Recovery and Wellness post ICU:

Using Patient Diaries

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Summary
The Intensive Care Unit (ICU) is situated in the Ulster Hospital in Dundonald, Belfast. The hospital is the major acute hospital for the South Eastern Health and Social Care Trust and delivers a full range of acute services for the population. Staff had noticed that ICU patients and their relatives returning to the follow up clinic were describing concerning issues including nightmares, sleep deprivation, hallucinations and flashbacks. These contributed to them being unable to adjust to being home and leading a regular family life, creating stress for both the patient and their family. To build on the work of the follow up clinic and to further improve the psychological support for patients, staff thought that a possible solution was the introduction of patient diaries. Intensive care patient diaries are a simple but valuable tool in helping patients come to terms with their critical illness experience (Bäckman et al., 2010). Developed extensively in the early 1990s in Scandinavia, the success of these journals in piecing together the fragmented memories of a stay in ICU and enhancing psychological recovery has been well documented (Egerod et al., 2011). A successful application was submitted to the Patients First Programme at the Foundation of Nursing Studies (FoNS) for support with the project.

The project team consisted of the staff development sister, research nurse, ward manager, clinical lead sister, deputy ward manager, 5 staff nurses and a health care assistant to represent each area of the nursing team. Key stakeholders were also identified and the team engaged with them throughout the development and implementation of the project. Practice development tools and methodologies were employed to maintain engagement and inclusiveness throughout the project. A workshop, which was facilitated by the project leaders and a FoNS facilitator, was held, primarily so that common ground in terms of values and beliefs could be established. Aims of the project were also explored and set. Subsequent monthly meetings took place to discuss implementation as well as the practicalities that this would involve. A member of the group was empowered to suggest the use of “About Me” templates for patients that could not communicate information about themselves. Informal education sessions relating to the diaries and templates were arranged during lunch breaks and prior to night shift to engage with as many staff as possible. When a sufficient number of nursing staff had attended the sessions, a launch was held to raise the profile of the project and celebrate the achievements of the group and staff within the unit.

Various skills were acquired by team members and staff who engaged with the project. Some examples include enhanced facilitation skills, knowledge of practice development concepts, report writing, project management and the skills required to approach relatives and support them to write diaries.

The project has brought about the use of patient diaries completed by relatives, with the support of the nurses at the bedside. Patient feedback has proved that diaries are a useful tool for patients who survive critical illness and have developed psychological problems as a result. The project has also created an increased awareness amongst nursing staff about the mental health problems that can occur after a stay in ICU. The project continues to flourish. The group have taken patient feedback on board and are now keen to look at the use of photographs with the diaries. The next stage of the project will involve evaluation of the impact of these, perhaps in the form of focus groups of patients, relatives and staff. Although the journey with the Patients First Programme has come to an end, it is the beginning of a new journey in relation to enhancing psychological care for ICU patients and families in the future.

Background
Context of study site
The Intensive Care Unit (ICU) is situated in the Ulster Hospital in Dundonald, Belfast. The hospital is the major acute hospital for the South Eastern Health and Social Care Trust and delivers a full range
of acute services for the population. This includes a type 1 Emergency Department which is open 24/7, a comprehensive range of diagnostic services, the full range of outpatient, inpatient and day-case medical and surgical services, cancer care, coronary care, obstetrics and paediatric services. The regional Plastic and Maxillo-Facial services are mainly delivered from the Ulster site. The Ulster Hospital has 90,000 Emergency Department attendances and over 4,000 births each year. ICU is in a modern Critical Care Complex which opened in November 2010. It has 16 beds with current funding for 6 ICU (level 3) and 4 HDU (level 2) beds. Patients are admitted with severe and life threatening illnesses which invariably lead to organ failure. As well as caring for many medical patients; patients requiring the aforementioned specialties may also be admitted to ICU for treatment. There are around 650 patients admitted to ICU per year.

The ICU Follow-up Clinic

The ICU Follow-Up Clinic was established in April 2011, by a multidisciplinary team (MDT) who identified that provision of a follow-up service had been shown to expedite recovery after discharge from ICU. The care provided at the clinic has been found to help patients in alleviating distress and anxiety which is associated with both physical and non-physical symptoms. The clinic was the first of its kind in Northern Ireland and was set up without any additional funding. Direct face to face follow up of critical care patients after discharge to the community is advocated by the National Institute for Health and Clinical Excellence (NICE) (Clinical Guideline 83, March 2009). A team including a physiotherapist, nurse and consultant anaesthetist were involved in the set up and management of this clinic. Patients who meet a set criteria are invited back to attend. They must have been ventilated for at least 4 days and have been discharged from hospital for at least 3 months. At the clinic, the nurse takes on the role of councillor, the physiotherapist gives rehabilitation advice and the doctor can address any on-going medical issues and make appropriate referrals. The patient is also given the opportunity to go back into the unit and look around.

ICU patients and their relatives returning to the follow up clinic were describing concerning issues including nightmares, sleep deprivation, hallucinations and flashbacks. This contributed to them being unable to adjust to being home and leading a regular family life, creating stress for both the patient and their family. Critical Illness and use of sedative drugs are believed to contribute to these on-going problems and Warlan and Howland (2015) attribute these long term psychological problems to Post Traumatic Stress Disorder (PTSD). The NICE guidelines for Rehabilitation after Critical Illness (NICE, 2009) highlight the importance of psychological, emotional and cognitive dysfunction in the care pathway. As yet many of these issues are not addressed adequately either during the patient stay in ICU or following discharge.

For many years there has been exceptional rehabilitation programmes offered to patients following illnesses such as stroke or myocardial infarction from well-established charities such as Chest, Heart and Stroke and from programmes provided by the NHS. Critically ill patients however currently receive little or no follow up care. Follow up care is improving, and in recent years there has been a greater emphasis on physical and psychological rehabilitation with the introduction of care after discharge. The Intensive Care National Audit and Research Centre (ICNARC) are currently piloting a study investigating the psychological effects of a stay in ICU.

The Practice Development Group

In ICU, a small group of nurses who met regularly to discuss practice issues had already been established in 2011. This started out as a Journal Club but after reviewing literature, the group decided that they wanted to take a more pragmatic approach and attempt to incorporate some of the evidence into everyday practice. This began with the implementation of a nurse-led protocol which was based on current literature and research. Execution of this project could be described as “top down” and initially, its success was limited. After exploration of practice development
literature, the group expanded to become more inclusive of other members of the multi-disciplinary team. Health care assistants, medical and clerical staff were also invited to join the formerly nurse-only group. At this time, the name of the group was changed to the “Practice Development” (PD) Group to reflect the group’s changing way of working. The core group consisted of a research nurse, staff development sister, ward manager, clinical lead sister, lead nurse for the Clinical Information System, consultant anaesthetist, a band 6 sister and 6 band 5 critical care nurses, audit support assistant, 2 health care assistants and a physiotherapist.

The current project began when participants were asked to take part in an exercise which involved facilitating them to imagine what it would be like to be a patient suffering from a critical illness, intubated and ventilated in ICU. Leading on from this, the group were asked to make a collage relating to the experience. Two main themes emerged namely, patients’ communication difficulties and delirium. Following discussion at subsequent meetings and after reviewing the literature, the group decided that introducing patient diaries could be a way to address some of these issues. Shortly after, one of the project leaders heard about the Patients First Programme supported by the Foundation of Nursing Studies (FoNS). The ethos of Patients First was in-keeping with what the group was trying to achieve and so the decision was taken to apply.

**Patient Diaries**

Intensive care patient diaries are a simple but valuable tool in helping patients come to terms with their critical illness experience (Bäckman et al., 2010). Developed extensively in the early 1990s in Scandinavia, the success of these journals in piecing together the fragmented memories of a stay in ICU and enhancing psychological recovery has been well documented (Egerod et al., 2011). The diary may take many formats and will include a brief outline of the patient’s history and a description of events that have occurred during their stay in ICU.

Comparisons of diaries maintained by nursing staff were found to be meaningful in explaining the patient’s illness and recovery. Where relatives contributed to the diary the patient felt that that it was more meaningful (Bäckman, 2001). Ackerman et al. (2010) have emphasised that the data regarding the usefulness of diaries to patients and their families following discharge is scarce and a more formal exploration of practice is required in order to identify the aspects that are valuable to the patient. The feedback received from the staff that facilitate the follow up clinic within the Ulster ICU suggests that relatives and patients might benefit from a diary.

**Aim of the Project**

To develop a tool to record a critically ill patient’s stay in ICU that can be used by the patient and their family to aid psychological recovery

Objectives:
- To engage with key stakeholders
- To gather information to guide the development and implementation of the tool
- To use PD methodologies to enhance culture in ICU so that the project is well received and embedded into practice

A timeline of the project is summarised in **Table 1**:

**Table 1: Patient Diary Project Timeline**

<table>
<thead>
<tr>
<th>November 2013- September 2014</th>
<th>October 2014- April 2015</th>
<th>April 2015- onwards</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attend FoNS workshop days</td>
<td>Visits from FoNS Facilitator</td>
<td>Continue to utilise PD methods learnt during the programme</td>
</tr>
<tr>
<td>Regular facilitation visits</td>
<td>Initial workshop</td>
<td></td>
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<tr>
<td></td>
<td>Project team meetings</td>
<td></td>
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</tbody>
</table>
Methods and Approaches

A number of methods and approaches were used within the project in order to facilitate change. These methods and outcomes are summarised in Table 2:

Table 2: Methods and approaches used

<table>
<thead>
<tr>
<th></th>
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</thead>
<tbody>
<tr>
<td><strong>Purpose of Exercise:</strong> A values clarification exercise is designed to clarify the values that we hold</td>
<td><strong>Purpose of Exercise:</strong> A useful way to establish the views of all stakeholders and capture opinions</td>
<td><strong>Purpose of Exercise:</strong> Stories can help staff better understand what is most important to the patient and their family</td>
</tr>
<tr>
<td>The project leaders used this in practice to explore the values of the team at the beginning of the project. This shared vision helped to determine the objectives of the project. Values discussed:</td>
<td>The project leaders used this method at the outset of the project in order to plan for on-going activity and to establish feelings and thoughts within the group. As it was so well accepted by the group at the outset of the project, the group leaders continued to use it during further project meetings.</td>
<td>Stories are a way of better understanding the patient and family needs. In ICU the patient and their family are both relying on the nurse at the bedside. The project leaders believed that involving the patient and family as key stakeholders within the project was vital.</td>
</tr>
<tr>
<td>- I believe the purpose of caring for someone who is critically ill is:</td>
<td>- A claim is a positive statement about the project</td>
<td>We used the help of trust personnel involved in an on-going project called 10 000 voices.</td>
</tr>
<tr>
<td>- I believe this purpose can be achieved by:</td>
<td>- A concern is a negative statement</td>
<td>This enabled us to interview a patient relative while in ICU whose story is included in Appendix 2. It not only influenced our project but both the patient and his wife became involved in the on-going development of the diaries providing much valued insight and feedback.</td>
</tr>
<tr>
<td>- The factors that help this purpose are:</td>
<td>- An issue is questions raised from the concerns that can be addressed by the group</td>
<td></td>
</tr>
<tr>
<td>- The factors that hinder this purpose are:</td>
<td>From these shared values the group developed an action plan for the project.</td>
<td></td>
</tr>
<tr>
<td>- Other values I consider to be important are:</td>
<td>From these claims and concerns, the group developed a plan of action for the project.</td>
<td></td>
</tr>
<tr>
<td>From these shared values the group developed an action plan for the project.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Communication within the Practice Development (PD) Group**

The PD group meetings were held monthly at lunchtime as this suited most staff involved. Initially the meetings were predominantly used to outline and develop the project. Communication was also maintained via email, texts, and the use of a noticeboard in the ICU staff room. The PD group consisted of a selection of people from the multidisciplinary team including nursing staff, administration staff and allied health professionals. Although they did not attend the meetings, there was also input from medical staff and by a past patient and his wife. While the group started out with a small number of members, as the project progressed the number of participants began to increase. Initially the style of the meetings was predominately hierarchical, led by the team leaders who at times found it challenging to step back and allow the group to become autonomous (Heron, 1999). As the project has progressed, the group has developed a more trusting dynamic feel with a higher level of shared participation.

The PD group encountered problems on occasions when arranging meetings and maintaining momentum. Issues, such as arranging a time that suits the majority of members as well as fits with the busy ICU environment, have caused problems. Other issues such as staff travelling from home to attend meetings and giving up days off have arisen; however, the ward manager being supportive of the project has allowed these members of the group to accrue hours owed. Keeping the group members focused and motivated has encouraged them to attend meetings, even on days off.

**Workshop**

The members of the PD Group decided to hold a workshop at the end of April 2015. The purpose of this workshop was to involve more stakeholders in the project and so an array of members of the MDT were invited. This included clerical, medical, allied health and nursing staff. The group decided to extend the invitation to everyone in these groups in an attempt to collaborate in a person-centred way. It was perceived that including personnel from such a diverse range of disciplines would enhance the project. There were 14 participants at the workshop with representation from all of the aforementioned groups.

The workshop lasted 4 hours with lunch provided afterwards. The planned format for the day was an introduction, values clarification, a patient story, claims concerns and issues and concluded with an evaluation.

According to McCormack et al. (2013), one of the key principles of PD is to integrate creativity with cognition. This process allows practitioners to free their thinking which in turn allows human flourishing to occur. Throughout the workshop, creativity was encouraged. The project leaders had purchased materials for a creative box with their bursary from the project. Evoke cards (www.evokecards.com) were used as an ice breaker and for introductions at the start of the workshop. A seminar room onsite, close to ICU, that staff were familiar and comfortable with was used. As mentioned, the ward manager of ICU was very supportive throughout the project and in fact is an active member of the group. When the project leaders approached her in advance about time allocated for the workshop, she was happy to release staff to attend. This was done well in advance of rotas so that staff attending could take time off the floor.

**Values Clarification Exercise**

The project leaders co-facilitated the exercise with the FoNS Practice Development Facilitator. This arrangement offered support and a feeling of security for the project leaders and proved to be a valuable learning exercise. The support from the FoNS facilitator throughout the project can be likened to that provided by a “Critical Companion”. Titchen (2004) describes a Critical Companion as a practitioner that accompanies another practitioner on a journey with a set beginning and set, mutual departure. The Critical Companion should possess the skills and expertise to offer high
challenge and high support to the co-learner. The FoNS facilitator collaborated with the project leaders so that this was fulfilled.

The project leaders and FoNS facilitator began with an explanation of the values clarification exercise. Everyone was asked, without discussion, to comment on the following 5 statements:

- “I believe the purpose of caring for people who are critically ill is…”
- “I believe that this purpose can be achieved by…”
- “The factors that help this are…”
- “The factors that hinder this purpose are…”
- “Other values and beliefs that I consider to be important are…”

The responses were put onto sticky notes and then onto flipchart paper for viewing by the other participants. After this, the whole group divided into two smaller groups to design a poster to reflect their collective values and beliefs, using the creative material. Photographs of the posters can be found in Appendix 1.

As the members of the group began to engage creatively, a positive energy could be sensed throughout the room. The group dynamic was balanced with all participants appearing comfortable and feeling secure enough to vocalise their viewpoints. Heron (1999, p 51) defines the group dynamic as the ‘combined configuration of the mental, emotional and physical energy in the group at any given time’. He describes different stages of group dynamics, the initial one being ‘defensiveness’. The project leaders were keen to co-facilitate the exercise so that all participants would reach the stage of ‘authentic behaviour’. It is during this stage that any conflicts, both intrinsic and extrinsic are resolved and the hierarchical approach of the facilitator is changed to co-operative (Heron, 1999). Heron likens this stage to ‘summertime’ because of the abundance of growth.

After completion of their creative posters, each group selected a member to present to the group as a whole. Both teams had similar values which truly reflected person-centeredness towards the patient and the ICU MDT (as seen in Appendix 1).

Follow-up Clinic Patient Story
After this exercise the nurse, who is the councillor at the Follow Up Clinic, told a powerful patient story. She was able to detail some of the terrible psychological effects that a stay in ICU can have on a patient. As she told this story, the mood in the room became more solemn. The story had an evocative effect and afterwards, discussion ensued and the group were more determined and enthusiastic to engage.

Claims Concerns and Issues
The team leaders were eager that the project was collaborative and that all stakeholders could have the opportunity to contribute to the design and development of the patient diaries. As such, the group of staff who attended the workshop were asked to consider claims, concerns and issues (Guba and Lincoln, 1989) relating to the introduction of the patient diaries. McCormack and Manley (2004) describe claims, concerns and issues as a constructive approach requiring the group to examine and set the agenda for the project. Claims are the positive statements or feelings about the project, concerns are the negative aspects that may impede the project and issues are the questions that are derived from the concerns.

Different coloured sticky notes for each topic were used and group members were asked to write down their claims and concerns. The project leaders facilitated a discussion to turn the concerns into questions. These questions would be used to benefit the further development of the project.
As planned, this exercise helped to create questions that the group would use to formulate an action plan for the project. The key issues that were generated are as follows:

- How do we include the patient voice in the project?
- Patient diaries - where do we start?
- Support networks for patients and their family – what is available?
- Explore the usefulness of providing an information leaflet or a DVD for patients and their families
- Explore available resources both within the trust and externally that may assist with the project

Subsequent Meetings
The project leaders then facilitated the project group at their next meeting in order to give feedback and reflect on the outcome of the workshop and how best to proceed to meet with the project objectives. One of the objectives was to explore available external resources. However, the group agreed, following further discussion, that as the Critical Care Network Northern Ireland (CCaNNI) was at that time establishing a Regional Support Network for patients, that it would not be necessary for the project team to explore this further at that time. The group then decided to prioritise “the patient voice” and patient diaries as the main aims. Subsequent meetings were used to explore issues such as practicalities involved in implementation, development of the education programme and how to maintain momentum. As the claims, concerns and issues exercise (Guba and Lincoln, 1989) was so successful during the workshop, that the project leaders adopted this format for team meetings.

Patient/Relative Story
Involving the patients’ voice in this project proved a difficult and frustrating task for the project leaders from the outset. Critically ill patients may be unable to give consent or even communicate effectively. The idea for patient diaries had been influenced by patient stories and patients’ and relatives’ experiences following discharge, told informally at the follow up clinic. The project leaders wanted to capture these experiences but were aware of the difficulties that the patients and their families faced. Advice was sought from the research office who directed project leaders towards an on-going study within the Trust. 10,000 voices is a project designed in conjunction with the Public Health Agency (PHA) that allows patients, their relatives and carers an opportunity to share their experiences of healthcare and influence future services (Public Health Agency, 2014). This allowed us to gain consent to interview patients or relatives. Consent forms and information leaflets had already been developed and our patient stories were integral with the study aim.

The patient/relative story found in appendix 2 was obtained by one of the team leaders and a member of the project group. A relative of one of the ICU patients had agreed to talk about her experience. The patient, who was still suffering from episodes of delirium was at this time, was not able to consent to talk about his experiences. The project leaders were unsure about the value of the story at the outset but listening first hand to the relative’s experiences, which were both honest and open, about her husband’s time in ICU, emphasised that each individual experience is unique and valuable.

During the interview the relative described feeling overwhelmed by all the equipment around the bed space even though it had been explained by the nurse. She did not fully understand all the information given. She suggested the use of a cartoon or diagram that labelled and explained the equipment. She provided other insights into the development of the project as she had actually kept a diary of her husband’s progress during his stay in ICU after reading about them online. The ideas
and suggestions that she discussed have led the project group to invite her to act as a consultant to future project development.

Odell, (2014) describes patient stories as a powerful way to reach staff and patients and the team leaders sought to utilise this relative’s story to glean further support for the project from other staff within ICU. At the next meeting, the story was read aloud by the project leaders in order to maximise impact. Following this, the project leaders facilitated a claims, concerns and issues exercise, and worked together to develop answers to the issues, these then formed an action plan. The issues that emerged were:

- When and how should we introduce patient diaries?
- How could we include the relative that had shared her story in the project?
- Do we feel that more patient/relative stories are required?

**Change in direction**

Initially, the group were keen to adopt the approach commonly found in the literature with regards to patient diaries (Jones and Bäckman, 2012). It was envisaged that the nursing staff and eventually, other members of the MDT would be the lead contributors to the diaries. However the group neglected to account for the time and resources it would take to hand over the diaries to the patients. When the project leaders calculated how many diaries would be generated, it equated to approximately 2-3 per week. In the current economic climate, it was deemed unfeasible to use nursing hours to carry this forward.

The group met to discuss ways around this and it was decided that the relatives could take the lead with the diaries. We would develop an information leaflet (Appendix 4) to support them and a plan of education for nursing staff. Additionally we would provide notebooks and pens for the relatives who chose to participate. The group apportioned the tasks and set to work. A group member brought up the idea of “About Me” templates (Appendix 3). These would be filled out by the patient’s relatives and would help the MDT to find out more about the person in the bed, who may not be able to communicate and this might help staff to view the patient holistically.

**Training and launch**

The group wanted to develop an informative education programme that would use PD methodologies to introduce the concept of using patient diaries to the rest of the ICU nursing team. At the same time the group had to consider factors such as timing, allocation of time, location and how we would facilitate working with almost 70 nursing staff. After discussions between the group and the line manager, it was decided that the most efficient way to overcome these obstacles would be to facilitate the sessions over lunch time for day staff and supper time for night staff. Sessions ran over 2 weeks and 40-45 minutes was allocated per session. As nurses’ break times were being used, the FoNS bursary was used to provide lunch and supper for attendees. The sessions were evaluated by asking attendees to complete a claims, concerns and issues exercise but due to time limitations, staff were asked to write their claims and concerns on sticky notes and then the project group members collated and themed the responses and shared them with staff on the notice board and via email inviting further comments.

The main responses were themed as “claims” or positive aspects. The themes included recognising that the diaries improve communication with families and may help relatives regain a sense of control. They also considered the patient perspective in helping to fill in the gaps in their treatment and established that there is a need for improved psychological care. The “concerns” addressed issues such as protecting patient confidentiality, families misinterpreting information or using the diary as a legal document against staff. These issues were addressed by advising staff that families
are responsible for the care of the diary and advice to document any conversations had with family members on nursing notes.

74% of nursing staff attended over the 2 week period. A week later the group arranged a launch party. The staff were provided with cake and party food, purchased from bursary funds, to mark the occasion and create a buzz. Photographs were taken throughout the project and can be found in Appendix 6. The launch event was also included in the Directorate Newsletter. A date for the launch of the patient diaries was agreed with the PD team, ward manager and clinical sister. The PD group members were available during visiting times to support and encourage the nursing staff to approach relatives of patients. A “patient diary box” was assembled by the PD team which included a flow chart to guide nurses as to whom they should approach (Appendix 5), a patient information leaflet (Appendix 4), an “About Me” template (Appendix 3) and items such as notebooks and pens. This was developed to make the process as simple and efficient as possible.

**Patient diary feedback**
Although a formal evaluation has not been undertaken of the patient diaries as yet, feedback has been provided by patients and their families who are attending the follow up clinic. They have discussed the benefits of the diary and have also included comments on how to improve the diaries for the future. Appendix 7 has a full extract and feedback from one patient who said he felt the diary had improved his recovery.

> “I found reading the diary after my discharge (I did wait quite some time before I started into it, I'm not sure why, maybe fear of knowing the anxiety my condition had caused everyone). I found it very emotional and certainly brought a lump to my throat and made me blink a lot. I am certainly glad that the record was kept; it has given me a glimpse into what had happened during my illness, how ill I had been and how everyone had coped.”

**Discussion**
The benefits of this project have been broad. In terms of patients and relatives, it has helped the relatives who choose to participate, to feel involved in the care of their loved ones. But there have also been benefits to the ICU itself. The culture in ICU has been enhanced by the introduction of PD tools and methodologies. Traditionally ICU is a technical environment and perhaps at times the psychological aspects of holistic care may be given less priority. However this project demonstrated to nursing staff the severe psychological trauma that critically ill patients may endure and there is a greater awareness amongst staff within the unit of the effects of delirium on patient outcomes. Manley et al. (2013) contend that understanding workplace culture is central to practice development. The project team did not formally examine workplace culture but anecdotally, some developments were noted. When discussing the psychological impact of being in intensive care with a new nurse, the project leaders were heartened to learn that the nurse’s preceptor had already taken the time to discuss this. The preceptor had used an example of an account that had been discussed at the workshop. This reaffirmed the transformational effect that the story had had on this nurse.

The implementation of patient diaries and “About Me” templates has demonstrated that small changes to patient care can have a significant impact on quality of care but with small cost implications. On a wider scale the project has helped to enhance the person-centred care and support given to patients and relatives. This is reflected in feedback provided by patients and their families attending the follow up clinic. They have discussed the benefits of the diary and have included comments on how to improve the project. One person’s feedback and an extract relating to a patient diary (see Appendix 7) is so powerful that it speaks for itself in endorsing the value of the
Several ex-patients commented that the inclusion of photographs could be beneficial in helping them understand more about their illness.

**Conclusion**

Although the introduction of the patient diaries was not without its obstacles, it is now embedded into the nursing care and practice in ICU. The project team had a preconceived vision of what the patient diaries model would look like, however PD approaches enabled a more flexible approach to be taken.

The project has led to the successful implementation of patient diaries and “About Me” templates. The next stage of the project will involve evaluation of the impact of these, perhaps in the form of focus groups of patients, relatives and staff. Although the journey with the Patients First Programme has come to an end, it is the beginning of a new journey in relation to enhancing psychological care for ICU patients and families in the future.

**References**


Appendix 1: Workshop - Values Clarification Exercise Posters
Appendix 2: A relative’s story

“During the early hours of the 4th June my husband woke with difficulty breathing and a raised temperature. We travelled to A&E where his condition deteriorated and the doctor told me that he required a tube to help him breathe. The doctor explained to me that he would have to be transferred to an Intensive Care Unit for further treatment and he was trying to locate a bed. We were relieved when we were told that a bed was available in Ulster hospital and we were waiting on an ambulance to transfer him. At this time I contacted the rest of my family as I was so shocked at what I had been told after all we had just been on holiday.

When we arrived at the Ulster we waited for news about his condition. We found the staff helpful and considerate but there was so much information to take in. I remember being shocked when our family first saw my husband all the tubes and wires around him. The nurse explained what they were for but I don’t feel that I took much of it all in. Thinking back a little cartoon diagram would be useful to explain what they are all for.

When we got to speak to the doctor he explained that my husband was the sickest patient in the hospital. We stayed in the hospital the first three nights of his stay in ICU; it was a stressful time but with support and compassion from the nursing staff my family and I coped. In fact by day 4 his condition had started to improve and I went home for the first time since his admission.

By day 7 I was reading information on the notice board in the waiting area and found an interesting poster about a website called ICU steps and curious to find out more I began to read the information on line. There was some interesting information about patient and relative experiences of ICU that helped me to know that others had been through similar experiences. One interesting bit that caught my attention was about a patient diary, a record of their stay in ICU. The web site talked about gaps in memory and the diary helping to patch information together. I bought a notebook and began to keep a record of what was happening with my husband each day.

I wasn’t sure what to write so I began to keep a record of who visited each day, any medical intervention and other comments about things that were happening at home. I found this valuable for me as it gave me something to focus on and I felt I was contributing to his care.

The consultant spoke to me about my husband’s progress and explained that he may require a tracheostomy; a tube in the neck to help him breath. While he was discussing his progress so far he described his Chest x-ray as horrendous and described how he had have to his heart shocked twice. Hearing everything summarised in this way hit home to me and his family just how sick he was. Looking back I wished I had known about and written the diary from day 1 it would have helped me piece together all that has happened during his stay in ICU and hopefully help him get better but time will tell as to how useful he feels it is. I have told him that I kept the diary but as he is still a bit confused at times I am not sure how much he has taken in. I have taken some photos for him to see when he is well enough at each of the milestones in his recovery.

My husband progress was at times frightening and distressing for us as a family to watch, he describes having his jaws wired and asking why he was in jail. He has also talked about walking with a frame in ICU but I am not sure if this happened as I didn’t get an update on that day and it would be good if the staff could contribute to the diary to help fill in the blanks.

It was distressing for us to watch him coughing with the breathing tube and seemingly at times in pain or discomfort but unable to communicate to us what he needed. The delirium was particularly difficult to observe and nothing that you read or are told by the staff prepares you for that experience. I know that it is caused by the drugs he received but to have him describe having tea with the Queen at her garden party till 3 in the morning was disturbing.

I understand that staff are busy but to be able to see a progress report each day would be helpful to feed information back to the family. I found it overwhelming at times trying to feed back to the family and friends on his progress so I set up a group text message to try and cut down on the amount of times I had to send information. I also found myself putting my head down in the shops just wanting to get my shopping and get home I was exhausted and although it is kind of people to enquire about his condition I found that I was repeating myself over and over again.

I have continued to try and maintain the diary now that my husband has moved to the respiratory ward but it difficult to keep it up as I don’t get to talk to the staff on the ward or have the same rapport with them as I did with the staff in ICU. He continues to make good progress each day but is still confused at times.

At the beginning when he first was admitted I didn’t dare to imagine that he would make it here I am just thankful that he recovered.”
Appendix 3: “About Me” Template
Appendix 4: Relative Information Leaflet

**What happens to the diary after intensive care?**
Let your loved one know when they feel better, that you have kept a diary of their stay in Intensive Care.

Explain to them that the diary is kept safely for them and let them decide if and when they would like to read it.

**Further Information**
If you have any questions about keeping an Intensive Care patient diary please do not hesitate to ask the nurse looking after your relative.

**Useful websites for more information:**
- [www.icusteps.org](http://www.icusteps.org)
- [www.ics.ac.uk/patients-and-relatives](http://www.ics.ac.uk/patients-and-relatives)

**Keeping an Intensive Care patient diary for your relative**

**What is an intensive care patient diary?**
The Intensive Care patient diary can be an ongoing record of events that have happened during a patient’s stay in Intensive Care (ICU) to include things that happen outside of hospital as well as in ICU.

It can be written by a close family member, partner or friend so that the patient can see how their condition changed, who came to see them and what was happening at home whilst they were in intensive care.

**Why is the patient diary useful?**
Patients may be in a relaxed, calm, or sleepy condition as a result of being given medication known as sedation which can lead to memory loss.

Additionally, ICU patients may suffer from a temporary state of confusion known as delirium. People with delirium may see and hear things that are not real and may lose track of their surroundings.

The diary helps to piece together the gaps in memory and make sense of what has happened while they have been unwell.

Diaries may help patients to understand their intensive care stay, which can help their recovery. If you choose to keep a diary, it may also help you to make sense of what is happening.

Often our memories are not good during periods of stress and anxiety and later you may wish to recall some of your experiences. Keeping a diary may also be useful as your relative might ask you questions about what happened to them.

**Can I keep a diary for my relative?**
Yes, you can start a diary when you feel ready, if you feel it would help.

Patients who are in intensive care greater than 2 days may benefit most from a diary. There are notebooks available for you to use. One of the nurses will give one to you if you tell them that you wish to start a diary.

It is not permitted to take photographs of your relative while they are in ICU.

**What could I write in the diary?**
When writing in the diary keep in mind that the diary is something the patient may like to read on recovery when they feel ready.

**Suggestions:**
- You could write about thoughts or feelings that you would like to share with the patient
- You could write about things that have happened to you or the family which the patient would like to hear
- You could add messages from friends and family, for example children’s homemade cards and supportive text/emails
- You could add information from the outside world such as weather or favourite sports results
- You could write about milestones such as “today you sat up in the chair”
- Please take care to keep your diary safe at all times as it may contain sensitive or private information about your loved one

We hope you find the information in this leaflet useful

Information and guidance for friends and relatives

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Appendix 5: Diary Flow Chart

**Patient Diary Flowchart**

Likely to be ventilated over 48 hours?

Who is the best family member to approach?

Have they been given an information leaflet?

Have they been approached about completing an “About Me” template

Have they agreed to keep diary?

Do they need a notebook?

Have you documented this in nursing notes?
Appendix 6: Project Photos
Appendix 7: Previous Patient Diary Extract & Feedback

“Re our conversation on Friday regarding my/my families ICU diary, kept during the period of my stay as a guest of SE Trust. It was really down to my eldest son, but the entries I think were a reflection of my whole families’ feelings during that very trying and anxious period for them.

My son divided the entries into 3 parts, the first being my condition for the day, ups, downs, blood pressure, how I was responding, the views of the medical staff etc. Second, how he and the family, especially his mum, were feeling, sad, optimistic, pessimistic, worried sick. Their hopes and wishes. Thirdly, what was happening in the world outside of the ward (my world) weather, what was on the news, things that had happened involving the family over the previous 24 hours, how I seemed to be the only person who knew how to start a lawn mower!

I found reading the diary after my discharge (I did wait quite some time before I started into it, I’m not sure why, maybe fear of knowing the anxiety my condition had caused everyone) I found it very emotional and certainly brought a lump to my throat and made me blink a lot. I am certainly glad that the record was kept; it has given me a glimpse into what had happened during my illness, how ill I had been and how everyone had coped. Some of the entries seemed familiar to me, the Rugby World Cup was on during my stay although I have no recollection of it, some of the scores between the nations seemed familiar. Nursing staff had put the matches on the TV even though I was sedated during that period.

Saturday 10th October
They lowered your support this morning but you didn’t cope so well so it went back up slightly, baby steps I guess. Your stats had a bit of a blip this evening but the nurses seem to be of the opinion that it’s just down to weakness of body. You’re also still taking a lot of breaths per minute, which looks really uncomfortable and distressing. The nurse told us that while it appears very cruel, but it is necessary to go through that to strengthen your lungs back up. Some positive signs as well today though, you’re effectively out of it, probably having some crazy ass dreams but you attempted to pucker up for a kiss when mum was leaving, think it cheered her up a good bit.

Outside world; Wales football team qualified tonight for Euro 2016, their first major tournament since the 1958 world cup.

Monday 12th October
You seemed very responsive today, able to open your eyes, nod, and even smile! I asked did you miss me, and you nodded no and smiled, was a nice moment. The breathing rate is down slightly as well, it’s now down to the low 40’s

Mum gave cupcakes to all the nurses and doctors in ICU today, just a thank you for everything they’ve done for you so far.

Tuesday 13th October
Well your stats are all very similar today and you’re trying to speak a lot, but with this trachy thing in, it’s going to be a while until your voice comes back. You’re also very grumpy! We’ve been warned that this could be a side effect though. They have started you on anti-depressants but they take a while to kick in.

In the outside world it was confirmed today that flight MH17 (that crashed over Ukraine) was downed by a missile.

Also, Paul O’Connell’s Ireland career is over, he injured himself against France and it was confirmed that’s him out of the tournament.

I hope this gives you an idea, I think the whole idea is marvellous, a thing I would suggest although I am not sure on the legal side of things, data protection etc. would have been if some pictures could have been taken during my time, I had some taken by family covertly which I have found amazing and wish there was more to help me get my memories and thoughts in order. Perhaps a camera held in the ICU and nothing released until the patient is aware and consents to the pictures being downloaded, just a thought, I would certainly donate towards any cost incurred.”