Inquiry Into Hyponatraemia Related Deaths (IHRD)

Review of the Co-Production Experience

1. Introduction

The implementation of the 96 recommendations made by Justice O'Hara in the IHRD report began shortly after its launch on the 31st January 2018. At the outset, the Department of Health (DOH) made a clear commitment to use a co-production model. On the 31st August 2018 it published the Co-Production guide for Northern Ireland – Connecting and Realising Value Through People. The ambition within the guide is clear:

*"Our goal is to support transformational change through a co-productive approach and promote the opportunity for all sections of the Northern Ireland community to partner with health and social care staff in improving health and social care outcomes. "(*p.7)

The work of the IHRD implementation programme was overseen by the Implementation Programme Management Group (IPMG). The Chairs of each of the programme work streams sat on this group and it was led by senior departmental officials. The membership of the workstreams contained representation from various groups including:

- Department of Health Officials
- Health Service Personnel from Trusts, The Board and various Arm's Length Bodies
- Third Sector Representatives
- Service Users / Carers
- Other specialists

As well as the workstreams the DOH also engaged the Public Health Agency (PHA) to provide experienced personnel to support the involvement of Service Users and Carers within the programme. In addition, the Service User / Carer Liaison Group (SUCLG) was established by the Service Users and Carers members to develop deeper knowledge-sharing across the programme, to act as an additional support mechanism and to provide representation on their behalf at the programme Board level. This was not in the original design but was adopted by the programme management as a welcome augmentation to the programme structure.

2. The Purpose and Scope of This Review

Having started in 2018, the IHRD implementation programme is the largest and most ambitious programme undertaken by the DOH using co-production as an approach. With 17 work streams working on the 120 actions that arose from the 96 recommendations, and hundreds of people involved it has been a huge administrative undertaking. The purpose of this review is to evaluate the experience of co-production primarily from the perspective of the Service Users and Carers who were involved. Additional information has also been gathered from other workstream members and departmental officials. As well as an exploration of the co-production experience, this review will provide some recommendations for how the co-production approach can be enhanced in future programmes, learning from the experiences of IHRD.

3. Methodology

Over November and December of 2021, individual interviews were held. All Service Users and Carers were offered the opportunity to be interviewed, 16 agreed. 3 independent work stream chairs were interviewed as well as 13 other workstream members, these included departmental officials and independent workstream members. 4 of the departmental officials also chaired some of the workstreams, and independent members of workstreams were randomly selected for interview. All interviews were carried out with the agreement that the identity of participants would remain anonymous.

A semi-structured approach to the interviews was used with the interview template attached as Appendix 1. The template was designed with the assumption that there was significant activity across all the work streams after the outbreak of COVID-19, however there is very little data relating to the post-covid experiences with most of the information relating to the experience up to March 2020. The main exception to this is the work of the Duty of Candour work stream that continued through a very significant public consultation in 2021. The template also used some numerical scales to determine levels of engagement. These were useful conversations starters but were too abstract to provide useful comparative data, and so the responses are reported in a narrative rather than numerical form.

4. Results of the Service User / Carer Interviews

a) The Service User / Carer Experience. (Pre and Post COVID)

- **A general appreciation of the intention to use co-production.** Most Service User / Carer respondents recognised that this was a laudable effort on the part of the DOH to involve them in a co-production approach. There was also positive appreciation of the scale and ambition of the programme.

- **The effectiveness of induction.** There was the recognition that attempts had been made to have an induction programme. The experience of respondents was varied. The elements of the induction discussed in the interviews were:

    - **Inter-personal.** Respondents welcomed meeting new people and the excitement of starting a new ambitious venture. Some identified the difficulty of feeling like the "outsider" at the table when the other members of the group seemed to know each other and worked together in the health service. Many respondents mentioned how overwhelming and intimidating it was for them to join a group with people they didn't know. While some mentioned large induction meetings which were general, there seemed to be less time spent at work stream level allowing people to get to know one another, acknowledging these inter-personal challenges.

    - **Work stream expertise.** Many Service User / Carer respondents reported experiencing a power differential between them and the perceived "experts" in the groups, feeling themselves to be at a disadvantage because of their lack of specialist knowledge. For some, this eased as they began to work together, and many described the benefit of being able to study meeting papers well in advance. Others mentioned the benefit of meeting the Chair of the work stream in advance of meetings to discuss any questions they might have about the material.

b) Positive themes in the Service User /Carer Experience:

Respondents gave a variety of answers, they…

- felt very supported by the system, specifically mentioning the work of the involvement co-ordinator.
- mentioned the introduction of the Service User and Carer Liaison Group as a very positive support for their involvement.
- mentioned the positive benefit of meeting new people.
- mentioned the warmth of the welcome they received, the benefit of the support provided to them inside and outside the work stream meetings, and how this helped them participate.
- mentioned the openness of others to what they were saying and suggesting, and the willingness they experienced of others to take on board and incorporate their views.
- expressed their appreciation of the opportunity to challenge and debate these important issues and to have their views meaningfully incorporated.
- mentioned the value of the diversity of work stream members and how this benefitted the breadth of discussion.
- mentioned the benefit of receiving their papers well in advance of meetings with the opportunity to seek clarification before the work stream met.
- mentioned the benefit of the support they received from DOH officials in providing additional information and helping with practical challenges.

c) Negative Themes in the Service User Carer Experience

Respondents gave a variety of answers, they…

- felt intimidated joining work streams where other members knew each other and had already worked together and "spoke their own special language".
- did not think that there was adequate preparation, training, and induction.
- doubted the genuine willingness of the DOH/health system to take on their views and incorporate meaningful change.
- described a power differential they experienced in relation to the other group members.
- described the hurdles they experienced in trying to get their point across and the effort that was required to be heard and taken seriously.
- reflected on the challenges and inertia of the large-scale bureaucracy of the system.
- feared that their involvement could be tokenistic.
- felt that "the system" was defensive and unwilling to listen to challenge or change.
- spoke of the differential contributions of work stream members, with some dominating and others saying nothing.

- spoke of the problems with the lack of contact from the DOH after the outbreak of COVID – they did not feel that their ongoing engagement was facilitated.
- thought that the questions they posed in the work streams were thought to be too difficult to deal with and that the intention was merely to "tweak" around the edges of the system, rather than meaningful substantial change.
- thought that there should have been wider engagement with the public.
- thought that there should have been more support:
    - practical support - in relation to transport and accessibility. Some expressed the view that there was a lack of understanding of the constraints experienced by active carers that made participation difficult. The use of ZOOM was seen to be a positive move.
    - support for engagement – in relation to the dissemination of information in accessible forms. Respondents generally appreciated the additional engagement with officials and Chairs to explain and discuss the issues.
    - support for co-production – in relation to service user / carer participation in shared decision making. Respondents referenced a lack of ongoing reflection on the success or otherwise of the co-production process.
- thought that there were decisions being made outside of the workstream meetings that should have been discussed and agreed by the workstream.
- thought that there was a general lack of understanding of the co-production process and that there was a significant variation in the ability and competence of Chairs to manage service user / carer engagement.

d) Service User Evaluation of Co-Production

Feedback from service users and carers on what worked.

- the direct support of staff.
- there was a genuine effort to incorporate all views.
- there was a friendly environment.
- it was enjoyable and people were not condescending.
- resources were invested in the process.
- service users and carers were encouraged to lead the discussions.
- the process started off extremely well.
- there was a respectful approach.
- this was the first time something like this had been tried.
- good chairs and good support from DOH officials.

Feedback from service users and carers on what didn't work.

- there should have been more induction / training at the start.
- there was a lack of understanding of the difference between consultation and shared decision making.

- there was an unhelpful power differential between service users/carers and the system.
- there needed to be more ongoing reflection on what was and wasn't working.
- it appeared that some decisions were being made or vetoed outside of the workstreams without service user / carer involvement.
- it appeared that everything was "set-up" in advance therefore it wasn't co-designed.
- there was the fear that the outcomes were predetermined – it was a "done deal".
- there was a lack of appreciation in "the system" of the scale of change required.
- there was defensiveness in the system to change because it might threaten jobs
- the same volunteers were involved.
- there was a tendency to focus on the work of specific work streams and lose sight of the work of the whole programme.

e) Views on the benefits of Service User / Carer Involvement:

- Lived Experience. Most respondents mentioned the value of "lived experience" of using health services and the insight this provided into the issues patients would be experiencing.
- Real "on the ground" experience. Respondents mentioned the value of input from those who had good and poor experiences of services on the ground to challenge assumptions about how these are being delivered.
- The authentic voice of the service user. Respondents noted the value of the authentic voice of the service user in decision making about service development. It was thought that this provided additional authenticity to the discussions.
- Challenge. Respondents thought that service user / carer involvement brought a significant challenge to assumptions by the system about the effectiveness of its service delivery.
- The human touch. Respondents thought that the involvement of service users and carers retained a focus on the human experience of services, not just the systems.
- Specialist service user experience. Respondents recognised the specific value of people who had used specific services being involved in the improvement of those services.
- Holding to account. Some respondents saw the role of service users / carers as holding the system to account for the delivery of services. For some, this was in the context of a lack of confidence in the willingness or ability of the health service to engage in meaningful change or transformation.
- Some respondents spoke of the distinction between the role of service users and the role of carers and some of the difficulties this can cause.

f) Service Users / Carers views on the next stage of IHRD Implementation.

- All the service users / carers were asked if they would like to remain involved in some capacity in the next stage of IHRD implementation, and without exception they all indicated their willingness to help.

There were a variety of responses, respondents…

- spoke of their frustration at the lack of engagement since the outbreak of COVID-19, and the hope that the momentum for implementation would not be lost.
- reflected on the positive impact of the IHRD implementation process and the hope that the model would be replicated for other issues – with the lessons from it being learned and incorporated.
- spoke of the public view of the IHRD implementation and the need to show progress and completion.
- recognised the significant changes in the system since the IHRD implementation programme started and the need to take these into account.
- identified the need for an ongoing assurance process to ensure that the changes that had been made persisted.
- mentioned the practical benefits of using ZOOM technology to facilitate engagement with service users and carers
- mentioned the importance of linking system change with culture change – this was specifically in relation the The Duty of Candour and Being Open work stream.
- mentioned the importance of role clarity for any future involvement of service users and carers, along with clear expectations of support and ongoing reflection of the effectiveness of the co-production approach.
- reflected on the different requirements of different types of work when considering service user and carer involvement. The specific distinction was between the requirements of technically specialist areas of work, and those areas that are more general in nature.
- mentioned the need to focus on the introduction of new legislation to precipitate meaningful change.
- highlighted the need for better communication both within the system as well as with the public.

5. Results of the interviews with other workstream members, Chairs and DOH officials.

Some work stream Chairs, DOH officials and other workstream members were selected at random for interview. The same interview template was used for these semi-structured interviews but adapted to seek respondents' views on the co-production process as they observed and experienced it.

a) Other work stream members views of the co-production experience:

- **A positive view of the effort to co-produce.** There was a general appreciation of the commitment to co-production and an acknowledgement of the effort and resource that had been committed to the process. There was recognition of the effort put in by Chairs and DOH officials to engage with service users /carers to support them to engage with the process.

- **Changes over time.** There was some reflection on changes in service user / carer engagement over time with more engagement at the start of the process, followed by a gradual falling off. This was then exacerbated by COVID-19. Some respondents reported a lack of continuity in attendance by service users / carers at meetings. Others reported the numbers of service users / carers expanding over time as the need for representation increased.

- **Different challenges depending on the topic of the work stream.** There was reflection on different experiences of co-production depending on the topic of the workstreams. Where the experience of the service users / carers aligned directly with the focus of the work stream, there were high levels of engagement and input. Where the topic of the work stream was of a more general or principled nature, it appeared to be more difficult to engage service users / carers in a focused way.

- **The impact of COVID-**19. There was a general acceptance that in effect, the work of the programme had been on hold for most of the work streams from March 2020 because of the profound disruption caused by COVID.

- **The benefit of support.** There was recognition of the positive impact of providing support to service users / carers. Specific reference was made to the positive influence of direct support staff on the programme, as was the recognition of the benefit of Chairs and departmental officials taking the time outside the work stream meetings to work with and support service user / carer workstream members.

- **Un-managed expectations.** Several respondents spoke of their perception that some of the service users / carers expectations about their role in the programme were in their view at times unrealistic. This was in relation to decisions that may have been outside the scope of the programme, or that may have been deemed to be impossible or impractical to implement. It seems that there were occasions when these expectations were mis-matched what was thought to be possible. In these circumstances, some staff felt reticent to directly challenge these expectations.

- **Anxiety about challenge.** Several of the respondents spoke of their concern about challenging or disagreeing with service users / carers because of the perception of their status as volunteers in the programme. Some also spoke of their fear that a robust challenge may result in criticism or complaints being raised by service users / carers against them, the possible public reaction, and the possible negative impact on the programme. The consequence of this appears to be that difficult or controversial discussions were sometimes avoided and that it was therefore difficult at times to deal with some important issues in the work streams.

- **Confusion between Patient and Public Involvement (PPI) and Co-Production.** There were some of the respondents who spoke of their perception of a confusion within the system between the requirement to involve and consult service users and carers on important changes within the health service (PPI) and the process of co-production. At its core was confusion around the issue of shared decision making and a lack of experience in involving service users / carers as partners in the complex decision-making processes involved in developing significant health service reform.

- **Shared decision-making challenges.** Some respondents described difficulties in balancing the input of service users / carers with the input of other group members. The main concern was that on occasion, there was a perception that service users / carers appeared to expect their views to carry more weight than the views of other group members. This resulted in either a mismatch of expectations, confusion and conflict, or the avoidance of important issues. The consequence was that sometimes there were significant challenges in achieving genuinely shared decision making.

b) Perceptions of other members, Chair and DOH Officials about what worked.

- the commitment of service users / carers to the process was impressive.
- the benefit of a very explicit commitment on the part of the DOH to co-production across all its initiatives.
- service users / carers added significant value to the decision-making process of the IHRD implementation programme.
- service users / carers brought a broader view to the issues, that ultimately resulted in better policy decisions being made.
- service users / carers brought reality of experience and personal life stories to the attention of policy makers, that enhanced the process.
- service users / carers reflected the views of the public and kept the core issues at the top of the agenda.

c) Perception of other members, Chairs and DOH Officials about what didn't work.

- Confusion about the role of service users / carers. Some respondents reported challenges with how highly specialised technical issues were dealt with. It was perceived that some service users / carers felt out of their depth with some of these issues, and there was some effort to provide additional support to help

them understand. Some thought this reflected a misunderstanding of the role of service users / carers in making decisions about these issues.

- Shared decision making. Some respondents identified a confusion between co-production and the inherently shared nature of decision making within it, and the legal duty of involvement and consultation associated with PPI.
- The avoidance of conflict and anxiety about challenge and disagreement. There was significant feedback from respondents about their anxiety about challenging service users / carers, and their fear of the implications of complaints being made against them. Respondents felt that on occasion, some of the service users / carers expected their opinions to take precedence.
- The dominance of negative personal experiences. Some of the respondents, reflecting on the benefit of the lived experience of service users / carers, noted that most of those involved had negative experiences of using health services and that this influenced the way they contributed to the process.
- The challenge to trust. Respondents identified trust as a significant issue in the process. This was both the perception of a lack of trust on the part of some service users / carers in the ability of the system to meaningfully change, and a lack of trust on the part of some of those working in the system that service users / carers could contribute meaningfully to pragmatic service delivery improvements.
- Time and progress. Some of the respondents expressed the view that too much time was spent in circular discussions, and that more clarity about expected outcomes and timescales would have helped expedite decision making.

d) Views of other members, Chairs and DOH Officials on the benefits of Service User / Carer Involvement:

- asked questions and raised issues that would not otherwise be raised.
- brought a very different perspective and healthy debate.
- were a litmus test for the public reaction to issues.
- challenged the assumptions of policy makers to create better policy decisions.
- maintained the focus of the IHRD issues.
- the specialist experience of service users / carers gave a valuable insight into how services were experienced on the ground

e) Other work stream members, Chairs and DOH Officials views on the next stage of IHRD Implementation.

Respondents identified:

- the need for role clarity in the co-production process, for chairs, service users /carers and all other members.
- the importance of a selection process that matched experience with the objectives.

- the importance of the distinction between service users / carers with specific experience and those with general interests; and the need to ensure appropriate skill matching within relevant work streams.
- the importance of some sort of selection to ensure appropriate matching of skills and experience with the task required.
- the importance of recognising the benefit of positive experiences of using the health service as well as negative experiences.
- the importance of support for all of those involved to maintain a focus on the core principles of co-production.
- the importance of investing in building trust and a sense of “common purpose” in the group.
- the importance of managing the expectations of group members about the challenges and limitations of the work.
- the importance of facilitating honest conversations within the group.
- smaller more focused working groups would work better.
- clear and co-designed terms of reference for the work of each group.

6. Discussion and Analysis

The feedback from those who were interviewed as part of this review can be aggregated under the following headings:

- **The benefits of co-production**. There was general agreement among both service users /carers and the other workstream members that the co-production approach for IHRD implementation was beneficial and that it resulted in better policy decisions. There was also the recognition that it was difficult, and that the system would benefit from support and development to make full use of it as a model of policy development or service transformation. There was also the acknowledgement that in the IHRD Implementation Programme, the Department of Health had embarked on a hugely ambitious co-production exercise, and that it had invested significantly in the human and other resources required to make it a success. The commitment to co-production for IHRD implementation was impressive, and that commitment continues with the department's openness to learning from the experience so that insightful local experience informs future HSC co-production initiatives.

- **The challenges of co-production.** While there is no doubt that there is an appreciation of the benefits of co-production, it is also important to have a full understanding of the challenges of this model. The feedback from this review would suggest that there were some issues about the management of the process that, with hindsight, could have been improved to produce a better result. Primary among these is that as a process co-production needs to be actively managed. It is a dynamic process that is arguably inherently conflictual and therefore needs ongoing support and engagement to maintain focus and efficacy. The focus of the management of a co-production project needs to be split between attention to the work plan and expected outcomes, alongside a focus on the group process and the relational dynamics.

- **The architecture of co-production.** From the feedback received within this review, it is possible to construct a framework for understanding the different components of a successful co-production process. They can be characterised as a sequence of:

    - preparation,
    - selection,
    - negotiation and
    - agreement setting, and reflection.

    These are described in more depth in the recommendations. The involvement of service users / carers in a process does not necessarily make that process co-production and working within a framework for co-production helps make explicit some of the more complex challenges associated with it.

- **Managing expectations.** One of the phrases most frequently heard in the feedback for this review was the importance of managing expectations. It was used most

often when speaking about the challenges of "shared decision making", and the anxieties of those within the system about the expectations of service users /carers about what could or could not be done. This reflected a much deeper issue which was the challenge of creating a "common purpose".

Much of the feedback in this process was predicated on a "them and us" assumption – a false division, that when left unchallenged had the potential to cause misunderstanding:

- From a service users /carer perspective, it was expressed as the sense that they held sole responsibility for ensuring change happened, "holding the system to account" – with the view that those within the system were perceived to be resistant to change and resistant to making the meaningful and radical changes that were required.

- For those within the system, it was expressed as the sense that they held responsibility for maintaining the stability of fragile and strained services, containing staff who were over-stretched, deeply committed to doing a good job but intensely conscious of the constraints within which they had to work.

At its most extreme each side of this false division, felt the other to be defensive, antagonistic, and not committed to doing the right thing. This was of course manifestly not true of either "side" but was a very real perception. The solution to this is to work hard to find "common purpose", a way of describing the work that allows those involved to connect with what they agree is important, and then work on the issues upon which they disagree. This reinforces two key components of co-production:

- **Role clarity –** it is important that in the preparation for a co-produced project, effort and thought is put into who really are the key stakeholders. Service users / carers are an obvious group, but it is important also to include others for whom the issue carries real importance and relevance. Some of these people will come from within the system, some from the wider health service community, the third sector and at times the general public. The purpose of convening such as group is to create a "common purpose", where there is clarity about the contribution that each can make.

- **Equality around the discussion table –** in the feedback for this review individuals across all groups expressed anxiety that others' views were given more importance than theirs. This was said both by service users / carers as well as other group members such as officials, clinicians etc. It is reflective of the need to make absolutely clear to all group members the value of all contributions, the acceptance that at times all will not agree, the possibility of conflict and finally the acceptance that decisions may not always be unanimous. By holding this tension within the group, decisions can be maintained within the group – rather than made elsewhere where there may be no conflict, but neither is there any consultation or consensus.

- **The Importance of Co-Design at the start of Co-Production.** Some respondents reflected that, because of the timing of their involvement, there were some important decisions about the design of the programme that had been taken before their inclusion. They understood that the extraordinary scale of the Hyponatremia Inquiry necessitated a robust but timely process of implementation but with hindsight, the desire to get a process up and running may well have overshadowed the need for a wider co-design phase at the start. In this instance, co-design began when the workstreams began their work and it continued throughout the remainder of the programme. The delay at the start clearly had an impact on the process, where some of the challenges could possibly have been predicted and avoided. The learning from this programme is that co-design is best introduced as early as possible to maximise a sense of common purpose, ownership and understanding expectations of the project.

- **It's difficult but it's worth it…**
  The purpose of this review was to explore the experience of co-production with a particular focus on the experience of service users / carers. In doing so it is necessary to identify both what worked well and what could have been improved. It is clear from these findings that co-production is not easy, however there was unanimous agreement from those who were involved that it made for better outcomes – that it was difficult but worth it.

7. Recommended model for the stages of a co-production project:

The Importance of proportionality

When planning any project where there is an expectation of co-production it is important to determine the level of engagement with other stakeholders that is appropriate. There is no value in a "one size fits all" approach, and the following description of a process is not intended to be formulaic but simply offers a sequence of principles to follow to consider how co-production might be applied. The decisions about how other stakeholders, including service users / carers, might be involved will be determined by factors such as the scale of the task and its nature, for example:

- Service Improvement Projects – will benefit from representation by those who use the services, as well as the wide range of others usually involved in delivery.
- Policy Development projects – will benefit from input from those impacted by the policy at certain stages of the policy development process.

In these circumstances, it is important to determine the stages within the process that require more engagement or less engagement with the wider stakeholder group and the general or specialist nature of the engagement. Consideration should be given to whether a project should be co-produced, or whether the outcomes could better be met with a PPI approach.

The Stages of a Co-Production Approach:

Stage 1 – Co-Design and Preparation – clarifying expectations:

- identification and mapping of the stakeholder groups relevant to the project
- description of the key outcomes expected from the project with timetables
- description of the skills and experience required to add value to the project and identification of the stakeholders needed to help design the process
- this process should involve individual representative stakeholders with experience relevant to each of the identified stakeholder groups to provide specialist insight to recruiting from those groups and maximising the benefit of their involvement

Stage 2 – Leadership – Getting effective people in the right roles:

- Identify if different types of leadership roles are needed within the project
- Match skills and knowledge of leaders to the tasks required
- Reflect the stakeholder make up in the leadership team to ensure a co-design approach is embedded in the project from the beginning.
- Define the project governance and reporting structures
- Identify co-production training for the leadership of the project
- Prepare a draft "terms of reference"

Stage 3 – Selection and training – getting the right skills and experience:

- the formality of the selection process will vary according to the scale and nature of the project. For some it will simply be that thought is put into who can best be involved, for a large-scale project it may be a formal recruitment process
- selection of those who might be involved should be carried out using the criteria of the skills and experience identified in the preparation stage
- the specific skills and experiences required should be explicit in the selection process – thought can be put into the preparation of "person specifications" for the roles depending on the scale of the project
- there should be the capacity allowed for additional skill sets to be recruited later in the project as the understanding of the needs develops

Stage 4 - Negotiation and Agreement – setting the ground rules:

- once participants are identified, time can be taken to negotiate working practices, these are simple questions that the team can take some time to consider together as part of an induction process. The purpose is to encourage discussion about the subjects rather to come up with fixed view on the answers, and the issues can be revisited throughout the process:
    - how will the group get to know one another?
    - how will the group ensure that everyone is able to have a voice?
    - how will the group deal with differences of opinion?
    - how will the group deal with specialist issues where not all members will have specialist knowledge?
    - how will the group share responsibility for decisions?
    - how will the group deal with dissent?
    - what support do individuals need to fully participate in the process?
    - are there any key stakeholders or other relevant groups not represented?
    - are there any required skills missing?

Stage 5 – Reflection and Closure:

- the opportunity for the group regularly to reflect on progress should be built into the timetable:
    - at the end of every meeting there should be a brief discussion and check-in with each member. This informal evaluation of the meeting should provide a check and assurance that everyone was able to participate.
    - there should be the opportunity for regular more formal reviews of progress, making the distinction between reviewing the progress against the task the group is set to achieve as well as the process of co-production.
    - there should be regular one-to-one meetings between the Chair and individual group members to check in with them and ensure they are feeling supported to contribute.
    - when the work of the group is complete, an evaluation should be undertaken of the effectiveness of the co-production process and any learning that needs to be incorporated into future projects

The challenges of each Stage of Co-Production.

STAGES	Service Users/Carers	Departmental personnel leading the project	Others: e.g. 3rd sector, external representatives
Stage 1 Co-Design / Preparation	Service Users/Carer representatives should be involved at this stage to co-design the process and advise on recruitment.	Those leading the project should have clear plans in place to manage the project, and to manage the co-production component of it.	Other personnel, or organisational representatives might be involved at this stage in the co-design of the process and to advise on recruitment.
Stage 2 Leadership	Service Users / Carers should have representation in the leadership of work-streams.	Depending on the nature of the project, there will be occasions where it is best that work is led by departmental personnel.	As with departmental personnel, there will be circumstances where work is best led by external representatives.
Stage 3 Selection	Depending on the person specifications of the service user / carer roles, different sources of recruitment can take place. Public advertisements, PCC etc.	Some specific personnel may be nominated by their departments, other may volunteer or be "head-hunted". As with the selection of service users / carers, clarity should be given about the skills and experience required.	Direct approaches can be made to specific organisations or representative bodies such as NICVA. As with the selection of service users / carers, clarity should be given about the skills and experience required.
Stage 4 Negotiation and Agreement	On the basis that Service Users /Carers may not be familiar with the workings of the systems, extra efforts should be put in to ensuring agreement about how they will feel comfortable participating. Discussion should be had about the supports necessary for them.	It should not be assumed that personnel within the health system are necessarily familiar or comfortable with the co-production process. Time and effort should be spent supporting them to explore what that means in practice.	Personnel from agencies external to the health service will not necessarily be comfortable or familiar with how the system operates. Time and effort should be dedicated to exploring how they can be facilitated to participate fully.
Stage 5 Reflection	As well as whole-group reflection, service users /carers should be given the opportunity to reflect with the Chair on the effectiveness of their participation and any further support they may require.	The impact of managing and participating in a co-production process on core staff should not be underestimated. It can be both challenging and personally demanding. Opportunities should be provided to get advice, support and to process the impact of this work.	Individuals from external organisations should have the same opportunities as others to be involved in reflection on the effectiveness of the project and of the co-production process.
Training Needs	Service users / carers would benefit from orientation training about the health service system, as well as specific training concerning the context of the project – policy, legal framework, clinical context etc. Training in co-production.	Those within the system will benefit from training in co-production.	Those others external to the system will benefit from some orientation training as well as co-production training

The experience and skills required of leadership to manage a co-production project are:

- **Ability to manage difficult conversations**: The co-production process is inherently conflictual. It is normal for there to be very different and conflicting views around the table about how things should be done. It is very important that the articulation of these differences is facilitated in a productive way, that conflict is not avoided but that it is handled sensitively and calmly. The Chair plays a critical role in brokering these discussions providing enough "containment" for the difficult issues to be aired. It can be useful to provide the opportunity for dissent to be recorded and "parked" to allow the discussion to proceed without needing to force immediate resolution.

- **Ability to deal with emotional distress**: It is sometimes the case that service users / carers or other group members, have very personal and distressing experiences of the services that are under discussion by the group, and that while others may view the discussions dispassionately from a policy or systems perspective, service users /carers (and indeed others) may be speaking from very personal, painful, first-hand experience. The Chair needs to ensure that these issues are dealt with sensitively, that painful connections can be acknowledged, and that conversation is facilitated to continue. Sometimes in situations like this, others may feel unwilling to speak if they think they are going to upset another group member – while this sensitivity is important, it is also important that the group is enabled to speak about these difficult and provocative issues. Group members should be facilitated to explore how these issues can be spoken about in a respectful, compassionate and supportive way.

- **Task orientated and focused:** Getting the balance between allowing discussion and exploration of difficult issues with getting agreement on a decision and being able to move on. The Chair is responsible for managing the discussions to come to some sort of consensus in conclusion. This will either be a unanimous group decision, or the group needs to decide how it deals with final disagreement on points. Circular and repetitive discussions should be avoided, and mechanisms such as recording dissent, should be used to progress decision making. Clarity about outcomes and timescales can help drive the decision-making process forward.

- **Compassionate and supportive:** It is the Chair's responsibility to create an appropriate environment in which the challenging process of co-production can take place. This involves both the management of the group process, as well as support for each of the individuals:

    - Group Process: The Chair should ensure that group discussions and activities are focused on the task and inclusive of all members participation. If there are distressing or controversial issues, The Chair is responsible for managing a safe enough environment for these to be explored, as well as ensuring that appropriate boundaries and safeguards are in place for individuals to feel supported to contribute.

- Individual Support: The Chair should be tuned into the well-being of all members of the group, and supportive to individuals who may be feeling excluded, overwhelmed, out of their depth or generally distressed. The Chair should have access to professional services for those who may need some emotional support and should have access to support and advice themselves.

Peter McBride

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