevant experts are drafted on to the team.

The workstream has developed Assurance Framework objectives for each of the six recommendations to ensure there is a clear, common understanding of the recommendation/action, what should be expected and the limitations of the objective.

The workstream has now benchmarked Health and Social Care organisations against the six recommendations. A draft summary document has been produced which will allow us to identify areas and means of performance improvement.

In addition a Strategy Framework document has been developed in collaboration with other workstreams to support how the education and training issues arising from the IHRD recommendations are identified and addressed; and how effective learning can be reflected in HSC practices, processes and behaviours. This includes an education and training planning tool and a template for other workstreams to refer recommendations to the Education and Training workstream.

Professor Keith Gardiner, Postgraduate Medical Dean and Chief Executive of the Northern Ireland Medical and Dental Training Agency chairs the Education and Training workstream.

His team comprises a wide range of people including those who are involved in either the commissioning or delivery of training, together with HR expertise from service providers.

He said: “We are responsible for six recommendations. We have to thoroughly understand each one, what gave rise to it, what it is intended to achieve and then defining precisely what it means. We also need to know how the recommendations we are working on link in with all the other recommendations in the other workstreams, how we will communicate the actions required, how we implement them and then make sure they are working.”

Some key principles for the planning and delivery of education and training have been agreed. These principles are intended to apply across the entire health and social care system, irrespective of the different ways that the different Trusts and other bodies do things. It also follows that all the organisations involved need to work collaboratively so that training is appropriate for every organisation, is consistent and duplication is avoided as well. Patients and their families need to be put at the centre and this may involve them being involved in co-designing and co-delivering training where this is relevant. Crucially the work needs to be outcomes focused. It is not a tick box exercise.

He said: “It is important that people have actually learned from any training and taken what they have learned back into practice, and furthermore that implementation of the recommendations makes a difference to the service, patients and their families.”

In parallel the team is developing a template for deciding who needs training within the system, whether it should be compulsory and what training needs should be prioritised.

It will also look at how people should be trained, whether the best method to meet varying needs will be face-to-face or e-learning. Resources will be factored in. It's not just a question of designing the training, there are other challenges to overcome as well – freeing up the time of people to deliver training and staff to receive it. This all in the context of a service which is under strain.

The content also needs to be right – if there is an existing national standard this needs to be identified and there is also the question of whether courses need certification and making sure the content is kept up to date.

A theme that constantly emerges as the various workstreams go about their tasks is the cultural barriers to change. Keith is acutely aware of this. “It is a significant challenge, one that starts at the top and requires leadership. People don't just need to know what to do, but also need to be supported to be open and honest rather than be subjected to criticism when care goes wrong, and therefore enabled to do the right thing.”

He says that changing the culture starts at undergraduate level by ensuring that people who are seeking entry to healthcare professional education are doing so for the right reasons, to recruit at every level right up to senior executives based on values, and to reinforce those values throughout the service through an appraisal and reward system based on values.

Keith also sees an important opportunity in the work. Health and social services in Northern Ireland are supported by fragmented and complex education systems. The workstream is bringing together people from these different bodies to work together. They are currently working on a roadmap which describes all these bodies and explains what they do.

“This is the first time this has been done,” he said: “This could lead to much closer working relationships between training organisations, it could even, ultimately, lead to them all merging into one.”

Dr Melissa McCullough is on the Education and Training workstream.

She is a senior academic of international standing in medical education, specialising in ethics and law. Melissa is also a Non-Executive Director of the Health and Social Care Board and has worked as a member of one of the National Institute for Health and Care Excellence (NICE) guideline committees and is a visiting academic at the Royal College of Surgeons in Ireland.

Melissa is a long-standing advocate of transparency in healthcare and has always had a strong interest in the need for a Duty of Candour.

She said: "Openness is something we need to work on in the health system. As a scientist and ethicist, I have taught students medical ethics, professionalism and leadership for over 15 years, and students often report the theory can be very different to practice. I have spoken with my students and colleagues who often feel a real fear of speaking up and a belief that if they do speak up or rock the boat there could be repercussions for them. Perhaps some of this is down to Northern Ireland being such a small place."

She says that it is crucial that senior management lead the way in changing the culture. What she says is required is a sense of collegiality throughout the system, where everyone feels included and transparency is actively encouraged. "My opinion is that you can't take away fear without ensuring trust and understanding - where everyone knows their voice is heard and that what they say is respected and valued within the organisations and teams where they work."

"Of course, this will take time, but I like the way the IHRD programme and workstreams are being run. It is very efficient and we're making progress, but there's a lot more to come."

That is certainly the case for the Education and Training workstream – many of the other workstreams are identifying training needs as they carry out their responsibilities – and these needs get passed on to Melissa's group to progress.

"The scale of all of this is a challenge," she says. "There is a lot of pressure on the system as it is, and the resources required are not just funding, but peoples' time to train as well. There is very little of either to spare. We can and will achieve the outcomes, but it will require everyone to be creative and collaborative in their approach."

Melissa is originally from New Jersey but has lived in Belfast for 25 years. With a family member in the medical profession in the US, she has knowledge of the health systems on both sides of the Atlantic. "Anecdotal, I believe they are better at communication, especially candour in the US. It seems respected." However, she said that on balance, she prefers our system. "If you have an acute or chronic illness the NHS, paid for through your taxes, is there for you. If you have an acute or chronic illness in the States, there is a chance you might struggle to get treatment depending on whether you have the appropriate insurance coverage. So for all the funding issues, waiting lists and pressures on the system, I'd still choose the NHS every time. I am deeply wedded to the ideal that good health and social care should be available to all, regardless of wealth, and that *no society can legitimately call itself civilised if a sick person is denied medical aid because of lack of means.*" (In Place of Fear, Aneurin 'Nye' Bevan, 1952).

Workstream 7 - User Experience and Advocacy

This workstream has the potential to transform the relationship between service users and their families and the Health and Social Care system.

One of the more radical and exciting proposals that is coming out of the User Experience and Advocacy workstream is to provide an online system to allow service users and carers to give feedback on their experience of health and social care services 'as it happens'.

Full details of this system will be provided in the next update.

The workstream is looking at how best to set up an advocacy service to help people who are experiencing difficulties with the system. One piece of research has been received and a further piece, which examines how advocacy is delivered in other countries will be available soon.

Over and above this it is looking at how to help people using the system to understand what they should expect from it, what questions they should ask about their care and how to go about raising any concerns.

Northern Ireland's Deputy Chief Nursing Officer **Rodney Morton** chairs the User Experience and Advocacy workstream.

He believes that the work they are doing has the potential to transform relationships between citizens and the health service. His workstream has a strong mix of service users and carers, clinicians, policy makers and, critically organisations that campaign for children, adults and older people.

He said: "We were always very keen to ensure that we had people on the team with knowledge of every age group so that what we come up with covers peoples' entire lifespans."

"We're working well, we are all absolutely clear on what we need to do and are having healthy, robust discussions about what is achievable."

What they are discussing will affect everyone who uses the health service. One recommendation concerns the establishment of an advocacy service to help families experiencing difficulties with the health service which can also provide independent expert advice. The team commissioned research on this which has proved crucial to their thinking.

They have concluded that it is vital to ensure that people are helped to be able to advocate for themselves from the moment they enter the health and social care system.

Rodney said: "People need to know what questions to ask, and know from the outset what they can expect from our health and social care system and importantly what they can do if things go wrong. What we need is a partnership Charter for people who need healthcare. Scotland currently have a patient right charter which we can learn from.

“In addition some people are especially vulnerable, for example those with mental health issues who do not have strong family support. In these cases we want to see peer advocates in place. Peer advocates are people who have had similar conditions who would ‘buddy up’ with them and advocate on their behalf. There are cost implications here, but we need to set this against the cost when things go wrong.”

He added: “Of course, the best outcome by strengthening partnership working with people, by being open and proactively addressing issues of concern of would be to significantly reduce the need for an independent advocacy service in the first place.”

In terms of the organisation that could offer independent advocacy, Rodney’s workstream is looking at how the Patient Client Council can be re-configured to take on that role, with the ability to work with a network of independent experts to advise patients and their families.

The third area the team is looking at is how to improve how the health system engages with citizens. Rodney explained the Department recently launched its Co-production guide which aims to improve the involvement of people at individual, family and community levels. It is within this context that the group will seek to develop a new guide called “You and I together” which aims to set out how people can be fully involved in their own care, as partners with clinicians, sharing decision-making. This guide would mirror the Charter for Patients.

The group is also looking at how patients can give online feedback in real time on the health system both to improve engagement and levels of care.

Molly Kane sits on the User Experience and Advocacy workstream.

Molly Kane has devoted her working life to the health service. She is also a carer, having retired from what she describes as ‘the best job in the world’ in order to look after her mother.

Molly is currently on the Northern Ireland board of the Royal College of Nursing. She is the former Regional Lead Nurse Consultant for mental health, learning disability and prisoner health care.

In that role she was involved in some of the first, tentative steps towards involving service users and carers in designing services.

“We were early adopters in mental health and found that having people with experience of mental illness on commissioning teams, for example, was very helpful.”

She wants to see more meaningful involvement across all service areas: “Everyone in Northern Ireland has a vested interest in getting the best possible service.”

Molly says that progress was initially slow in her workstream but momentum is now building: “We have three recommendations that nobody disagrees with – the issue is how we make them work.”

For example one of them calls for the Department to set up an organisation to identify matters of patient concern and to communicate patient perspectives. The issue here is which organisation this should be. Northern Ireland already has a Patient Client Council, so one question that the workstream is grappling with is how that might need to change to satisfy the recommendation.

Another concerns the remit of the Patient Advocacy Service as recommended by the report – how and when it would support patients and their families who have experienced problems in the system.

She says she has been impressed with the level of support given by the Department to the work. “We get all the information we need and a regional service user and carer group has been established which gives all services users and carers involved in the various workstreams the opportunity to get together and compare notes about everything that is going on. Nothing is Nirvana but people are being heard.

Everyone is very helpful and willing to listen to and address concerns. We are all working to the same outcome, Nobody wants another child to die from hyponatraemia.”

For Molly open communication with families is the key. “When people don’t listen to families, that’s when things go wrong and why co-production with service users and carers is so vital.”

Joan O’Hagan is a Non-Executive Director who sits on the User Experience and Advocacy workstream.

She is a Non- Executive Director of the South Eastern Health and Social Care Trust, which she joined over two years ago following a long and varied career in health and social services and the voluntary sector. Joan was a former Director of Nursing at the Newry and Mourne HSS Trust and Director of Asthma UK Northern Ireland.

Joan stresses that she and the other Non -Executives participating in the various workstreams are representing themselves, bringing their own skill sets to the work. They are not representing their trusts.

However she says that as well as inputting to this programme of work, Non- Executive Directors will increase their knowledge on a range of issues, which will allow them to contribute more effectively at Trust Boards both in supporting and challenging their executive colleagues.

Joan said: “The recommendations of the Hyponatraemia Inquiry has implications for the wider health and social services and will impact everything we do, not least in ensuring that there is a culture of openness and transparency where users and carers are partners in their care.”

She adds that the work is complex and will take some time to fully implement but she acknowledges that health and social services in Northern Ireland has already made huge strides in progressing many of the recommendations.

An example of the complexity is Recommendation 37, which states that “a fully funded advocacy service should be established, independent of individual trusts, to assist families in the Serious Adverse Incident (SAI) process. It should be allowed funded access to independent expertise and advice in complex cases.”

Joan explained “It is important, therefore, that there is a common understanding of what we mean by ‘complex’, so defining it is extremely important. I think that we are at a point now in the workstream where we better understand the recommendations and what the intention is behind them. There is also some overlap between the work of the workstreams and this is being addressed in order to ensure that the actions flowing from the recommendations are clear and understood.”

One important task for the workstream Joan is involved in is looking at user and carer involvement in serious adverse incidents (SAI).

She said: “There is a sincere attempt to ensure that users and carers play a meaningful role in this process at all stages. It is always difficult to do this, particularly when trying to involve wider groups of people who use our services. However, much has, and continues to be done by the service as a whole, to not only have users and carers as partners in their care and treatment but also in the whole area of co-production. The actions flowing from the Hyponatraemia report will further this work.”

She said that “resource constraints and legislation can, at times, make it extremely difficult to always respond to the wishes of users and carers but that every effort must be made to engage and involve them both at an individual level and within the wider population.” She concluded: “Staff need support, training and time to do this and this workstream, with the expertise of all involved, is making excellent progress in setting the direction for this to be a reality.”

Workstream 8 - Workforce and Professional Regulation

The workforce and professional regulation group has completed an initial assessment of the recommendations which fall to it. These recommendations are closely linked to the work of other workstreams on other recommendations. Therefore this workstream's recommendations will be completed once the work of other workstreams has progressed further. However it is planned to ensure that workforce leads become involved in other workstreams to ensure that HR and employment law considerations are included at as early a stage as possible.

Workstream 9 - Assurance

All the other workstreams have to create what is known as an “assurance framework” for each of the recommendations they are responsible for. This details what needs to be changed together with the evidence and measures to be taken to ensure successful implementation. These are then sent to the Assurance workstream for feedback. This work will continue until all of the workstreams and sub-groups have developed the content of the assurance framework for each of their recommendations including proposals on how implementation will be assessed.

Recommendations being overseen by the programme

There are three recommendations which are not being considered by individual workstreams. Instead these are being directly overseen by the Implementation Programme Management Group which is responsible for ensuring all recommendations are progressed. Two are addressed to the Department and the third will require the return of an Executive and Assembly to put in place. Here are the details of recommendations together with an update on progress:

- **Recommendation 85 – that the Department of Health should appoint a Deputy Chief Medical Officer with specific responsibility for children’s healthcare;**

The Department currently has two Deputy Chief Medical Officers who report to the Chief Medical Officer together with a number of other medical posts. The programme team is now working with the Department, looking at existing roles and responsibilities and examining how the team needs to be reconfigured in order to best meet the recommendation. This work is well underway and a set of draft proposals are currently being considered.

- **Recommendation 88 – The Department should engage with other interested statutory bodies to review the merits of introducing a Child Death Overview Panel;**

The Department is working with the Public Health Agency to finalise a proposal paper relating to the establishment of a Northern Ireland Child Death Overview Panel (CDOP). The draft paper will describe the purpose and scope of the CDOP, the principles and assumptions which will underpin its operation and proposed membership. The paper will also outline the specific roles and responsibilities of the Public Health Agency, the Department of Health and the Safeguarding Board for Northern Ireland and identify indicative costs. The proposals have been discussed with the Northern Ireland Commissioner for Children and Young People, who has maintained a strong interest in the introduction of a CDOP for Northern Ireland.

It is intended to undertake a targeted consultation on the proposals.

- **Recommendation 94 – A Government Committee should examine whether Clinical negligence litigation as it presently operates might be abolished or reformed and/or whether appropriate alternatives can be recommended.**

This is one of the recommendations which will require a Minister in place to progress.

Next Update

The next update will be published on 17th October 2019 and will focus on progress made by each workstream against individual recommendations.

Appendix 1

Workstreams

The 120 individual actions arising from the 96 recommendations have been delegated to 9 workstreams that report to the Implementation Programme Management Group.

Workstream	Workstream name	Number of actions
1	Duty of Candour	11
2	Death Certification Implementation Working Group	22
3	Duty of Quality	28
4	Paediatric-Clinical Collaborative	21
5	Serious Adverse Incidents	18
6	Education and Training	6
7	User Experience and Advocacy	3
8	Workforce and Professional Regulation	7
9	Assurance	1

Sub-Groups

There are seven standing sub-groups tasked with taking forward a subset of recommendations within their workstream.

Linkages

There are linkages between the recommendations being looked at by different workstreams and sub-groups.

Appendix 2

Group Chairs

Name:	Group
Quintin Oliver (Stratagem)	Duty of Candour workstream
Peter McBride (Inspire Wellbeing)	Being Open sub-group
David Best (DoH)	Death Certification Implementation Working Group (DCIWG) workstream
Vivien McConvey (VOYPIC)	Preparation for Inquests [and Litigation] sub-group
Paul Finnegan (Cruse Bereavement Care)	Independent Medical Examiner sub-group
Sharon Wright (DoH)	HSC Bereavement and Pathology Network sub-group
Eddie Rooney (Former HSC)	Duty of Quality workstream
Jim Moore (Translink)	ALB Board Effectiveness sub-group
Lynn Charlton (Northern Ireland Ambulance Service)	Clinical and Social Care Governance sub-group
Linda Greenlees (DoH)	RQIA Remit sub-group
John Simpson (Former HSC)	Paediatric-Clinical Collaborative workstream
Conrad Kirkwood (DoH)	Serious Adverse Incidents workstream
Keith Gardiner (Northern Ireland Medical and Dental Training Agency, NIMDTA)	Education and Training workstream
Rodney Morton (DoH)	User Experience and Advocacy workstream
Andrew Dawson (DoH)	Workforce and Professional Regulation workstream
Olive MacLeod (Regulation and Quality Improvement Authority, RQIA)	Assurance workstream