The Extent and Application of Patient Diaries in Australian Intensive care units: A National Survey.

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Abstract

Background: Critical illness can be a psychological stressor for patients and family members. Scandinavian studies have portrayed patient diaries as a supporting catalyst for patients and their families through a process of reflection and fact presentation. However, the small number of randomisation trials exhibits theoretical and methodological limitations. Given the increased interest amongst Australian Critical Care Nurses, further understanding of nurses’ perceptions and use of patient diaries was warranted. Objectives: To identify nurses’ perceptions of patient diary use and to describe their application within Australian ICUs. Method: A descriptive, exploratory study design using an online survey of the Australian College of Critical Care Nurses was used. Descriptive statistics illustrated participant responses and textual data were subjected to content analysis for emergent themes. Results: Out of the 194 participants, 19% (n = 37) reported patient diary use in their unit, with nine indicating some form of evaluation. Fifty (70%) of the non-diary users, who responded, indicated hesitancy to introduce them. Respondents noted a lack of guiding policies and potential medico-legal ambiguity. Content analysis revealed three themes, considering diaries as: communication tool, patient recovery tool and a family centred care strategy. Conclusion: Patient diary use appears to be in its infancy in Australia with a lack of guiding policy for format and processes including evaluation. Nurses using diaries were enthusiastic about the initiative, holding optimistic perceptions about the potential positive impact of diaries on patient and family outcomes. Further research on their efficacy is required.
**Introduction**

Over the past decade the psychological outcome of patients following admission to intensive care has attracted the interest of clinicians and researchers alike. During an admission to an intensive care unit (ICU), patients experience multiple, acute, often overwhelming physical and psychological stressors due to the nature of their illness or injury, which extends beyond their discharge.\(^1\), \(^2\) These problems may be related to the ICU environment, sleep deprivation; or health related issues like, illness, pain and an inability to express needs.\(^2\)-\(^4\)

Patients’ can be affected by limited recall and/or inaccurate or hallucinogenic memories. These may lead to poor psychological recovery post ICU admission.\(^5\), \(^6\) Conversely, the presence of accurate ICU memories, that may be distressing to patients have been associated with a positive emotional outcome.\(^5\), \(^7\), \(^8\) Studies have suggested that as many as 20\% to 25\% of ICU patients may go on to develop Post-Traumatic Stress Disorder (PTSD), posing limitations on their return to an optimum functioning level.\(^9\), \(^10\) The prevalence of poor psychological outcome for ICU patients has led to many ICU clinicians acknowledging the need for patient psychological assessment and support during and beyond the ICU admission.\(^11\), \(^12\)

A novel strategy using ‘patient diaries’ has emerged and developed from Scandinavian countries’ academics in the past decade. The initiative was originally designed to provide factual accounts of the patient’s ICU stay through cataloguing key events through texts and photographs by staff, family and friends.\(^7\)
**Literature Review**

A search for published research in CINAHL, Embase, Medline and PsychInfo databases using MeSH and textual terms related to ‘intensive care’ and ‘patient diaries’ was conducted. Two hundred and twenty-one articles were identified. Duplicate articles were excluded and remaining article abstracts were examined. Those articles that did not pertain to an intensive or critical care context were excluded. Eleven original research articles were reviewed in detail and their reference lists were checked for relevant articles.

Early research in this area was largely limited to small descriptive, qualitative studies exploring patient and staff experience of diaries as well as their content and format. Initial evaluations and reports on patient diary use with ICU patients, suggested that they assisted patients in accepting the severity of their illness, and helped relatives cope with feelings of grief and loss, with subsequent studies reporting diaries improved communication channels.\(^6\), \(^13\), \(^14\) These descriptive studies served to explore patients’ and families’ views of diary use, their content and processes, which generally indicated a positive reception, and laid the foundation for subsequent studies.\(^6\), \(^13\), \(^14\)

There have only been three trials that have examined the impact of diaries on patient and family psychological outcomes.\(^7\), \(^15\), \(^16\) A small Randomized Controlled Trial (RCT) conducted in 2009 examined the effect of diaries on the levels of anxiety and depression in 36 ICU patients, using the Hospital Anxiety and Depression scoring System (HADS).\(^7\) Participants were assessed at two time points: Time 1 had a median of 30 days post ICU discharge and Time 2 was three weeks after the first assessment. The control group received their diary after the Times 2 test whereas
the experimental group, the week following the Time 1 assessment. Analysis revealed that the experimental group displayed a statistically significant decrease in anxiety (t (1, 17) = 2.65, p<0.05) and depression scores (t (1, 17) =3.33, p<0.005) at Time 2. There were significantly fewer anxious patients in the experimental group at the Time 2 assessment (p<0.05) but no significant difference in the number of those with depression when compared to the control group (p=0.07). The wide variation in when participants were first tested, (range from 21 days to 8 months) and therefore when they received their diary, it may have impacted upon the results; which suggested that diaries may assist in decreasing anxiety but there is no evidence that there is a significant effect on depression. 7

A larger RCT with 352 ICU patients across six European countries was performed to test whether the provision of an ICU diary reduced the occurrence of new cases of Post Traumatic Stress Disorder (PTSD) in patients.15 The ICU Memory Tool (ICUMT) was completed by all participants one to two weeks post ICU discharge and again three months later. The intervention group could elect when they received their diary, whilst the control group received theirs after the three month follow-up questionnaires were completed. Participants were generally given their diaries with explanations by the research nurse or doctor during an out-patients visit but some received theirs via post with discussion occurring via telephone. Base-line assessment was conducted at randomization using the Post-Traumatic Stress Syndrome 14 (PTSS-14) screening tool. At the three month post ICU testing time the PTSS-14 was repeated and the post-traumatic stress disorder diagnostic scale (PDS) was administered.
Over 85% of the intervention group elected to receive their diary at randomization. At three months there was no significant difference in PTSS-14 scores between the two groups but in post-hoc analysis when the researchers tested the PTSS scores above a cut-off of 45, there was a significant reduction for the intervention group ($p=0.04$). When the PDS results were analyzed, there were fewer probable cases of PTSD in the intervention group (5% versus 13%, $p = 0.02$). More importantly, the PDS was not used at baseline and the use of the PTSS-14 as a surrogate measure for PTSD was not adequately rationalized. Aitken and colleagues highlighted that the use of the PDS, which is designed to be a self-reported tool, was not validated for administration by interview as occurred in Jones et al.’s study. In addition there is the potential for unequal treatment of study groups relating to the interviews with limited descriptions provided on the specifics of how and where they were conducted within the six European countries.

Jones and colleagues also studied the impact of patient diaries with a pilot study of close relatives ($n=30$) of ICU patients in two of the 12 sites in the study above. The authors hypothesized that families of ICU patients may benefit psychologically from the delivery of the diary. The theoretical concepts underpinning this study are not clearly defined and would benefit from further exploration.

In the family member study, the aim was to test whether a patient diary delivered to the patient at one month reduced the levels of PTSD symptoms for close relatives who had read the diary after the patient returned home. Relatives’ baseline PTSD-related symptoms were assessed one month after ICU discharge using the PTSS-14 screening tool and again at three months. Families of patients who received the diary during the treatment period (less than 2 months post
ICU discharge) had lower PTSS-14 scores at the three month follow-up in comparison to the control group (median PTSS-14 score change -5 for intervention group versus +5 change for control group, p=0.03), indicating that at three months family members of patients in the intervention group had fewer psychological symptoms. This is the first study of its kind and larger studies are required to both understand conceptually and further evaluate the impact patient diaries may have on their family members’ psychological wellbeing following patient discharge from ICU.

A number of other studies aimed to quantify the extent of patient diary use. These studies were conducted by researchers in Scandinavia and Northern Europe, where overall diary use ranged from zero use in Germany to 76% in Sweden.\textsuperscript{18-21} Studies performed in Denmark, highlighted the legal and ethical ambiguity of the diaries, whereas the Swedish and Norwegian researchers emphasized the need for a systematic follow-up program.\textsuperscript{12,19,20,22} The predominance of diaries in Scandinavian countries has been attributed to efficient networking among nurses in the region.\textsuperscript{23}

In summary, diary use appears to be limited to selective countries in Scandinavia and Northern Europe, with isolated reports in the UK. Reports of patient diary use in Australian ICUs are currently limited to conference presentations and anecdotal reports.\textsuperscript{24-26} The authors’ review of the literature highlights the need for further studies that explore diary format, use and delivery in Australia, as well as trials that evaluate its benefits or potential harm to patients or families. The emerging interest and use of patient diaries in ICUs is the impetus for this study, that aimed to identify Australian ICU nurses’ perceptions of the application of patient diaries in their ICU.
Methodology

This study used a descriptive, exploratory design, with the aim to:

- Identify nurses’ perceptions of patient diary use in Australian ICUs,
- Describe the application of patient diaries in Australian ICUs.

Survey development

The survey was a modified version of the questionnaire used by Dr Ingrid Egerod, who gave permission for its use and modification.\(^{18}\) The survey was modified for the Australian setting and population by adding items relating to respondents’ workplace (for example, public or private hospital; ICU bed capacity); participant demographic details including their gender and years of experience as a nurse. There were items relating to the processes associated with diaries such as “Who co-ordinates the diary process in your unit?” and “To whom is the diary given?” They were also asked if diaries were evaluated in their unit. In addition their perceptions on the positive and negative aspects of diaries were sought. Ultimately, the survey contained 26 items, with 18 fixed response items; four demographic and four open-ended items (see Appendix A). The survey was administered electronically and had those respondents who answered “no” to the first item (i.e. Have you used diaries in your current workplace?) move directly to item 11 as the intervening items did not pertain to them. This allowed all respondents to record their perceptions on diary use in a general sense in response to the latter survey items. The survey’s content and face validity was assessed by two experienced critical care nurses and by online pilot-testing by four nurses (independent of the main sample), who were familiar with patient
diaries and worked in an adult tertiary ICU. The survey was found to be comprehensive, easy to follow and logical and therefore remained unchanged.

Sample

The target population was approximately 2,400 current Australian College of Critical Care Nurses (ACCCN) members, working across the critical care spectrum. The sample included a proportion of members who had indicated their interest in being contacted for research projects on their membership form (n =1,563).

Data collection

The survey was administered via an online survey portal called, ‘Lime survey’, supported by the Griffith University Research Survey Centre (www.griffith.edu.au/survey-centre). The ACCCN national office forwarded an email with project information to the 1,563 members. The email contained an introductory letter outlining the study background, a hyperlink to the survey website and the participant information sheet. In accordance with the ACCCN policy, a single reminder email was sent three weeks later. Responding to the survey automatically implied participant consent. The online survey website did not record internet protocol addresses, hence maintaining respondent anonymity and privacy.

Ethical considerations

Ethical approval was sought and received from the University, through its Human Research Ethics Committee (GU Ref No: NRS/06/12/HREC).
Data management and analysis

Survey responses were captured and exported into Predictive Analytics Software (PASW) Statistics, version 19.0 (SPSS Inc. Armonk, NY: IBM Corp). Descriptive analytical statistics were used to illustrate participant responses, using counts and percentages. Textual data from the four open-ended items were subjected to content analysis to identify the key themes.27

Results

One hundred and ninety-four participants completed the online survey providing a response rate of 12.5%. All responses were expressed as a percentage (%) of the total number of responses for that item. It should be noted that different numbers of respondents answered some of the survey questions according to applicability.

Demographic variables

Of the 194 respondents, 93% (n=167) were females, the majority with extensive nursing experience, practicing mostly in metropolitan units, and caring for adult patients 79% (n=141) (see Table 1).

Patient diary use in Australian ICUs

Nineteen percent (n=37) of respondents, reported patient diary use with nearly half of these being for two years or less (43%; n=15). Sixty-one percent of diary users (n=27) were from metropolitan public hospitals (see Table 2). Eleven respondents who were diary users (35%)
identified that their unit has a diary policy. They largely reported that the diaries in their units were not guided by a definite structure (85%; n=28).

Respondents using diaries identified family members and nurses as the main authors of diary entries. Nurses largely coordinated the diary process through initiating, maintaining and giving it to the patient before ICU discharge, or immediately upon transfer to the ward. A small percentage of the respondents (30%; n=9) reported that there was an evaluation of patient diaries in their unit.

**Diary awareness in Australian ICUs**

Only 53% (n=77) of respondents were aware of the existence of patient diaries, and a large proportion did not use them in their unit (81%; n=154). The majority of respondents (79%; n=56), reported being hesitant to introduce diaries in their units, although some (21%; n=15) indicated that “yes, seems like a good idea” (see Table 3).

Textual data from the open-ended questions were subjected to content analysis and were consolidated into thematic exemplars. The main concepts to emerge from the nurses perceptions about diary use were: communication strategy; patient recovery tool; and a component of Family Centered Care (FCC), as in- person diary follow-up was perceived to be beneficial (see Figure 1). Textual examples of nurses’ feedback are reported below under the relevant theme.

**Communication strategy**
Respondents wrote that diaries potentially provided a useful record of events for patients and families which could support later communication about the patient’s time in ICU.

“They use it to record events for communicating with others. It is a record for families to view and reflect upon and to gauge patient’s progress” (R45).

“(Diaries) provide patient with information about their treatment” (R178).

Some respondents’ comments indicted that they felt threatened or were guarded in regards to what could be recorded in diaries with some respondents considering entries were communicating more than the facts as they related to the patient. One respondent wrote the nature of their concern was that they could be exposed to criticism of their clinical practice by the family.

“It felt threatening, like they (nurses) are being watched and recorded by the family in matters of what they (nurses) do, and who looks after the patient and when” (R74).

If diaries are to be used as an effective communication strategy, respondents considered that a uniform method for their development and delivery to patients was important and could be improved. These process issues also included concerns about potential issues with confidentiality and legality of diary entries.

“There is no consistency in its (the diaries) follow-up process, and there is a need for more organizational involvement to enhance the project (diaries)” (R4).

“Confidentiality issues when contributed to by hospital personnel [sic]” (R14)

"Legal issues when we write something down in the diary are of concern." (R69).
Diaries were seen to be a useful communication tool that recorded patient events but required guideline and policy development. Patient diaries were also perceived by some respondents to be a recovery aid for the patient and their families.

**Patient recovery tool**

The study identified potential therapeutic benefits of diary use as a long term patient care strategy, echoed in statements such as:

“It (patient diary) is a recovery aid… fills in gaps” (R80).

“It is psychosocial support for patients” (R194).

Some nurses referred to the diaries as “patient stories” (R76) and a “memory aid” (R202). Alternatively, respondents considered that the use and compilation of diaries may not be for everyone and that the decision to receive a patient diary should be a personal choice as indicated this quotation:

“Patient should not feel obligated to contribute to or read the diary” (R15).

Respondents considered that one beneficial aspect of diaries was that it gave them the opportunity to give the patient their diary in person.

When the nurses handed out the diary in-person to the patient they wrote that it gave them a chance to opportunistically evaluate, not only the patient’s progress to enhance recovery, but also the care that was given. This study highlighted the desire for ICU nurses to meet, converse and obtain feedback from patients upon discharge. Remarks below are amongst others that are indicative of a general sentiment and desire for an opportunity to follow-up with the patient.
"It’s lovely to talk to patients upon discharge and I think the patients feel a sense of wonder when one goes through the diaries" (R32).

“It was beneficial to evaluate our care of patient and family. These stories were feedback to all nursing staff in the unit, including the NUM. Positive aspects of our stories include: positive feedback to staff for the care they provide/positive reinforcement to staff” (R76).

Respondents considered that diaries may not only be for patients but that families may benefit from them. The underlying assumption that families are legitimately integrated into ICUs was noted and respondents highlighted that diaries provided a supporting mechanism to involve families.

**Family centered care**

Nurses indicated that diaries potentially acted as a way for families to be included and to connect with the patient during the critical illness and recovery phase. A number wrote comments where they thought that diaries could be helpful to patients’ families who were at a loss of what they could do whilst the patient was in ICU.

“(Diaries) help relatives feel like they are contributing to care of their loved one” (R135).

“(A diary) gives family something positive and tangible to focus on” (R175).

“It helps in bonding between families and nurses” (R2).

“(A diary) aids recovery for both family and patients” (R15).
Respondents also highlighted the potential usefulness of diaries which may serve to enhance families’ limited autonomy as indicted in the following where, contrary to usual practice, the family member commenced the diary:

“the relative initiated (the) long term patient tool (diary)” (R15).

Although some nurses perceived that the diaries provided a meaningful activity for the families through their entries, there were also reservations in the type of some diary entries, as seen below:

“Families may contribute inappropriate entries or negative comments about the patient’s ICU experience” (R194).

Discussion

The aim of this study was to identify nurses’ perceptions of patient diary use and application in Australian ICUs. Respondents reported that patient diaries are a recent addition to a number of Australian ICUs with a relatively small percentage (n=37, 19%), largely from metropolitan hospitals (n=27, 61%), using patient diaries in their unit. This was in contrast to Scandinavian studies where patient diaries are common place with reported diary use in up to 76% of ICUs. In fact, patient diaries have been in northern European countries since the 1990s, where they evolved from hand-written notes and the inclusion of photographs to more formalized portfolios. Notably, the practice of patient diaries appears to be limited to selective countries in Scandinavia and Northern Europe.

Respondents in this current Australian study and others perceived diaries to be an effective communication tool, recording significant and routine events in ICU which are best arranged in
chronological order.\textsuperscript{31,32} Few respondents, however, have a unit patient diary policy which is likely to lead to large variations in both format and consistency of diary entries. This may in itself not be problematic, but some respondents expressed concern regarding what they considered to be inappropriate comments where they felt exposed to criticism in relation to their nursing care and therefore cautious about the content of diary entries. A policy document or guideline that provides the legal standing of diaries, clear directions and a set format could provide diary writers with the information they need to ensure appropriate diary entries that could assist with these concerns.\textsuperscript{32}

Respondents considered a patient diary may have a therapeutic component which could enhance patient recovery. The information contained in the diary could potentially aid patients’ memory and subsequent psychological recovery. Similarly, other studies considered diaries provided an opportunity for patient reflection and assisted in restoring reality by dismissing misinterpretations or confusion of events and so enhance patients’ long-term psychological recovery.\textsuperscript{15,20,22,31} Aitken and colleagues caution that as an intervention to promote psychological recovery, diaries have not been adequately assessed from both a theoretical and impact perspective and until this is done they should not be routinely introduced\textsuperscript{17}

Evaluation studies have largely assumed diaries as having a positive impact on patient’s psychological outcome with current trials examining the \textit{timing} of giving out the diaries, in relation to anxiety, depression or PTSD. The discreet impact that diaries have on patient or family psychological wellbeing remains unclear. Likewise, the impact of any follow-up interview or service that may or may not accompany the imparting of the diary remains broadly
unexamined. Responses from this current study highlighted nurses’ desire to connect with patients after ICU discharge and complement an earlier qualitative study in the UK that found patients also like this opportunity to obtain answers to their questions (R46).\textsuperscript{33} In countries where follow-up is relatively common (for example in Norway), dairies are considered to be an important mechanism to support on-going patient care.\textsuperscript{20} The actual impact on patient outcomes, as mentioned above, requires closer examination.

The respondents in this study perceived the diaries to have potential benefits, not only for patients, but also for family members who often seek direction and opportunities on ways to engage meaningfully in their relative’s illness and recovery. They considered diaries provided an opportunity or vehicle for them to support families’ needs which they saw to be important. They felt diaries assisted relatives to take an active role in contributing patient care. Other studies have indicated that providing family members with opportunities to actively participate in their relatives care have lead to better family/patient/nurse partnerships.\textsuperscript{34,35}

The overwhelming majority of respondents in this study were non-diary users. Many indicated limited interest in introducing patient diaries into their unit which may be due in part to their apprehension of the legal implications as was highlighted in a Danish study.\textsuperscript{18}

This study indicates that the use of patient diaries is in its infancy in Australia. Prior to widespread uptake of diaries in Australian ICUs formal trial evaluations of their impact, format, and handover processes (i.e. follow-up interview, when and by whom) is required. Importantly, a greater understanding of the psychological impact of diaries on patients and families is required.
The results of subsequent studies will in turn inform and guide policy development and practice if they are found to be beneficial.

**Strengths and weakness**

The strength of this study is its uniqueness as the first study conducted in Australia on the extent and application of patient diaries. The survey study design did not allow for in-depth responses to all items. The sample was ACCCN members who agreed to participate, which may not reflect the wider critical care nursing population. In addition, there was a low response rate (12.5%), despite being an on-line survey with a reminder email. All the responses were self-reported data, which may not reflect the actual practice or that of the non-responders. The authors also acknowledged that this study surveyed nurses' perception of diary use by individual nurses rather than by units which occurred in other studies18-21, which makes comparisons difficult.

**Conclusion and Implications**

Patient diary use appears relatively new in Australian ICUs with a lack of guiding policy for format and processes. Nurses using diaries were enthusiastic about the initiative and perceived the diaries to be a useful communication tool, an aid to recovery, and an important way to meet families’ needs. They valued in-person patient follow-up opportunities not only to be able to explain diary entries but also to assess patient progress. However, the strategy may not be appropriate for all patients and families. There appears to be a moderate level of awareness of diaries amongst non users and Australian nurses share parallel concerns about the need for a guiding policy and medico-legal direction with Scandinavian authors. The absolute impact of diaries on patient or families psychological outcome has yet to be established. If they are to be
incorporated into nursing practice, further rigorous research is required to establish optimal content and delivery and to ensure patients and families are not harmed.

**Acknowledgment**
The authors are grateful to the support of the Australian College of Critical Care Nurses for the access to the membership for distribution of the survey and to all the respondents who gave their time.

**References**


APPENDIX A: SURVEY

1. Have you used patient diaries or anything similar at your current workplace? (Those respondents who answered “no” to this item were taken to Item 14 as the intervening items did not pertain to them)
   - Yes
   - No

2. If yes, how long have you been using patient diaries in your unit?
   - Less than 2 years
   - 3-5 year
   - 6-10 years
   - More than 10 years

3. Can you please outline why patient diaries are used in your unit (e.g. as a patient recovery aid, follow-up clinic tool; nursing care tool; long-term patient care tool; research etc)?

____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________

4. Do you have a written unit policy or guideline on the use of patient diaries in your unit?
   - Yes
   - No
   - Not sure

   If yes, does the policy or guideline state the ownership of the diary?
   - Yes
   - No
   - Not sure

5. Do the diaries have a definite structure in their writing method (i.e. pre-printed format and introduction, specific page for pictures etc.)? Please explain.

____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________

6. Who writes in the diaries in your unit? Choose more than one if needed.
   - Nurses
   - Family and friends of the patient
   - Medical staff
   - Social worker
   - Other- Please indicate:________________________________________________________
7. Who co-ordinates the diary process in your unit (i.e. initiates and manages it)? Choose more than one if needed.
   • Bed-side nurse
   • In-charge nurse
   • Social worker
   • Doctors
   • Family member
   • Other-Please indicate: ____________________________________________

8. To whom is that patient diary given?
   • Patient
   • Family member
   • Family member if patient is deceased
   • Not given out

9. When are the diaries given out?
   • Before discharge from the unit
   • Immediately upon transfer to the ward from ICU
   • 1 week after transfer from ICU
   • 3 weeks after transfer from ICU
   • Follow-up visit
   • Other (please specify): __________________________________________

10. Does your unit evaluate the patient diaries?
    • Yes
    • No
    • Not sure

    If yes, please specify the nature of the evaluation:
    ________________________________________________________________
    ________________________________________________________________
    ________________________________________________________________
    ________________________________________________________________

11. Please describe what you think are the positive aspects of patient diaries.
    ________________________________________________________________
    ________________________________________________________________
    ________________________________________________________________
    ________________________________________________________________

12. Please describe what you think are the negative aspects of patient diaries.
13. Do you have any further comments on the patient diaries and its use?

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

14. If you currently do not use patient diaries, in your unit, have you heard about them?

- Yes
- No

If yes, where did you receive your information?

- From a colleague
- An article in a journal
- A conference presentation
- Other (please specify): ____________________________________________

15. If you currently do not use patient diaries in your unit, would you like them to be introduced?

- Yes
- Seem like a good idea
- Not sure
- No, not really
- No, definitely not

If you indicated that you do not wish to introduce patient diaries, could you state the reasons

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

If you indicated that you would like patient diaries introduced, could you please state your reasons?

________________________________________________________________________
________________________________________________________________________
Demographic questions:

1. Please indicate your gender.
   - Female
   - Male

2. Please indicate your years of experience in nursing.
   - Less than 2 years
   - 2-8 years
   - 8-14 years
   - 14 years and above

3. Please indicate the number of beds in your unit.
   - Metropolitan Public Hospital
   - Metropolitan Private Hospital
   - Regional Public Hospital
   - Regional Private Hospital
   - No longer work in Critical care

4. Please indicate the number of beds in your unit.
   - Less than 6 beds
   - 7-12 beds
   - 13-18 beds
   - 19 beds and above

5. The patient in your unit are generally:
   - Adult patients only
   - Paediatric patients only
   - Combined Adult and Paediatric patients.

End of survey
<table>
<thead>
<tr>
<th>Characteristics</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong> *(n=180) *14 missing</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>167 (93%)</td>
</tr>
<tr>
<td>Male</td>
<td>13 (7%)</td>
</tr>
<tr>
<td><strong>Years of experience in nursing</strong> *(n=180) *14 missing</td>
<td></td>
</tr>
<tr>
<td>3 to 8 years</td>
<td>19 (11%)</td>
</tr>
<tr>
<td>9 to 14 years</td>
<td>34 (19%)</td>
</tr>
<tr>
<td>15 years and above</td>
<td>127 (70%)</td>
</tr>
<tr>
<td><strong>Location of practice</strong> *(n=179) *15 missing</td>
<td></td>
</tr>
<tr>
<td>Metropolitan Public Hospital</td>
<td>106 (59%)</td>
</tr>
<tr>
<td>Metropolitan Private Hospital</td>
<td>15 (8%)</td>
</tr>
<tr>
<td>Regional Public Hospital</td>
<td>51 (29%)</td>
</tr>
<tr>
<td>Regional Private hospital</td>
<td>5 (3%)</td>
</tr>
<tr>
<td>No longer working in critical care</td>
<td>2 (1%)</td>
</tr>
<tr>
<td><strong>Number of beds</strong> *(n=179) *15 missing</td>
<td></td>
</tr>
<tr>
<td>Less than or equal to 6 beds</td>
<td>17 (10%)</td>
</tr>
<tr>
<td>7 to 12 beds</td>
<td>65 (36%)</td>
</tr>
<tr>
<td>13 to 18 beds</td>
<td>38 (21%)</td>
</tr>
<tr>
<td>19 beds and above</td>
<td>59 (33%)</td>
</tr>
<tr>
<td><strong>ICU characteristic</strong> *(n=179) *15 missing</td>
<td></td>
</tr>
<tr>
<td>Adult patients only</td>
<td>141 (79%)</td>
</tr>
<tr>
<td>Paediatric patients only</td>
<td>9 (5%)</td>
</tr>
<tr>
<td>Combined adult and paediatric patients</td>
<td>29 (16%)</td>
</tr>
</tbody>
</table>
Table 2: Patient diary use in ICU.

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient diary is currently being used (n=191)*3 missing</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>37 (19%)</td>
</tr>
<tr>
<td>No</td>
<td>154 (81%)</td>
</tr>
<tr>
<td>Length of diary use (n=35)*2 missing</td>
<td></td>
</tr>
<tr>
<td>≤ 2 years</td>
<td>15 (43%)</td>
</tr>
<tr>
<td>3-5 years</td>
<td>13 (37%)</td>
</tr>
<tr>
<td>6-10 years</td>
<td>5 (14%)</td>
</tr>
<tr>
<td>≥ 10 years</td>
<td>2 (6%)</td>
</tr>
<tr>
<td>Evidence of written policy (n=31) *6 missing</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>11 (35%)</td>
</tr>
<tr>
<td>No</td>
<td>20 (65%)</td>
</tr>
<tr>
<td>Not sure</td>
<td>0</td>
</tr>
<tr>
<td>Statement of ownership in the policy (n=11) *26 missing (all participants were able to respond)</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>7 (64%)</td>
</tr>
<tr>
<td>No</td>
<td>4 (36%)</td>
</tr>
<tr>
<td>Not sure</td>
<td>0</td>
</tr>
<tr>
<td>Diary ownership in the policy (n=33) *4 missing (all participants were able to respond)</td>
<td></td>
</tr>
<tr>
<td>Patient</td>
<td>14 (42%)</td>
</tr>
<tr>
<td>Family of patient if patient deceased</td>
<td>2 (6%)</td>
</tr>
<tr>
<td>Health professionals</td>
<td>1 (3%)</td>
</tr>
<tr>
<td>Others (hospital administrators)</td>
<td>16 (49%)</td>
</tr>
<tr>
<td>Structured format of diary in the policy (n=33)* 4 missing</td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>5 (15%)</td>
</tr>
<tr>
<td>No</td>
<td>28 (85%)</td>
</tr>
</tbody>
</table>
### Table 2: Patient diary use in ICU contd’

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Responses</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Contributors to the diary</strong> (Multiple response were permitted)</td>
<td>n</td>
</tr>
<tr>
<td>Nurses</td>
<td>27</td>
</tr>
<tr>
<td>Family members</td>
<td>31</td>
</tr>
<tr>
<td>Social worker</td>
<td>17</td>
</tr>
<tr>
<td>Doctors</td>
<td>15</td>
</tr>
<tr>
<td>Allied Health</td>
<td>14</td>
</tr>
</tbody>
</table>

**Diary coordinator** (Multiple response were permitted)

<table>
<thead>
<tr>
<th>Contribution</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bedside Nurse</td>
<td>17</td>
</tr>
<tr>
<td>In charge Nurse</td>
<td>11</td>
</tr>
<tr>
<td>Social worker</td>
<td>4</td>
</tr>
<tr>
<td>Doctors</td>
<td>1</td>
</tr>
<tr>
<td>Family member of the patient</td>
<td>9</td>
</tr>
</tbody>
</table>

**Diary recipients** (Multiple response were permitted)

<table>
<thead>
<tr>
<th>Recipient</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
<td>23</td>
</tr>
<tr>
<td>Family members of the patient</td>
<td>15</td>
</tr>
<tr>
<td>Family members if the patient deceased</td>
<td>14</td>
</tr>
<tr>
<td>Not given out</td>
<td>1</td>
</tr>
</tbody>
</table>

**Time period of receiving the diaries (n=28) *9 missing**

<table>
<thead>
<tr>
<th>Period</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Before discharge from unit</td>
<td>12 (43%)</td>
</tr>
<tr>
<td>Immediately upon transfer to the ward from ICU</td>
<td>10 (36%)</td>
</tr>
<tr>
<td>Follow-up visit</td>
<td>6 (21%)</td>
</tr>
</tbody>
</table>

**Diary evaluation (n=30) *7 missing**

<table>
<thead>
<tr>
<th>Evaluation</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>9 (30%)</td>
</tr>
<tr>
<td>No</td>
<td>21 (70%)</td>
</tr>
</tbody>
</table>
Table 3: Patient diary awareness

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Have you heard about diaries (n=146)</strong></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>77 (53%)</td>
</tr>
<tr>
<td>No</td>
<td>69 (47%)</td>
</tr>
<tr>
<td><strong>Source of information on diaries (n=97)</strong></td>
<td></td>
</tr>
<tr>
<td>Journal</td>
<td>43 (44%)</td>
</tr>
<tr>
<td>Conference</td>
<td>24 (25%)</td>
</tr>
<tr>
<td>Colleagues</td>
<td>20 (21%)</td>
</tr>
<tr>
<td>Others</td>
<td>10 (10%)</td>
</tr>
<tr>
<td><strong>Interest in introducing diaries (n=71)</strong></td>
<td></td>
</tr>
<tr>
<td>Yes, seem like good idea</td>
<td>15 (21%)</td>
</tr>
<tr>
<td>Not sure</td>
<td>50 (70%)</td>
</tr>
<tr>
<td>No, not really</td>
<td>5 (7%)</td>
</tr>
<tr>
<td>No, definitely not</td>
<td>1 (2%)</td>
</tr>
</tbody>
</table>
Nurses' perception of patient diaries

Communication tool
(example statements)
- Record of events for communication
- Assist in reflection
- Discussion platform for patient, family and healthcare professionals.
- Guiding policy required (format, purpose, content, delivery and ownership.

Family centered care
(example statements)
- Family contribution in patient care, through diary entries
- Positive and tangible focus for the family
- Assist in connecting families and nurses
- Allow expression of feelings by family
- Helpful in grieving process also.

Recovery tool
(example statements)
- Memory aid
- Relative initiated long term patient care tool
- Psychosocial support from family and healthcare
- Follow up tool