



Department of
Health

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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Foreword by Richard Pengelly – Permanent Secretary – Department of Health

This report is the first of a series of updates to let people know how work is progressing in response to the recommendations of the Hyponatraemia Inquiry report.

The health and social care service belongs to all and is cherished by all. Yet the inquiry found serious failings in the way that we work and in some of the systems we adopt. We know that we have to restore public confidence in the care we provide. To do that, we have to change.

I have taken full personal responsibility for this process and all those working on implementing the recommendations from the Inquiry are directly accountable to me.

Once we had studied the report, it was clear that how we go about making changes is every bit as important as the changes themselves. The restoration of public trust and confidence requires a different approach.

That is why we have reached out to service users, carers, our partners in the voluntary sector, regulatory bodies, the Coroner's Office and a whole range of other experts in order to help us with this important work. For us this is a new way of doing things. This will ensure that what we put in place is robust although it means it will take a little longer than if we had pushed through changes without working with those most affected. Such an approach would have been fundamentally flawed.

We now have over 200 people from a broad range of backgrounds working together on how we can together provide safe and accountable care. It is important to remember that the 96 recommendations within the report have implications not just for cases involving hyponatraemia, but for the whole health and social care system. It is vital that we get this right.

There are areas where we need to await the return of an Executive and Assembly to implement because new legislation will be needed – for a Duty of Candour Act, for example.

But most of what needs to be done can be done – the changes are operational in nature and do not need legislation or Ministerial direction. I anticipate that the vast majority of recommendations will be implemented by summer 2020.

There is a huge amount of commitment and enthusiasm within the various teams working on this project. I am confident that what will emerge from their efforts will be a stronger, more accountable health and social care system with public trust restored.

It will also be important for the general public not just to know about the work we are doing, but also to have every opportunity to express their views as well.

“There is much for all who work in the health service to reflect upon and learn from in the sad narratives of this report.”¹

Background

The Inquiry into Hyponatraemia-Related Deaths (IHRD) was set up to investigate the deaths of five children in hospitals in Northern Ireland. It published its findings on 31 January 2018.

It found that some of the five deaths were avoidable. It also concluded that the culture of the health service at the time, the arrangements in place to ensure the quality of services and the behaviour of individuals had all contributed to those unnecessary deaths.

Mr Justice O'Hara acknowledged in the report that progress had been made in hyponatraemia practice and guidance since the fatalities. He also concluded that a more comprehensive approach for learning from error was needed for further unnecessary harm to be avoided. He set out 96 recommendations across 10 themes where he had identified failings in "competency in fluid management, honesty in reporting, professionalism in investigation, focus in leadership and respect for parental involvement".²

Mr Justice O'Hara was also scathing of how the families were treated in the aftermath of the deaths and also of the evidence given to the inquiry by medical professionals. He said that:

"doctors and managers cannot be relied on to do the right thing at the right time" and that they had to put the public interest before their own reputation; and some witnesses to the inquiry "had to have the truth dragged out of them".

In total, 120 actions are required to implement the 96 recommendations. This document is the first of a series of quarterly progress reports from the implementation team.

More detailed information about work to implement these actions is shown on the Department of Health website at www.health-ni.gov.uk/topics/hyponatraemia-implementation-programme

How the process works

We have gathered together over 200 people from widely differing backgrounds to work through how best to implement the recommendations.

They include service users and carers, representatives of the voluntary and community sector, staff from health and social care organisations, non-executive directors of health and social care organisations, and Department of Health staff. Every one of them brings a unique perspective on the challenges we are working through whether through their expertise or, in the case of service users and carers, their personal experience.

All those taking part have had detailed induction sessions on the recommendations and their implications. This means that they have a grasp of the detail.

In the course of this work, we will also be reaching out to the general public to canvas their views on the proposals that emerge.

In some areas, public confidence in the system is at stake. Groups examining these issues are chaired by independent people from outside the health and social care system.

There are significant numbers of staff from the Department and Health and Social Care bodies involved as well. This is important because they will have to implement new policy and changes in practice on the ground.

Nine workstreams have been set up to examine themed groups of recommendations and some of them have sub-groups to drill down into specific areas.

A fuller breakdown of how the programme works is included as an appendix to this report (Appendix 1).

All those taking part are committed to being open, honest and truthful with each other in their work, in how they communicate it to the public and that the changes they make helps ensure that the entire health service upholds this vision.

They will work together, so that people both within and outside the health and social care system, shape its future together. And, they will insist that no recommendation is deemed implemented until there is sufficient evidence that it has been on a sustained basis.

Membership representation across the workstreams and sub-groups is broken down. A list of workstream and sub-group Chairs is shown at Appendix 2 and Appendix 3. Full details of the membership of workstreams and sub-groups has been published on the Departmental website.

How You Can Get Involved

We want to ensure that people have a say in how the recommendations from the Inquiry are implemented, so we have developed an Involvement Strategy.

It is important that everyone with an interest, including service users, carers and the public get their say. Working in partnership leads to better results because we can use the knowledge, expertise and experience of a wide range of people.

Those involved include: Health and Social Care bodies, Community and Voluntary Sector organisations, those who provide education and training and those who provide services. It is vital to ensure that the public also take part.

We want to involve organisations and people in ways that work for them. Some have agreed to be part of the workstreams that drive forward our work, but we want to involve other people and you can help by registering your interest on our website www.health-ni.gov.uk/topics/hyponatraemia-implementation-programme or by going to one of our meetings and/or taking part in some of the surveys and consultations that we plan to run.

The work is happening now, so let us know if you are interested in talking to us or working with us to ensure that the recommendations from the Inquiry are implemented in a way that improves services, improves safety, quality and outcomes.

We want people and organisations from right across Northern Ireland to be involved. We intend to bring meetings out across the region and make use of technology to enable people to participate no matter where they live.

You can also register for future updates by emailing: ihrd.implementation@health-ni.gov.uk.

Workstream 1 - Duty of Candour

Structure

Five key recommendations from the IHRD Report have been delegated to the Duty of Candour workstream. The main group, chaired by Quintin Oliver, is responsible for developing the implementation plan for eight actions from the recommendations focusing on the legislation required for a legal duty of candour.

The 'Being Open' sub-group, chaired by Peter McBride, is the part of the Candour workstream responsible for developing the plan for three of the recommendations.

“Of all the themes emerging from the evidence to this Inquiry, the most disquieting has been the repeated lack of honesty and openness with the families.”

(Section 8.101, The Inquiry into Hyponatraemia-related Deaths Report January 2018)

The focus of this group is on the culture of the health and social care service. Initially on the guidance and support needed for organisations and staff to be able to change the culture in advance of a statutory duty of candour coming into place, and to fulfil their legal duties once a statutory duty is in place.

The workstream consists of a wide range of public, third sector and service user and carer members supported by Departmental staff and, as required, by independent consultants/ advisors who are commissioned by the group to undertake specific pieces of work on their behalf.

Process

After members had undergone an induction to the IHRD programme earlier in the summer, the Workstream had an all-day engagement workshop in October. During this, the group mapped out the intention behind each of the delegated recommendations, considered how they linked to the findings in the IHRD report and looked at each from the perspective of service users and carers/families, staff members and healthcare organisations. The key themes that emerged were: respect; compassion; information; safe environment; speaking out; empowerment; expectations and accountability.

After hearing from experts from England and the Republic of Ireland, as well as from a service user and carer and a doctor's experience, the group considered the principles that should underpin the work and how it might approach this challenging task.

Following the initial workshop the groups have been meeting separately to focus on the individual recommendations with a plan to come together in January to share the work so far. In preparation for this, each group has commissioned research into the practice and procedures in the UK and elsewhere in the world and initiated a stocktake of the current position in Northern Ireland. The Duty of Candour Workstream plans to publish the research which has been completed to date.

Existing Trust policies that guide staff behaviour towards patients and families in being open and operating the principle of candour have also been examined. This research was presented to the 'Being Open' group and further analysis has been commissioned.

The work of the Duty of Candour workstream is likely to have the highest profile. It is chaired by public policy expert **Quintin Oliver**.

So what does candour mean?

He says: “It is about more than openness and more than that court room cliché “the truth the whole truth and nothing but the truth.”

“It is about trust – and that means changing the relationships in health and social care. There is a need to remember the humanity of the people involved in care – on both sides – in order to re-establish trust and an unbreakable bond between them.”

“The public sector has struggled with this, because of scale, complexity and pressure; so processes can be so dominant that the fact that there are human beings involved can be forgotten.”

His workstream has had two meetings to date – to go through all the recommendations on Duty of Candour and then to start to scope out their impact, how they should be prioritised and how they can be implemented.

Quintin believes that this is a good time to be doing this work. “We will need legislation to bring new policies into effect: a Duty of Candour Act. This will require Ministerial approval but what we are able to do in the meantime is to do all the preparatory work so that a draft bill is in the Minister’s first red box once we have one in post.”

He says that government resources are being used well in the absence of The Executive. Researchers from the Assembly have been freed up to look at best practice in Duty of Candour in other jurisdictions.

For him, though, the involvement of service users and carers is crucial. “It was one of the reasons why I was persuaded to accept the role – so that it’s not just the “experts” that shape policy. This needed a culture change.

“And of course they are able to use their own experiences to help – they can say back to the experts and professionals “well, that wasn’t my experience, or it did not feel like that to me.”

Quintin predicts that as discussions progress, one of the key debates will be between unions and professional bodies arguing that when things go wrong it should be the organisation rather than the individual who is held responsible, and many in the public who believe that the individuals themselves have to be held accountable for their errors.

Brian O’Hagan sits as a member of the Duty of Candour workstream. Brian, a systems analyst from Newry, knows all too well what it is like to be a carer.

He looked after his mother for almost 15 years after she developed dementia, and also his father when he suffered a severe stroke.

He first got involved with health authorities when he had to make a complaint to the Southern Trust.

He said: “I was actually very impressed with the person I dealt with. Instead of being defensive, she asked me how we could resolve the problem.”

Since then he has been involved in lobbying the health service to include users of health care in decision-making.

“It’s not a question of telling a medical professional how to do their job, but to do with health professionals and managers working with people to meet their needs,” he explains.

And he is very quick to point out that the health service has a statutory duty to include people in decision-making.

He describes the way that the Department has set about responding to the Inquiry’s recommendations as “an important first step. It is taking the public to a different place, and as a member of the public it opens up your eyes – you do see just how difficult it is to manage a health service.

“It is not easy to change an organisation as big and complex as the health service. In the past that has been used as an excuse to do nothing. This is not the case here and I think doing this work in a political vacuum is not a bad thing and you do need the support of the public to make it work.”

For him, public involvement in changing the health service for the better is crucial.

“It is important to work with the public – in my case for example, I know exactly what it is like to be a carer because I looked after my mum for over a decade. Senior managers can sometimes make decisions without that kind of knowledge.”

He says that the work he is involved in is in its early stages, but trust is developing between all those taking part, the officials, medical professionals, people from outside bodies, service users and carers. “Trust is always what makes this kind of process work.”

He wants to see even more public involvement as the work continues with more people brought in with a series of panels to give feedback on the policies that emerge.

Workstream 2–Death Certification Implementation Working Group

The process of death certification and registration has remained largely unchanged in the UK for over 100 years. However, there have been calls for greater scrutiny of the processes mainly due to the activities of a GP in England, Dr Harold Shipman, who killed over 200 of his patients before being detected.

As a result, the Death Certification Implementation Working Group was established in Northern Ireland in 2014 and a number of reforms to the processes have already been made which provide greater assurance for families and the general public.

There are a number of recommendations within the Inquiry Report which are being taken forward by the Death Certification Implementation Working Group and three sub-groups have been set up to consider the recommendations.

- **Preparation for Inquests and Litigation** – When someone dies suddenly or unexpectedly, the death is usually reported to the Coroner for investigation. It is essential that the Coroner is provided with all information relating to the circumstances of a death in order to decide what action is required and whether an inquest is necessary. This sub-group has been considering how to improve systems to ensure that the Coroner is provided with all the relevant information required when investigating a death and how that information may impact on potential legal processes.
- **The Independent Medical Examiner** – when someone dies of natural causes, a doctor usually completes a certificate stating the cause of death. In completing the death certificate, the certifying doctor will draw on their knowledge of the patient's medical history. However, for the most part, there is no independent verification that this cause of death is appropriate or correct. This sub-group has been considering how to introduce the role of Medical Examiner to Northern Ireland to provide proportionate independent scrutiny of deaths without causing additional stress to families or undue delays to funerals. Members of the sub-group are looking closely at the arrangements for independent scrutiny in the rest of the UK and have already visited Sheffield and Edinburgh to see how the systems work there. The introduction of an Independent Medical Examiner for Northern Ireland will require changes to legislation and development of necessary support structures and consequently this recommendation will take time to introduce.
- **Pathology and Bereavement** – In some cases following a death, it may be useful for doctors or families to have a hospital post-mortem to understand more about the death and what may have caused it. This sub-group has been considering how to improve the process for hospital post-mortems and how to make sure that the right support is in place for bereaved people after a death.

All three sub-groups have been meeting on a regular basis and include membership from a wide variety of organisations as well as service users and carers. Each of the sub-groups are dealing with complex issues and time has been taken to ensure that all members have been given sufficient induction and information to help them fully understand the matters at hand.

Davy Best works in the Department of Health and chairs the Death Certification Workstream which oversees the work being taken forward by the 3 sub-groups.

“It is probably the most important piece of work I have ever been involved in. It is also complex and challenging and throws up important issues about how we deal with the departed from the time of their death to their funeral – matters that need to be debated by all in society.”

One complication for one sub-group is that the different Health Trusts vary in size and, partly as a result of this have different organisational structures for dealing with issues when things go wrong.

The Belfast Trust is Northern Ireland’s largest employer with 22,000 staff and has four main hospital sites which deal with a range of complex regional cases. It is staffed in a manner that those dealing with the Coroner are not the same people as those involved in dealing with litigation.

But some Trusts are not so well placed. This can mean that the same staff who liaise with the coroner also deal with litigation, and this could be seen as a conflicted position. “This needs to be separated,” he said.

The work of the pathology and bereavement sub-group is also taking place against the loss of the paediatric pathology service in Northern Ireland from the start of next year. An interim arrangement has been established with Alder Hey Children’s Hospital in Liverpool to provide this service.

Around 240 autopsies are carried out every year in Northern Ireland: typically on miscarriages and stillbirths in order to help parents understand the underlying causes of death, which might then help their planning for the future or the identification of genetic issues.

Davy and his team face the challenge of striking the right balance between providing appropriate scrutiny of the recording of deaths to ensure accuracy whilst at the same time respecting the strong cultural tradition in Northern Ireland of funerals within three days of a person’s death.

“We’ll need to implement a new system which minimises delays to the funeral process,” he says. “And we will also need to test both the general public’s views and those of hospital doctors and GPs.”

Paul Finnegan Northern Ireland Director of Cruse Bereavement Care is chair of the Independent Medical Examiner sub-group. This group is looking at how to implement the recommendation to appoint an Independent Medical Examiner, a measure that will take legislation, and therefore an Executive and an Assembly to pass into law.

He said: “The Examiner will scrutinise deaths not referred to the Coroner and will strive to ensure that people will be made aware of the circumstances of their loved ones deaths.”

“The independence of the role is very important. He or she will have the ability to work closely and establish effective links with key organisations built on integrity and trust and will act on behalf of everyone including bereaved people.”

There are around 16,000 deaths in Northern Ireland per year. Currently when someone dies a death certificate issued by a doctor needs to be with the Registrar’s Office within five days. The registrar will then issue a certificate allowing the person to be buried.

An Independent Medical Examiner would introduce a new layer to this process. He or she would check that the details in a death certificate are completed correctly and also compare this to treatment records at the end of life.

In Scotland where this office is already in place, 10% of deaths are scrutinised. In England and Wales, where legislation is planned, all deaths will be scrutinised.

Paul said: "The idea is to make sure that the person died in the way that the death certificate states. So for example a death certificate states that they died of pneumonia but their records might state another condition which can raise a concern. In that circumstance the Medical Examiner could look further into the certificate, perhaps contacting the GP or past records pertaining to the deceased person."

"But one of the widely accepted aspects of how we deal with death in NI is that from the moment of death to the funeral is typically just three days. This is often helpful to bereaved people because it means that they can start to get back to their lives. In England they often have to wait on the funeral for several weeks which can cause many problems for bereaved people and their families.

"It is important that we make sure that whatever system we have does not unduly delay this cultural tradition. This will be a significant issue which will take a lot of negotiation to get it right."

His team comprises people from every relevant area – three government departments, the regulator, registrar, Coroner, health Trusts and funeral directors. They all have great expertise in this area and it will be crucially important that they all input to the role and work of the Medical Examiner.

"This is important work and it is great to be involved in it – Cruse are delighted to take on this extremely important role of chairing this group." he said.

"The fundamental truth is that death is not a curable disease, it is the final part of life and if people have had a bad experience at hospital or there is poor quality of care then that is devastating and can seriously impact mental health.

"The determinants of health and wellbeing are the conditions in which people are born, grow, live, work and age. They also need to include how people die."

Paul is insistent that the wider public get a say in all this – after all death affects every single one of us.

Dori-Anne Finlay is on the Preparation for Inquests and Litigation sub-group.

Dori-Anne has been through the double tragedy of losing two children to cancer, a son when he was a young child and a daughter in adulthood.

Today she is a passionate and committed volunteer with Northern Ireland Cancer Research and has advised, as a lay person, on a number of clinical trials, so whilst the scientific researchers concentrate on the technical aspects of research she is able to inject humanity, her own practical experience and compassion into the process. She also advises on how new treatments are explained to patients to make sure that they understand exactly what they have signed up for.

She is currently advising on a clinical trial into end of life treatments which is taking place in London.

Dori-Anne says that it is important that lay people are involved in helping to shape health policy and that the programme is starting to work very well.

“We are able to help because we have direct experience as service users and carers of how policy works in practice.

“An example would be when my daughter was having treatment. The medical professionals were encouraging patients to use alternative therapies as well – which was great. But she also had to have her dressings changed by the district nurse. This worked out okay if she came to see her in the morning but if she came later in the day it might be too late to go for the other treatment. I eventually learned to change her dressings myself to solve this.”

“So a lot of what we do is inject common sense into the discussions – and as my husband says – common sense isn’t so common!”

But she says that there is change in the air: “To be fair the system is a lot better than it used to be. In the past it was all about listening to the doctor and he told you what would happen next, and that was it.”

“It’s all about getting the balance right and service users and carers can put their personal experience to use to help the medical professionals see whether what they think is the right thing to do, actually is.”

Nikki Graham is also a member of the Preparation for Inquests and Litigation Group

Nikki is now helping to fix a system she once used to hold to account. She has previously worked as an investigator for the Northern Ireland Ombudsman, investigating health complaints.

“I’ve now left the public service but am still very keen to make a difference,” she said.

Last October her grandmother who she was really close to passed away. She said: “She got amazing end of life care from the home she was a resident in. This made the grieving process slightly easier - knowing that she passed away in a peaceful and loving environment, and this is another reason for me trying to get involved in the bereavement network and thus the hyponatraemia inquiry.

“I think that good end of life care, which includes openness and transparency and also two way communication, is vital to help those who are bereaved.”

To date she has been impressed with the process.

“It is very well run – our chair is excellent and ensures that she hears from everyone on the team - and we get great support from the officials in the department.”

Yet she also has some concerns.

“It’s early days but there is a massive amount of work for us to do and I’d be concerned about that.

For example at the last meeting we had to get people in from all of the Trusts because each of them have different procedures in dealing with deaths and inquests.”

And ensuring that everyone on the team grasps the detail can take time as well. “It is very important to have service users and carers on the team. It adds so much if you have had the experience of bereavement, for example. But it does take time to get people up to speed, not many people in Northern Ireland are familiar with how inquests work, for example,” she says.

Yet Nikki is determined to help ensure how people can get their voices heard with the authorities, especially when there is a problem.

“In my time as an investigator I was already aware that not many know how to complain when things go wrong and in this area it is complicated because you will have complaints departments, litigation (legal) departments, and the coroner who all have different ways of dealing with complaints.”

Workstream 3 - Duty of Quality

Structure

The Duty of Quality workstream, chaired by Eddie Rooney, is responsible for developing the implementation plan for 28 actions from 23 recommendations.

“Each Health and Social Services Board and each HSS Trust shall put and keep in place arrangements for the purpose of monitoring and approving the quality of: (a) the health and personal social services which it provides to individuals; and (b) the environment in which it provides them.”

(HPSS (Quality, Improvement and Regulation) (Northern Ireland) Order 2003)

The work is being undertaken by three sub-groups, each responsible for specific recommendations. Recommendation 9, which focuses on leadership, is being taken forward by the main group.

The ALB Board Effectiveness sub-group, chaired by Jim Moore, has a number of members with experience as non-executive directors of boards within the health and social care sector as well as service user and carer representatives. The group is looking at how board members can be trained to scrutinise the performance of the Trusts to ensure that they can effectively call management to account, particularly on issues of candour, child healthcare and learning from adverse incidents.

The second sub-group covers the clinical and social care governance recommendations and is chaired by Lynne Charlton who is supported by members with experience in governance in the health and social care sectors as well as service user and carer members. Its focus is on the audit of clinical standards and the analysis needed to identify poor performance regarding patient safety. The recommendations include improvements to how serious adverse incidents are investigated. These are priorities for early implementation.

The third sub-group is focusing on recommendations regarding the remit of the Regulation and Quality Improvement Authority. This group is chaired by Linda Greenlees Department of Health whose team has also begun the process of a wider review of the role of RQIA.

Process

In preparation for the work, a stock take was undertaken with the HSC Trusts and Public Health Agency against each of the recommendations. The whole workstream took part in a workshop in September to consider the intention behind each recommendation, what was likely to be included and what constraints there might be in implementation and what Trusts are currently doing. For the clinical and social care governance recommendations the group worked through real life examples of when things go wrong in hospitals and in social care and how these should be addressed.

The Board Effectiveness group identified what work had already been done to improve processes and set out to identify best practice in Northern Ireland and elsewhere. They considered the priorities for the work and the key stakeholders who needed to be involved.

Following this these two sub-groups have met separately to complete the first stage of their assurance framework (see Workstream 9) and to commission further research.

The definitions for each of the Duty of Quality recommendations have been completed, including expectations of when and where it will apply and what (if any) exclusions exist. These drafts will be shared with other workstreams with an interest in specific recommendations and the group will meet with the Assurance Workstream for independent scrutiny of the process and outcome of the work on the objectives.

The groups are now looking at the internal policies and procedures that need to be set in place. The Board Effectiveness group, for example, has linked up with the regional ECHO project to consider how non-executive directors can be supported through the development of a handbook, a structured programme for continuous professional development and a mentoring system.

The workstream chair and chair of the Clinical and Social Care Governance group are holding meetings with Trust Oversight Groups to identify and share best practice and to consider the regional work that needs to be undertaken in partnership.

The workstream has identified a key aim as developing both a change of culture and a culture of change in the governance and leadership of healthcare.

Workstream 4 – Paediatric Clinical Collaborative

This workstream has been tasked with overseeing the implementation of the more clinical, or frontline, recommendations of the Inquiry. Doctors and nurses from across Northern Ireland have been brought together to form an expert group, alongside service users and carers and others drawn from public life to develop a regional approach.

The group began its work in June 2018 and has been meeting every month. An early emphasis has been on two recommendations which are important to help make sure that care is as safe as possible.

In particular, the group is using its expertise to translate the Inquiry's recommendations into achievable objectives which will improve the quality of care in children's hospital wards. In doing so, it has become clear that the management of fluids for our children in our hospitals has already improved significantly.

The group has been in regular contact with all of those involved regionally to coordinate activity so that examples of good practice, and the experience gained, are shared across all of our hospitals.

It is also the responsibility of this group to ensure that tangible evidence can be provided to assure the general public that things have improved in line with the Inquiry's recommendations.

It is estimated that the group will have largely completed its work well before the end of 2019. The need to coordinate quality improvement work thereafter will be carried forward by a newly established regional group, the **paediatric network**, supported by the Public Health Agency.

Workstream 5 – Serious Adverse Incidents

Openness is a major theme of the Inquiry report. Service users/carers are experts by experience. The Serious Adverse Incident workstream has put service users/carers first by working on guidelines to make it clear what you should expect if you are involved in a Serious Adverse Incident. This is about encouraging openness. The Workstream expects to engage with a wide range of stakeholders over the next two months to finalise the guidelines.

What is a Serious Adverse Incident?

A Serious Adverse Incident is when something happens with someone's treatment or care which could have or did lead to harm. That harm may be unexpected or unexplained and could lead to serious injury or death.

A Serious Adverse Incident is an opportunity to learn from when things go badly. Service users/carers have a big part to play in that learning. They often know what care is needed and they have first-hand experience of the health and social care system and a unique perspective on the care they receive. We want service users/carers to get involved early and to stay involved. To help them, they should be involved in setting out how the Serious Adverse Incident will be reviewed. They will want to know who will be reviewing the Serious Adverse Incident and to raise any concerns about the Review Team. The process should be explained. They should be kept up to date, be told how long things should take, receive regular feedback and see the documentation as it develops. They should be able to respond to the final report and be informed as to what changes have been made as a result of the learning.

Despite the harm caused, reviewing a Serious Adverse Incident can be a positive experience. In this video Margaret and Gary share their story after the death of their daughter Emilie.

www.youtube.com/watch?v=Kz5icTleIB8&feature=youtu.be

Being involved in the Serious Adverse Incident process is complicated as it comes at a time when service users/carers are likely to be in great distress.

The Workstream is also considering how to make a single point of contact/liaison available to help support them through the process.

Conrad Kirkwood works in the Department of Health and is chair of the Serious Adverse Incident Workstream.

Service users and carers are not the only people for whom this process is a new challenge.

Conrad said: "Here I get to know people so well – I know their personal stories and what they have been through and they bring a lot to the work.

"It can be uncomfortable. It is not what I'm used to, but when people can show me that what is being proposed is at odds with their own personal experience then that is all to the good."

Conrad says that genuine respect is developing within his group – an experience which appears to have been shared by all the other workstreams as people from very different backgrounds and with different expertise and experience work together for a clear common purpose.

He concedes that such broad involvement does mean that the process will take longer than if a policy was solely created by the Department but says: “I genuinely believe that the full and direct experience of service users and carers in developing policy will make our conclusions more robust than they otherwise would have been.”

“As to time scales, I’m as impatient as anyone to get this done and I want the group to finish their work quickly but it does need to be done in a sensible way, planning all that we do carefully and making sure it is tested, consistent with all the other work that is going on and is the right thing to do.”

Conrad says that as work progresses his group will get more feedback from service users, carers and also staff – who can also be seriously traumatised as a result of being involved in a Serious Adverse Incident.

He says good progress is being made. His group have 18 actions arising from the recommendations to work through. To date, seven are ready to go to the assurance group for checking, five are nearing completion and the rest should be finalised by autumn 2019.

Workstream 6 - Training

The training working stream was initially chaired by Angela McLernon, Chief Executive of the Northern Ireland Practice and Education Council for Nursing and Midwifery. Angela has recently had to step aside from the role of chair due to other work commitments. She will however continue to be a member of the workstream. Professor Keith Gardiner, Chief Executive/Postgraduate Dean of the Northern Ireland Medical and Dental Training Agency will step up from his current role as a member of the workstream to take over as chair in January 2019.

The education and training needs of the existing health and social care workforce will continue to be met by their employers. This workstream is considering those elements which need to be delivered as part of the education of our future and emerging workforce and will provide advice to workstreams on developing training and education material.

The group is currently undertaking work to map out existing responsibility for the education and training of the health and social care workforce.

Workstream 7 – User Experience and Advocacy

This group is chaired by Rodney Morton, Deputy Chief Nursing Officer in the Department of Health. Rodney led work on the development of the Department's Co-production Guide (Connecting and Realising Value Through People) and has policy responsibility for the Department and Health and Social Care systems arrangements for involving service users.

The health and social care system is complex. It is no less complex when you are involved in a Serious Adverse Incident. The best outcomes are when communication is good between HSC staff and service users and carers. However service users or carers often also benefit from support and advocacy to help them through the entire SAI review process from the point of a problem emerging through to the review being completed.

It may be helpful to have a Liaison Officer available to you as a single point of contact when you are involved in a Serious Adverse Incident. He or she can explain the process and help you through it. The Patient Client Council will also be able to offer help. This workstream will be looking at ways to support people better when they have an adverse experience by increasing the availability of independent advocacy.

The workstream has also commissioned research to find out if there are better ways of providing advocacy to help service users and carers which we can learn from elsewhere. This workstream includes a number of service users and carers and people from the third sector. Their experiences will help make our work more robust and help compare the research findings with how we currently do things here. There will be obvious links between this work and that of the Serious Adverse Incidents and the Duty of Candour workstreams.

Workstream 8 – Workforce & Professional Regulation

Structure

This workstream is chaired by Andrew Dawson, Department of Health. The group is considering seven recommendations continue on sentence from there.

Process

These recommendations are closely linked to recommendations being considered by other workstreams. Andrew will bring his group together from time to time during 2019 to assess other group's progress with implementing linked recommendations and to consider the timeframe for implementing his group's seven recommendations.

Workstream 9 - Assurance

Structure

This workstream, chaired by Olive Macleod, Chief Executive of the Regulation and Quality Improvement Authority, has one vitally important recommendation to work on. It is responsible for advising the Department through the management group whether or not there is evidence that each recommendation has been implemented and sustained in practice. The workstream consists of a range of public, third sector and service users and carer members with experience in the scrutiny or overview of standards.]

Process

Earlier in the year it developed a framework with four areas that could assure the successful implementation of the recommendations.

The assurance framework is based on contributions from the eight other workstreams to show that there is clear evidence that actions are taken to cover each of the recommendations, and that they can be properly monitored into the future.

It therefore plays a key role in the oversight of all of the other work. The bulk of its work will come as the proposed actions are passed over to it, but members also need to have a clear understanding of the other workstreams and how they fit together.

It expects each workstream in the programme to take an agreed approach to identify the objectives of each recommendation; the internal processes needed for implementation (training and education for example); the evidence needed to show that the recommendation has been implemented and to identify and mitigate any risks to implementation.

Individual workstreams are now working through this process, initially setting out objectives. A scrutiny meeting with the Paediatric Clinical Workstream has also taken place where limitations in the definitions were identified and recommendations for improvement set out.

Jimmy Hamill is on the Assurance Workstream

The Assurance team has been pulled together to provide independent verification that all the recommendations have been implemented on a sustainable basis.

Jimmy is a retired accountant. He had cancer five years ago which is now cleared up and is also a full time carer for his wife who has a brain condition.

He said: "I see service and carer involvement on several levels. Level one is for people to be involved in their own care, this seems relatively easy for health bodies to grasp and to progress, but what they find more difficult is involvement at the higher levels – involvement in strategy, decision making, allocation of budgets and the like this is where you get resistance."

Jimmy is critical of the length of time that the process is taking. “They were slow off the mark at first – I was invited to take part in May but my induction session was not until August.

“It is slow moving – the report was massive and there is a lot of important work to be done, and yet if I were one of the families affected by the Hyponatraemia inquiry I would be extremely impatient for progress.”

He also believes that the selection process could have been improved – he is working on it because he was invited to, but he believes that there should have been a well-communicated public route for people to become involved who have strong interests in health but were not invited to take part.

However he has been impressed by the inclusion of service users and carers in the process and with the assurance they have been given that they are full members of the team who will be involved as much as any others.

There is also a liaison group consisting of all the service users and carers from across all of the workstreams so they can confer and discuss the issues that they are dealing with, which Jimmy sees as an important mechanism. He is hopeful regarding the good intentions of the implementation programme management group and gives the positive example of the addition of a service user/carer to this group as a result of representations from the service users/carers themselves.

“I do see a keenness and willingness to accept that health staff can learn from service users and carers,” he says.

Next update

The next programme update will be published on 21st March 2019. In the meantime, the individual workstreams and sub-groups will continue to publish information on the Departmental website.

Appendix 1

Senior Responsible Officer (SRO)

The Permanent Secretary, Richard Pengelly, is the SRO for the programme and, in the absence of a Minister, holds the overarching responsibility for progress with the implementation of the recommendations from the IHRD Report.

Implementation Programme Director (IPD)

The Deputy Chief Medical Officer (DCMO), Dr Paddy Woods, is the Implementation Programme Director. In this role he discharges functions and takes operational decisions on behalf of the SRO on a day to day basis. He is supported by a programme manager, deputy programme manager, Department of Health policy staff and a small number of external facilitators.

Programme Manager (IPM)

The IPM manager is responsible for managing the programme and chairs an Implementation Programme Management Group. The programme manager and his deputy oversee and support the individual workstreams, identifying resources to support their work, receiving and analysing progress reports; collating the Issue Log from the working groups and developing the Risk Register for the programme.

The Implementation Programme Management Group (IPMG)

Chaired by the Programme Manager the IPMG comprises the individual Workstream Chairs and Subgroup Chairs and is also attended by representatives of the Patient and Client Council.

A recent change to the programme is that the Service Users and Carers who are members of the different workstreams and sub-groups are electing their own representative to join the programme management group.

It is responsible for the signing off strategies and frameworks that cross all workstreams, such as:

- Involvement strategy
- Communication strategy
- Training strategy
- Assurance Framework

The IPMG will also ensure that appropriate links are maintained between relevant workstreams and with existing initiatives. It will be responsible for the implementation of three recommendations not delegated to a workstream.

The IPMG also provides an opportunity for Workstream Chairs to share knowledge and experience, support each other's work and act as a leadership forum for the Programme.

Appendix 2

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	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 from within their workstream.

Linkages

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

Appendix 3

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 workstream
Vivian McConvey (VOYPIC)	Preparation for Inquests (and Litigation) sub-group
Paul Finnegan (Cruse Bereavement Care)	Independent Medical Examiner sub-group
Sharon Wright (DoH)	HSC Bereavement & Pathology Network sub-group
Eddie Rooney (Former HSC)	Duty of Quality workstream
Jim Moore (Former Translink)	ALB Board Effectiveness sub-group
Lynne Charlton (Northern Ireland Ambulance Service)	Clinical & Social Care Governance sub-group
Linda Greenlees (DoH)	RQIA Remit sub-group
John Simpson (Former HSC)	Paediatric Clinical workstream
Conrad Kirkwood (DoH)	Serious Adverse Incidents workstream
Keith Gardiner (Northern Ireland Medical & Dental Training Agency)	Training workstream
Rodney Morton (DoH)	User Experience & Advocacy workstream
Andrew Dawson (DoH)	Workforce Planning & Professional Regulation_ workstream
Olive Macleod (RQIA)	Assurance workstream