Report of the Findings of the
Focus Groups for Older People and Carers

Acute Geriatric Service,
Northern Illawarra Hospital Group,
Southern Hospitals Network

September 2006
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<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>AHS</td>
<td>Area Health Service</td>
</tr>
<tr>
<td>NIGH</td>
<td>Northern Illawarra Group of Hospitals</td>
</tr>
<tr>
<td>SESIAHS</td>
<td>South Eastern Sydney and Illawarra Area Health Service</td>
</tr>
</tbody>
</table>

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Paula Blanch, Senior Nurse Manager, Acute Geriatrics, NIGH
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Executive Summary

Along with the rest of Australia, the population of the Southern Hospital Network (SHN) within the South Eastern Sydney and Illawarra Area Health Services (SESI-AHS) is ageing. The population aged over 65 years is projected to increase from 34,907 people in 2001 (15.6% of the population) to 72,250 people by 2026 (22.6% of the population). Older people also represent an increasing proportion of admissions to NSW public hospitals. By 2011 it is estimated that patients aged over 65 years will comprise 38% of NSW public hospital admissions and 52% of bed days.

In addition as our population ages over the next two decades, the number of people with dementia in NSW (especially in the oldest age groups) will increase dramatically. Approximately one in 20 people aged over 65 years and one in 5 aged over 80 years will have some form of dementia. The numbers of older people using our hospitals with cognitive, sensory and long term chronic conditions as disabilities will also increase. For these people it is often their families and carers who play an important role in supporting them in the community, acting as their advocates and often assisting them in decision making.

Therefore the reason for undertaking this focus group project was to understand the “experience” of the older patient and carer of the hospital system. The need for understanding this experience was also highlighted in the NSW Health framework for integrated support and management of older people in the health care system (known as “the Framework”). This document underpins the commitment of the Northern Illawarra Group of Hospitals (NIGH), now part of the SHN, to improve the experience of both the older patient and carer when in hospital.

The aim of the project was to improve the quality of care for older people and their carers within NIGH hospitals. The project would achieve this by:

- Gaining an understanding of how older people and their carers experience the NIGH hospital services.
- Gaining an understanding of what factors contribute to both a positive and negative hospital experience for older people and their carers.
- Identifying and promoting good practice strategies which can be transferred across hospital sites.
- Identifying and implementing strategies to improve the quality of the care for older people and their carers.

The target group was people aged over 65 years who had been a patient at Kiama, Shellharbour, Wollongong and Bulli hospitals over the previous 12 months, and people who cared for someone aged over 65 years who was a patient at Kiama, Shellharbour, Wollongong and Bulli hospitals over the last 12 months.

Facilitated focus groups of older people and carers were held at two hospital sites, Bulli and Kiama, in May 2006. Separate focus groups were held for patients and carers at each site. A total of 23 patients and 15 carers participated.

In summary the focus groups highlighted:
• Differences in the experience of the hospital system depending on whether the reason for admission to hospital was acute or chronic. Generally patients and carers reported much higher satisfaction when presenting with an acute condition.

• Differing perceptions regarding staff. This related to the role of staff, staffing levels on wards, the perceived level of care and treatment provided, and the perceived attitude of staff.

• Differing experiences of communication between patients, carers and health professionals. Issues highlighted included consultation regarding care and treatment, involvement in discussions about the health condition, and understanding the role of staff and how the ward and/or the Emergency Department functioned.

• Differing experiences of discharge planning, with the majority of participants finding it a less than satisfactory experience. The issues raised included availability of information on relevant support services, inclusion of a discharge planner and other health professionals (if relevant) in the planning process, the time it took to be discharged, the paperwork involved in a discharge, and the availability of relevant health professionals to enable the discharge to take place. This then potentially impacted on issues regarding parking and transport.

• Provision of care for people with significant cognitive impairment or behavioural disturbances in the same ward areas as alert and oriented patient was an area of concern.

It should be noted that the responses provided by participants in the focus groups as reported in this document have remained as faithful as possible to the feelings and sentiments of the participants. This report documented their perceptions. The observations of the participants are not here to be disputed; they have given us valuable insight into how they see the system. If there are any misconceptions, then the system needs to better communicate its intentions and actions.

The report concludes with a series of recommendations around the key themes of communication, participation, environment and discharge planning. Monitoring and implementation has also been included. It is hoped that this will be the beginning of an on-going process that improves the hospital experience of the older patient and carer.
Summary of Recommendations

Communication

1. Improve staff awareness of the needs of older patients and carers by ensuring hospital health professionals, including nursing and medical staff, are provided with education in the following areas:

   - Awareness of the needs of the older person as a patient.
   - Working with patients with chronic or complex conditions including people with disabilities.
   - Carer awareness and the availability of carer services.

   Consideration should also be given to including such education as part of mandatory education for health professionals.

2. Enhance the understanding of the older patient and carer on how the ward functions by providing information and/or orientation about the health services they will be using e.g. information on the role of a particular ward, the role of the staff, who to approach, how to access staff, what to expect.

3. Ensure older patients and carers are informed about what is happening at the ward level, by implementing strategies to encourage them to approach staff with questions and to ask for further information, and to be able to easily identify the staff that they should be approaching.

4. Ensure that older patients and carers are informed about what is happening while waiting in the Emergency Department and its surrounds, by implementing strategies to regularly inform those waiting of reasons for waiting times and why others may have “jumped the queue”.

Participation

5. Improve participation of older patients in their care and treatment by ensuring that they are kept informed about their illness/diagnosis, treatment options and plans. Older patients should be encouraged as far as possible to take an active role by asking questions, expressing their preferences and providing information to health professionals.

6. Improve participation of carers of older patients in the care and treatment of the person they are caring for by ensuring they are kept informed about the illness, treatment and care options and be included in decision making. Carers should be encouraged to share their knowledge and expertise about the patient with health professionals.

Environment

7. Better meet the needs of the older patient and carer while in hospital by improving ward layouts and designs e.g. older patients be cared for in an area separate from more challenging patients to minimise distress; possessions are secured and are moved safely when the patient is transferred to another ward.

8. Improve privacy and retain dignity by giving consideration to the provision of care of patients with high or complex care needs in single rooms wherever possible.
9. Minimise distress, for patients with challenging behaviours and their carers e.g. with dementia, by caring for them in a specialised ward area with appropriate staffing levels.

10. Provide car parking concessions at Wollongong Hospital car park for carers who may be visiting frequently or spending long periods in the hospital, to enable them to utilise the car park at a subsidised cost.

Discharge Planning

11. Discharge planning for older patients, particularly those with chronic or complex conditions and disabilities, is commenced on admission to hospital and includes the discharge planner.

12. Carers should be included in the discharge planning processes, particularly around being kept informed when the patient is being discharged and their need for support in their caring role, as well as ensuring carers have access to information on community supports available.

13. Discharge should occur in a timely fashion with all discharge information and scripts available.

14. GPs should receive discharge summaries within 48 hours of their patient being discharged from hospital.

15. Older patients are educated about their medications on discharge and kept informed about any changes to their medication regime.

Monitoring and Implementation

16. The recommendations contained in this Report will be implemented by requiring each Stream within the Southern Hospital Network (with the exception of the Child and Adolescent and Women and Babies Streams) to develop and implement an Action Plan based on these recommendations. Each Stream will then be required to report yearly to the Network Executive on the progress in implementation.
1. **Background**

The Northern Illawarra Hospital Group (NIGH)\(^1\) made an application for funding under the “SESIAHS Carers Program On-Off Grants Initiative” to support a focus group project aimed at determining the older patient and carer “experience” of the hospital system.

The Project was undertaken as a part of NIHG’s commitment to the NSW Health framework for integrated support and management of older people in the health care system (known as “the Framework”).\(^2\) The Framework aims to guide and coordinate the necessary improvements to service delivery for older people in NSW and to achieve a level of consistency in approach across the state.

The anticipated outcomes of this approach, as outlined in the Framework, are:

- The older person and their families/carers will more easily access the services required to meet their needs.
- The health system will deliver timely and more appropriate services to meet the needs of older people and their families/carers.

It was envisaged that though this focus group project, NIGH would be able to gauge the scope of the gap between older people and their families/carers, and the services being provided. To truly comply with the sentiment of the Framework, NIGH must take the necessary steps to create an organisation that is responsive to the needs of the older person and their families/carers.

Carers refer to people (usually family members, friends and neighbours) who provide regular support to a person with a disability, chronic illness or the frail aged. They are unpaid for this (however may be receiving a pension or benefit).

With the exception of child and family services, the overall demographic of hospitals and health services is older people and their families/carers. As many older people are only able to be maintained at home by committed, stressed carers, NIGH wants to ensure their needs are known, validated and included in service plans.

The numbers of people aged over 65 years in South Eastern Sydney and Illawarra Area Health Service (SESIAHS) is estimated to be 167,389 (2005). This is estimated to increase to 267,289 in 2026, an increase of approximately 60%. Greater numbers of older people will be living with chronic and complex disease or long term disabilities. Many of these older people will be relying on their family and friends to keep them living independently in the community. There may be greater burdens placed on these carers in the community as a result of the ageing population.

In the area covered by NIGH, the number of people aged over 65 years was estimated to be 34,907 in 2001 or 15.6% of the population\(^3\). This is expected to increase to 72,250 people by 2026, or 22.6% of the population. This is an increase of 107% over the period 2001 to 2026\(^4\).

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\(^1\) NIGH incorporates the Bulli, Wollongong, Shellharbour and Kiama Hospitals and services the area covering the Wollongong, Shellharbour and Kiama Local Government Areas.

\(^2\) NSW Health (2004) Framework for the integrated support and management of older people in the NSW health care system 2004-2006 (referred to as “the Framework”)

\(^3\) Australian Bureau of Statistics, CDATA 2001

\(^4\) Australian Bureau of Statistics via HOIST
Older people also represent an increasing proportion of admissions to NSW public hospitals. In 2011 patients aged over 65 years will comprise 38% of NSW public hospital admissions and 52% of bed days. Furthermore approximately one in 20 people over 65 years and one in five over the age of 80 have some form of dementia. The prevalence of dementia doubles approximately every five years from aged 60. In the next two decades as our population ages, the number of people with dementia in NSW especially in the oldest age groups will increase dramatically.\(^5\)

In 2005/06, people aged over 65 years comprised 43.5% of all patients discharged from NIGH hospitals. The major reasons for hospitalisation for people aged over 65 years of age were renal dialysis, cardiology, respiratory, orthopaedics, non subspecialty surgery, no subspecialty medicine, neurology, urology, gastroenterology, and ophthalmology. These ten reasons for hospitalisation accounted for 79% of all discharges from NIGH hospitals for people aged over 65 years in 2005/06.\(^6\)

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\(^5\) Ibid p.4

\(^6\) Performance Management, SHN, SESIAHS 2006 - Patients aged over 64 years by SRG Version 3.0 for Bulli, Kiama, Wollongong and Shellharbour Hospitals in 2005/06 - from HIE
2. AIMS AND OBJECTIVES

Aim:
To improve the quality of care for older people and their carers within NIGH hospitals

Objectives:
- To gain an understanding of how older people and their carers experience the NIGH hospital services.
- To gain an understanding of what factors contribute to a positive hospital experience for older people and their carers.
- To gain an understanding of what factors contribute to a negative hospital experience for older people and their carers.
- Identify and promote good practice strategies which can be transferred across hospital sites.
- Identify and implement strategies to improve the quality of the care for older people and their carers.

Target Group:
- People aged over 65 years who had been a patient at Kiama, Shellharbour, Wollongong and Bulli hospitals over the previous 12 months, and
- People who cared for someone aged over 65 years who was a patient at Kiama, Shellharbour, Wollongong and Bulli hospitals over the last 12 months. There was no age restriction for the carers.

Where a caring relationship existed between a patient and a carer, it was not a requirement that both must be interested in attending a focus group in order to participate. Patients and carers could attend independently of the other person. They were, of course, both welcome to participate if that is what they wanted.

Strategy:
The key strategy to achieve the aims and objectives as listed above was the facilitated focus groups of older people and carers who had been users of inpatient and outpatient services. These groups were encouraged to provide feedback on their experience of being users of the health care system, with a particular emphasis on the role and involvement of carers. The types of questions the Project were interested in having answered were:

- Have they been involved?
- How much involvement do they want?
- Does the hospital and health service environment meet their needs?
- How do they “feel” when they are using the service?
- How might things be changed and improved?

Section 3 outlines the methodology for organising and conducting the focus groups. Section 4 reports the results of the focus groups. Section 5 is a discussion of the findings. Section 6 outlines the recommendations to be implemented as a result of this Project.
3. METHODOLOGY

A small working party was formed to oversee the implementation of this project under the auspices of the Acute Geriatrics Stream within NIGH. The working party consisted of:

- Senior Nurse Manager, Acute Geriatrics Stream, NIGH
- Carer Support Coordinator, Wollongong Hospital
- Chronic Care Program Manager
- Registered Nurse, Acute Geriatrics Stream, NIGH.

The Registered Nurse was also the Project Officer.

The working party met regularly between February (when notification of funding was received) and May 2006.

It was decided by the working party that the focus groups would be held in two locations, Bulli and Kiama Hospitals. The reasons for this were:

- Both were smaller and therefore quieter hospitals which were believed to be more conducive to the conduct of focus groups.
- Both had reasonably appropriate meeting rooms that could be used (not too hot or cold, kitchen facilities available, etc.).
- Both had good parking facilities.
- Both sites provided good coverage across the NIGH area.

The working party also decided that the patients and carers would need to be in separate groups rather than mixed into one group. It was believed that this would facilitate more frank discussions than if a carer and the person they were caring for were in the same group. Particularly in the case of the carers, it was important to capture their experience of being a carer. So this meant that at each of the sites, there would be two groups, one for patients and one for carers.

Participants to be invited to the focus groups were identified in three ways:

- A letter was sent to a random sample of people aged over 65 years discharged from a NIGH hospital inviting them to participate.
- An advertisement was placed in the local newspapers inviting people to participate.
- A flyer was distributed through various organisations.

A Briefing Note outlining the recruitment strategy was forwarded to the General Manager, Southern Hospitals Network who approved the process. She agreed to sign the letters to patients inviting them to participate in a focus group. (Appendix 1)

All patients aged over 70 years who had been discharged from Kiama, Shellharbour, Wollongong and Bulli Hospitals over the period 01/06/05 to 09/01/06 were identified by Medical Records through the electronic Disease Index System. Using this method, 310 people were identified. Of these, 21 people had since died, leaving 289 people. Of this group, 40 were randomly selected. They were each sent a letter asking them if they would like to participate in the focus groups.
Initially there was a very low response to the letter. The Project Officer then made follow up phone calls to see if she could encourage more people to participate. A number of people reported that they had not received a letter. The initial 40 letters were then resent and the Project Officer continued with the follow up phone calls.

The working group had established that a minimum of 6 people would be needed to conduct a focus group with a maximum of 12 people. As the minimum number had not been reached after this initial mail out, an additional 40 people were randomly selected and sent a letter of invitation. Follow-up phone calls were also made by the Project Officer. This increased the response rate. However numbers for the carer groups were lower than for the patient groups so an additional 25 letters were sent and follow-up phone calls made. A further 30 people were rung (no letter of invitation was sent) to try and encourage a few more people to participate.

Altogether, 105 letters were sent (with approximately 60 follow-up phone calls made). A further 30 phones calls were made where no letter of invitation had been sent. Therefore, 135 people were contacted and invited to participate, which was 47% of the group identified by Medical Records (excluding deaths).

Recruitment via an advertisement in the local newspapers, the Illawarra Mercury and the Advertiser, was problematic. There were many delays with the Communications Unit in getting the advertisements placed in the papers in a timely fashion. This resulted in the dates for the groups being rescheduled twice. Fortunately the initial letters of invitation referred to above were not sent out until the dates were finalised so these did not need to be changed. (Appendix 2)

The advertisements that were placed in the newspapers were quite small. One person did ring and complain about the size of the advertisement.

A flyer was also developed for distribution within Retirement Villages. (Appendix 3)

The Project Officer kept track of the people who agreed or did not agree to participate. For those who agreed to participate, a form outlining the criteria for selection of participants was used to ensure that participants would meet the criteria as well as ascertaining their transport and caring needs, and their dietary requirements. (Appendix 4) The project would meet the costs of providing transport and respite care as required.

A follow up letter confirming details was then sent to each participant. (Appendix 5)

For participants who required transport to the either hospital to participate in the focus group, transport was arranged through the Transport for Health system who provides mini buses for transport between health facilities. Pick up times were confirmed with participants the day before the focus group. This service was at no cost to the participant.

Respite care was also available for carers to enable them to participate in a focus group. No participant asked for respite care to be provided. If they had, this would have been organised through the Commonwealth Carer Respite Centre at no cost to the carer.

In terms of the conduct of the focus groups, each group would have a facilitator and a scribe. The facilitators were the Carer Support Coordinator (for the Carer group) and the Chronic Care Program Manager (for the patient group). The Project Officer, NUM of the Day Hospital at Bulli Hospital and the Aged Care CNC were the scribes.
The focus groups were held on 12 May 2006 at Bulli Hospital and 19 May 2006 at Kiama Hospital. The Program Outline for each day was as follows:

10.30 am - 11.00 am  **Welcome and Introduction** (tea/coffee) by Senior Nurse Manager, Acute Geriatrics Stream, NIGH

- Patients and Carers together
- Introduce facilitators and scribes
- Purpose of focus group explained
- Framework for integrated management and support of older people explained
- Explain what will happen to information collected
- Feedback to participants
- Confidentiality of responses

11.00 am - 1.00 pm  **Focus Groups**

- Divided into separate Patient and Carer groups
- The carer group were taken to a different room
- Conduct of a focus group explained
- Process undertaken with a set of questions to guide discussions (Appendix 6)
- Facilitator led discussions with scribe capturing key discussion points

1.00pm - 1.30pm  **Lunch and Farewell**

- Participants from both groups brought back together
4. FINDINGS

4.1 Group Participants

A total of 23 patients and 15 carers participated in focus groups at both Bulli and Kiama Hospitals. The breakdown of attendance is shown in Table 1 below.

<table>
<thead>
<tr>
<th>Participants</th>
<th>Bulli Hospital - 12 May 2006</th>
<th>Kiama Hospital - 19 May 2006</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Registered to Attend</td>
<td>15</td>
<td>12</td>
<td>25</td>
</tr>
<tr>
<td>Apologies</td>
<td>4</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Additional on Day</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>TOTAL in Group on Day</td>
<td>12</td>
<td>11</td>
<td>23</td>
</tr>
<tr>
<td>Carers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Registered to Attend</td>
<td>10</td>
<td>5</td>
<td>15</td>
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<tr>
<td>Apologies</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Additional on Day</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>TOTAL in Group on Day</td>
<td>9</td>
<td>6</td>
<td>15</td>
</tr>
<tr>
<td>TOTAL BOTH GROUPS ON DAY</td>
<td>21</td>
<td>17</td>
<td>38</td>
</tr>
</tbody>
</table>

The gender distribution of the groups is shown in Table 2 below. Overall there were more male participants in the patient groups and more female participants in the carer groups. The only exception was the Bulli patient group where there were slightly more females. Overall there were more participants in the patient groups than the carer groups.

<table>
<thead>
<tr>
<th>Participants</th>
<th>Bulli Hospital - 12 May 2006</th>
<th>Kiama Hospital - 19 May 2006</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>5</td>
<td>8</td>
<td>13</td>
</tr>
<tr>
<td>Female</td>
<td>7</td>
<td>3</td>
<td>10</td>
</tr>
<tr>
<td>Total Patients</td>
<td>12</td>
<td>11</td>
<td>23</td>
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<tr>
<td>Carers</td>
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<tr>
<td>Male</td>
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<td>11</td>
</tr>
<tr>
<td>Total Carers</td>
<td>9</td>
<td>6</td>
<td>15</td>
</tr>
<tr>
<td>TOTAL IN BOTH GROUPS</td>
<td>21</td>
<td>17</td>
<td>38</td>
</tr>
</tbody>
</table>

The minimum participation age for the patient groups was 65 years of age. The oldest participant in each of the patient groups was as follows:

- Bulli Hospital patient focus group - 92 years
- Kiama Hospital patient focus group - 85 years.

A number of people from non-English speaking backgrounds participated in the groups. These included Italian, German, Austrian, Greek, Vietnamese, Dutch and Finnish. They did not require an interpreter.

The relationship of the carer to the patient is shown in Table 3. The majority of carers were a family member although a friend and legal guardian (who was not a relative) were also carers.
Table 3: Relationship of Carer to Patient

<table>
<thead>
<tr>
<th>Participants</th>
<th>Bulli Hospital - 12 May 2006</th>
<th>Kiama Hospital - 19 May 2006</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer Relationship</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wife</td>
<td>4</td>
<td>3</td>
<td>7</td>
</tr>
<tr>
<td>Husband</td>
<td>3</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Daughter</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Friend</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Legal Guardian</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>TOTAL CARERS</strong></td>
<td><strong>9</strong></td>
<td><strong>6</strong></td>
<td><strong>15</strong></td>
</tr>
</tbody>
</table>

Length of time spent as a carer is shown in Table 4. The majority of carers had been caring for greater than 4 years. The longest time spent caring was 27 years for one carer and the shortest time was approximately 6 months.

Table 4: Length of Time Spent Caring

<table>
<thead>
<tr>
<th>Participants</th>
<th>Bulli Hospital - 12 May 2006</th>
<th>Kiama Hospital - 19 May 2006</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>12 months or less</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>1-3 years</td>
<td>2</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>4-10 years</td>
<td>3</td>
<td>4</td>
<td>7</td>
</tr>
<tr>
<td>Longer than 10 years</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td><strong>TOTAL CARERS</strong></td>
<td><strong>9</strong></td>
<td><strong>6</strong></td>
<td><strong>15</strong></td>
</tr>
</tbody>
</table>

Table 5 below outlines the main hospitals in NIGH that both patients and carers had attended in the last 12 months. Wollongong Hospital accounted for half of the attendances.

Table 5: Hospitals Attended by Focus Group Participants in Previous 12 Months

<table>
<thead>
<tr>
<th>Participants</th>
<th>Bulli Hospital - 12 May 2006</th>
<th>Kiama Hospital - 19 May 2006</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wollongong Hospital</td>
<td>10</td>
<td>9</td>
<td>19</td>
</tr>
<tr>
<td>Bulli Hospital</td>
<td>3</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Shellharbour Hospital</td>
<td>2</td>
<td>4</td>
<td>6</td>
</tr>
<tr>
<td>Kiama Hospital</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Port Kembla Hospital</td>
<td>0</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>15</strong></td>
<td><strong>16</strong></td>
<td><strong>31</strong></td>
</tr>
<tr>
<td>Carers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Wollongong Hospital</td>
<td>8</td>
<td>1</td>
<td>9</td>
</tr>
<tr>
<td>Bulli Hospital</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Shellharbour Hospital</td>
<td>1</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td>Kiama Hospital</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Port Kembla Hospital</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>11</strong></td>
<td><strong>6</strong></td>
<td><strong>17</strong></td>
</tr>
</tbody>
</table>

Note: could have been admitted to more than one hospital in previous 12 months.

Table 6 below outlines the many services and reasons that both patients and carers attended hospitals in NIGH over the last 12 months.
Table 6: Service & Reasons Hospital Attended by Focus Group Participants in Previous 12 Months

<table>
<thead>
<tr>
<th>Patients</th>
<th>Kiama Hospital - 19 May 2006</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SERVICE</strong></td>
<td><strong>REASONS</strong></td>
</tr>
<tr>
<td>4 East</td>
<td>Colon Cancer Surgery</td>
</tr>
<tr>
<td>Cardiology</td>
<td>Orthopaedics</td>
</tr>
<tr>
<td>C3</td>
<td>CVA</td>
</tr>
<tr>
<td>ICU</td>
<td>Cardiac</td>
</tr>
<tr>
<td>B4</td>
<td>Pelvis</td>
</tr>
<tr>
<td>Surgical Ward</td>
<td>Dialysis</td>
</tr>
<tr>
<td>4th/8th/7th floors</td>
<td>Orthopaedic Care</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Carers</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SERVICE</strong></td>
<td><strong>REASONS</strong></td>
</tr>
<tr>
<td>Acute Geriatrics</td>
<td>Orthopaedics</td>
</tr>
<tr>
<td>ICU</td>
<td>Cardiac</td>
</tr>
<tr>
<td>Cardiology</td>
<td>Osteoporosis</td>
</tr>
<tr>
<td>C3</td>
<td>Dementia</td>
</tr>
<tr>
<td>4 East</td>
<td>Quadriplegia</td>
</tr>
<tr>
<td>B4</td>
<td>Viral Infection</td>
</tr>
<tr>
<td></td>
<td>Rheumatoid Arthritis</td>
</tr>
<tr>
<td></td>
<td>Frailty</td>
</tr>
</tbody>
</table>

Note: could have used more than one service in the previous 12 months

Table 7 below outlines how participants found out about the focus groups. Letters and phone calls appeared to be the most successful strategies.

<table>
<thead>
<tr>
<th>Participants</th>
<th>Bulli Hospital - 12 May 2006</th>
<th>Kiama Hospital - 19 May 2006</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Letter Only</td>
<td>3</td>
<td>2</td>
<td>5</td>
</tr>
<tr>
<td>Letter and Phone Call</td>
<td>0</td>
<td>2</td>
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<tr>
<td>Phone Call Only</td>
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<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Advertisement</td>
<td>2</td>
<td>3</td>
<td>5</td>
</tr>
<tr>
<td>Flyer</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Not Known</td>
<td>5</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>TOTAL</td>
<td>12</td>
<td>11</td>
<td>23</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Care</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>SERVICE</strong></td>
<td><strong>REASONS</strong></td>
</tr>
<tr>
<td>Letter Only</td>
<td>1</td>
</tr>
<tr>
<td>Letter and Phone Call</td>
<td>0</td>
</tr>
<tr>
<td>Phone Call Only</td>
<td>1</td>
</tr>
<tr>
<td>Advertisement</td>
<td>2</td>
</tr>
<tr>
<td>Flyer</td>
<td>0</td>
</tr>
<tr>
<td>Not Known</td>
<td>5</td>
</tr>
<tr>
<td>TOTAL</td>
<td>9</td>
</tr>
</tbody>
</table>

4.2 Patient Perspective

It should be noted that the responses reported in the following section by participants in the patient focus groups have remained as faithful as possible to the feelings and sentiments of the participants. This report documented their perceptions. The observations of the participants are not here to be disputed; they have given us valuable insight into how they see the system.
4.2:1 Understanding the hospital experience of patients

- Patients generally related more positive experiences of hospital when they were admitted for an acute condition e.g. cardiac condition or stroke. Admission to hospital via the Emergency Department was seen to be a very quick process if presentation to the Emergency Department had been via the Ambulance Service.

- Patients generally related more negative experiences of hospital when they had chronic illnesses or complex care needs. Again this was reflected in the Emergency Department experience right through to admission and discharge. Areas of concern included length of stay in the Emergency Department, lack of understanding by staff of their illness, and lack of adequate staffing levels.

4.2:2 Factors that contribute to a positive hospital experience for patients

Emergency Department

- Those with positive experiences of the Emergency Department tended to be those with a life threatening illness. They had a short stay in the Emergency Department and a quick admission into hospital e.g. required coronary surgery. They were very happy with the promptness of attention.

In Hospital

- A number of participants stated that they felt safe in hospital. Both Wollongong and Shellharbour Hospitals were specifically mentioned. One participant stated that they had marvellous attention in the Emergency Department at Wollongong Hospital.

Communication

- Several participants stated that they had positive experiences with their doctors and being spoken to by the specialists. They felt were able to ask questions.

Discharge Planning

- Some participants reported good experiences with discharge planning.

- For some participants, the waiting time for discharge was short. In one case it was only 30 minutes.

- Some participants had Discharge Planners involved in the planning of their discharge and found this to be very good, particularly at Wollongong Hospital.

- In a number of cases, the Social Worker, and/or Occupational Therapist and/or Physiotherapist were involved in the pre-planning of the participants discharge home.

- One participant reported that an Occupational Therapist home visited as part of the pre-planning for their discharge.

- Several participants reported receiving a discharge letter.

- Some comments were made about post discharge care. One participant found the “home nursing” was very good. Another participant found ComPacks very helpful.
4.2.3 Factors that contribute to a negative hospital experience for patients

Emergency Department

- Several participants reported waiting a long time in the Emergency Department, four hours and eight hours being the main times stated.
- Waiting also occurred in the corridor to get into the Emergency Department on a stretcher, and in the Department itself while a bed was found.
- There was a perception that other patients were admitted into the Emergency Department first who had not waited as long in the corridor.
- Concerns were also expressed at the mix of patients all together in one Emergency Department (e.g. alcoholics, drug addicts, mental health patients).

In Hospital

- A number of participants were not happy with their in-hospital experience. One participant stated that they would not go to Shellharbour Hospital and that it should be closed or upgraded immediately. Another stated that communication in Shellharbour Hospital was poor.
- Concern was expressed about the many ward moves that had been experienced. For one participant, this resulted in lost clothing. Difficulties were then experienced trying to resolve this issue with staff being perceived as not overly sympathetic or helpful.
- There were varying perceptions of staff. Many participants reported the difficulty in being able to distinguish between the different staff on the ward, and in some cases, even being able to identify who the staff actually were.
- Some participants also believed that there were too large a large number of patients to staff on the ward while others believed that too many people doing one job. It was noted however that staff are doing double shifts.
- Some participants believed that nurses are no longer nurses, they are more like technicians; “old nursing is gone”.

Communication

- There was a lot of comment around the issue of communication. On the whole, participants felt that it was not as good as it could be. Both doctors and nurses were identified as bad communicators.
- An area were communication was seen as poor was where the diagnosis was not explained and the pre-op was not explained by staff. In one case, the operation was held up as the heart medication was not known.
- Not listening to the patient was also seen as a major problem that could have serious consequences. In one case, a patient told staff about their iodine allergy but was not believed. Iodine was then put on their leg causing a large reaction. This patient now has a Medic Alert Card and gives this to staff whenever they are in hospital.
- Staff attitudes were also seen in a poor light. Some of the problems reported included staff not introducing themselves and feeling like they were being interrogated rather
than spoken to professionally. One participant observed that “doctors talk about you, not to you”. Some participants commented that family were not often involved in discussions regarding their care.

- Participants did recognise that there were constraints in the system. Some observed that as there were too many patients to be looked after, staff, cannot spend time with you. Therefore a nurse is not always available.

- Some participants believed that if they were assertive, then this caused problems with staff with some staff put off by assertive patients and their rights. One participant stated that it was difficult for them as the philosophy of their age group was “to be seen and not heard”.

**Discharge Planning**

- A number of problems were identified with discharge planning. Many of these problems were associated with the lengthy wait to be discharged. Reasons that some participants had lengthy delays with their discharge included discharge papers being lost, availability of doctors and pharmacy, and the need to wait for paperwork to be signed.

- All of this meant that staff were not able to keep to the “planned” time for discharge resulting, in one case in a large parking fine for the son who came to pick up his father.

- Another problem identified was the time of discharge. One participant reported being discharged in the middle of the night.

- Appropriateness of discharge and the plan for care after discharge were also identified as problematic areas. Areas of concern included not seeing a discharge planner, and being discharged with no care at home. One participant reported that there was no follow-up post stroke at home, with another reporting that speech therapy was not followed up due to staff member going overseas. Another participant reported being sent home with little information regarding medications.

- Information relayed back to their GP about their hospital admission was also identified as an area that required improvement. Problems reported included the GP not having a received a discharge letter to GP about their hospital stay when they next visited their GP. Often the GP needs to contact hospital regarding the discharge letter.

- If a discharge letter or referral was received by the patient on their discharge, it often was not in an envelope and not addressed to any particular doctor. Some participants expressed concern about this situation.

- The paperwork for admission and discharge was also seen as a problem, in particular in relation to private health cover. One participant stated that it was a negative experience (due to having private health cover) and was considering not admitting to having private cover next time.

- Several participants also noted how hard it was to find a good GP.
Provision of Care and Understanding and Recognising of Patient needs

- A number of problems were identified by participants with their care and treatment. The lack of recognition of the needs and abilities of the patient was a major concern. One participant was put in a bed that was not suitable for a spinal problem. They complained about the pain but they were not taken seriously. The patient was told there was no suitable bed available; they ended up having to put up with it. Another participant was not supervised in the shower. They had tubes etc so found showering difficult and needed assistance.

- Staff attitudes to patients experiencing difficulties managing were also a problem. A participant reported being told off by a staff member for spilling a couple of drops of faeces from colostomy bag on the toilet seat. The same participant was a patient at Wollongong Hospital and was not taken to see his wife in the Palliative Care Ward at Port Kembla Hospital (a request had been made several times) who died a few days later.

- Other problems reported included wanting to go to the toilet but the staff would not take the patient, and being left in the bathroom for 2 hours. Another participant reported that despite not being able to walk, they were accused of sexually harassing another patient.

- The quality of care was also of concern. One participant was discharged four days post op with a swollen abdomen swelled up. They ended up back in Wollongong Hospital Emergency Department. Another participant reported being sent back home from the Emergency Department, but then collapsed at home.

4.2:4 Concerns about Shellharbour Hospital

- A number of concerns were expressed about Shellharbour Hospital. In particular, it was expressed that:
  - Care is not good, particularly diagnostic knowledge.
  - Communication was seen to be poor. One participant reported that staff did not explain diagnosis their diagnosis.
  - There was concern that diagnostic knowledge was not good and that this was leading to care that was not good.
  - There was a perception that staff do not listen

- Several participants reported that it was a very noisy hospital. They could hear night staff arguing in the middle of the night. Police were being called to other patients, with some patients being seen as “mad”.

- One participant believed the hospital should be closed or upgraded immediately. They felt so strongly about this that they drove straight past the hospital when they were having a heart attack.

- However, other participants did identify that their care at Shellharbour Hospital was good and they had no complaints.
4.2:5 Perceptions of Wollongong Hospital

- On the whole, participants were very happy with their care at Wollongong Hospital. One participant was very impressed with their treatment in the Emergency Department.

- The Coronary Care Unit in particular was identified as very good as was the medical care provided in general.

- The perception was that it was a very good hospital with fantastic staff; “cannot fault them”.

- One participant stated that the hospital was good at providing clean flannels and towels.

- Interestingly, while participant believed the food and care was better at Wollongong Hospital than the Prince of Wales Hospital, another participant believed the opposite.

4.2:6 Other Issues

- The availability of religious visitors was commented upon. One participant saw the chaplain everyday and found this very helpful. However, another participant said that nothing had been offered to them.

- Comments were also made about the food available in hospital. One participant was not able to have a piece of fresh fruit. They were told it was too expensive. After they spoke to a dietitian, fruit from tins was provided.

- Another comment from the same participant was that the diabetic diet does not always suit each diabetic; they had a hypo on the hospital diabetic diet.

- Another participant observed that when you are in hospital you are sick and therefore do not feel like eating; “not a luxury hotel”.

4.3 Carer Perspective

It should be noted that the responses reported in the following section by participants in the carer focus groups have remained as faithful as possible to the feelings and sentiments of the participants. This report documented their perceptions. The observations of the participants are not here to be disputed; they have given us valuable insight into how they see the system.

4.3:1 Understanding the hospital experience of carers

- Carers generally related more positive experiences of hospital when the patient was admitted for an acute condition e.g. cardiac condition or stroke. They generally had a more positive experience in the Emergency Department where they felt they were seen quickly and admitted onto a ward. Comments around their care and treatment whilst an inpatient were also more likely to be positive.

- Carers generally related more negative experiences of hospital when the patient had chronic illnesses, complex care needs or disabilities. Again this was reflected in the Emergency Department experience right through to admission and discharge. Areas
of concern included length of stay in the Emergency Department, lack of understanding by staff of their illness/disability or care needs, lack of a holistic approach to their health care, lack of adequate staffing levels, changes made to medications, and lack of involvement of carers in patient assessment, care planning and discharge.

4.3.2 Factors that contribute to a positive hospital experience for carers

**Emergency Department**

- Long waits in the Emergency Department were generally accepted when the patient and carer felt they received good care. “Good care” related to the competence of medical and nursing staff, being listened to, feeling that staff were approachable and that they could ask questions.

- Patients presenting with acute conditions in the Emergency Department were generally seen quickly and admitted to a ward. In these situations there was a belief that the triage system worked well even when the perception was that staff were overworked.

- When the patient’s GP was involved in the admission there was a belief that this assisted the process.

**In Hospital**

- Generally when health professionals were seen as competent i.e. knowledgeable and experienced, carers reported more positive views of staff. There were positive comments made about health staff across the four hospital sites.

- There was an acknowledgment and understanding at both focus groups that health professionals, particularly nursing and medical staff, are under a lot of pressure. Some participants rated staff as excellent despite this while others had a perception that this contributes to an attitude of “not caring”.

- There was an acknowledgment of the difficulty in providing 24 hour supervision to all patients and the difficulty in caring for some patients i.e. when aggressive or have dementia. There was a belief that there are staff shortages in being able to care for patients with high needs.

- Participants generally had positive experiences of specialist aged care staff. This included nursing staff in the Wollongong Hospital Acute Geriatric Unit, Aged Care Assessment Team, and Geriatricians. These positive experiences related to the competence of staff, the efficiency in which the care and treatment occurred and the way patients and carers felt they were consulted, listened to and provided with information about ongoing care and services to assist in the community. Carers felt that aged care staff were generally good at focusing on the carers as well as the patients.

**Discharge Planning**

- When planning for discharge included an assessment of the home environment i.e. by an Occupational Therapist, this was rated very highly by participants.
• When carers felt prepared for discharge they had more positive experiences. This included being given information on services in the community and the care needs of the patient. Carers commented on the fact that when they saw a Discharge Planner or Social Worker prior to discharge they had a greater understanding of what was required for care and what was available.

• When information on medication was provided prior to discharge there were more positive experiences. This was either by a Pharmacist explaining the medications to both the patient and carer and/or receiving written information.

Consultation and Inclusion of Carers in Patient Care

• Generally carers related more positive experiences when they were included in discussions about the patients care and treatment. This tended to occur more frequently with nursing staff than medical staff however it still was generally the exception rather than the rule.

• Carers who cared for patients with limited communication abilities felt they were consulted and included in more cases than carers of patients with no communication difficulties.

• There was a general belief that carers need to be more assertive in being heard however this took courage and an understanding of how the system works and who to approach i.e. on wards.

• Carers generally rated flexibility of visiting hours positively as in many instances the carers were spending a lot of time on the wards assisting with the care needs of the patient. This included ensuring the patient could manage their meal, were comfortable, could get to the toilet, and advocating on the patient’s behalf to staff. Many carers stated they would often assist patients in other beds whilst there with some of these tasks. This is related to the belief that there is not enough staff to adequately provide the care needed and also that for many carers they find it difficult to relinquish care to the hospital. This is particularly the case for long term carers caring for patients with complex or chronic conditions or who have high care needs/disabilities.

Understanding and Recognition of Carer Needs

• Generally when the carers felt there was acknowledgement of their role as carers and some consideration of their needs they had much more positive experiences. This usually meant they received relevant information on support services including respite.

• This mainly happened when carers were seen by a Social Worker. However this usually occurred in a sub-acute setting with most carers having no Social Work contact in an acute setting. Although some carers related positive experiences of feeling supported by nursing staff with discussions around the need to look after themselves as carers.

Information and Education

• When carers received information on ongoing care and support services in the community, they had more positive experiences.
4.3.3 Factors that contribute to a negative hospital experience

Emergency Department

- Experiences were generally perceived to be more negative if they didn’t match their expectations of care, e.g. a wait of 4 hours in the Emergency Department for a fractured hip was not considered acceptable by one carer. Carers who had been caring long term, particularly for people with complex and chronic conditions, did comment that their expectations of health and community care have decreased over the years.

- When patients with chronic conditions presented to the Emergency Department with acute illnesses they generally related negative experiences. These included multiple presentations with the same symptoms over short periods without resolution or admission.

- If the care received was perceived to be poor there were more negative experiences e.g. 4 or 5 unsuccessful attempts to insert an IDC to a patient in great pain before finally being admitted after four presentations to the Emergency Department.

- Long waiting times and extended periods on trolleys led to negative experiences of patients with high or complex care needs or disabilities.

- When carers presented with the patient in the Emergency Department with information on the patients medical history and test results, if these were ignored by staff there were more negative experiences related. Carers felt they had valuable information to contribute to the overall assessment of the patient’s situation which was not considered or asked for.

- Older patients being sent home from the Emergency Department late at night caused concern for carers.

- Perceptions of poor organisation in the Emergency Department e.g. after long waiting times to be seen if X-rays were needed, the X-ray Department had closed causing further delays.

In Hospital

- For carers of patients with chronic conditions and complex disabilities, there was an expectation that the patient be looked at holistically, not just focus on the presenting problem. This generally led to greater negative experiences.

- There was a perception that nursing and medical staff did not have a good understanding and knowledge of care of patients with disabilities e.g. a patient with quadriplegia – how to lift, tum and the support needed.

- There were negative experiences related to changes of medications being made for patients on complex medications or trials of medication without consultation with the GP or specialist involved in ongoing care. Again this mainly related to people with chronic conditions or disabilities and in many cases had negative effects on the illness or condition.
• There were negative experiences related to incorrect information being in the medical records on the medication history that compromised the patients care. This also occurred at times when the correct information had been provided by the carer but had not been transferred along the continuum of care from the Ambulance Service, Emergency Department and to the Ward.

• For patients on the ward who were not able to reach the buzzer to contact staff, or when staff did not answer the buzzer, this contributed to negative experiences.

• Transfer of older patients to different wards or hospitals particularly at night can cause confusion for family/carers that may not be advised and also adds to the confusion of the patient.

• Perceived lack of understanding of patient needs or lack of staffing particularly around dementia care e.g. a patient with dementia was put into incontinence pads when he was not normally incontinent at home because staff did not assist him with toileting. This caused increased agitation and a perception of being treated with a “lack of dignity”.

• There were a number of examples where the carer had not been advised of patient care incidents whilst in hospital. This included patients being discharged with pressure sores, foot ulcer and a broken tooth.

• There was a general perception that the role of nursing staff had changed with many carers stating that nursing staff are spending long periods at the nurses’ station or completing paperwork and not regularly checking patients on the wards. There was a belief that nursing was not as “hands on” as it used to be.

• Carers generally found it difficult to identify the roles of the staff and mostly had little orientation to the ward or ward staff. This contributed to a lack of understanding by carers of how the ward operated and who to approach when requiring assistance.

• There were more likely to be negative experiences if carers perceived medical and nursing staff as having a poor attitude to the patient. This was reflected in talking over the patient, or not addressing the patient directly.

• Negative experiences were related when it was felt that there was a lack of continuity of care between ward staff on different shifts and lack of understanding of the patients needs by all staff involved, resulting in inconsistent care and poor outcomes.

**Discharge Planning**

• Carers related how they felt the pressure for patients to be discharged. Situations where carers felt the patient was discharged too early led to negative experiences. This often resulted in the burden of care falling on the carers before the patient had recovered, the patient actually being readmitted not long after discharge, or in one example, whilst awaiting discharge in the Wollongong Hospital DAT Ward.

• Negative experiences were more likely to be related when the carers received little or no information or education on the care needs of the patient on discharge e.g. a carer not being shown how to change an IDC, the patient not being able to manage independently resulting in multiple re-presentations and re-admission.
• More likely to be negative experiences with discharge when the carers and patients did not receive information or referrals to community support services. There was also a lack of understanding of the process of referral to services.

• Very few of the patients or carers received discharge summaries and there were mixed experiences of whether or not the GPs received one.

• Negative experiences were also related to the time delay in discharge and when services were put in place.

Consultation and Inclusion of Carers in Patient Care

• When the patient had chronic or complex condition and had a long term carer, there were more likely to be negative experiences related by the carer. Carers will often have many years of experience in caring for that person and an understanding of their health and care needs.

• Carers were more likely to relate negative experiences with the following:
  - When medical staff did not include the carer in explanations of procedures and treatment, particularly when the patient may not easily understand e.g. due to cognitive or hearing impairment.
  - Lack of consultation with the carer and patient around assessment, treatment and care planning, medical history, behaviour at home etc.
  - Difficulty in accessing the doctor in charge of treatment particularly specialists.

• Carers of patients with high level disability e.g. quadriplegia, reported more negative experiences when trying to advocate for the patient. They felt they were labelled as “pushy and difficult” and perceived a poor attitude and rudeness from staff to their input.

• Carers related that they were often reluctant to speak up when not informed about patient care and decisions as they were concerned this may influence the care the patient receives. They did not want to be seen to “rock the boat”.

Understanding and Recognition of Carers Needs

• Carers related that often there was little understanding by staff of their role and what they do at home, particularly when the patient requires 24 hour care. There is often no attempt to assess the home situation or ask how carers are managing.

• The majority of carers did not receive information about carer supports and services available in the community, particularly about respite services.

• Carers generally felt there was a lack of understanding and acknowledgment of respite arrangements that need to be put in place when carers are patients and the implications for carers when procedures are cancelled or rescheduled at the last minute.

4.3:4 Other Issues

• There were many negative experiences related when patients with behavioural issues e.g. with dementia, were in the same wards as alert and oriented patients. There was a strong belief that there should be a separate ward for people with dementia and challenging behaviours as this can cause distress to other patients. This also related to
recognising the need for adequate staff to monitor and provide care to a specialised dementia ward.

- Negative comments regarding the environment were more likely from carers of patients with complex care needs or disabilities e.g. quadriplegia. These related to the difficulty in providing adequate care in a dignified manner on a general ward because of the need to use lifts, administer enemas, use commodes, etc.

- There were some negative experiences related to the use of equipment and the health risks e.g. damage to the skin of a patient caused by use of a hoist/sling lifter.

- In relation to food and beverages, there was a:
  - Lack of food available to patients after hours, particularly after long periods of fasting.
  - Lack of water available at the bedsides.
  - Lack of hand wash available on wards.

- In relation to parking and transport, problems were identified as:
  - Parking at Wollongong Hospital, particularly at night.
  - Lack of good public transport to access the hospital.
  - Expense of car park for carers who may be frequent and long stay visitors.
5. DISCUSSION OF FINDINGS

5.1 Differences in Experience – Acute versus Chronic

The hospital experience for the older person and carers appears to be quite different depending on whether the patient is admitted with an acute health condition or with a chronic condition or complex care needs. Patients and carers both reported much higher satisfaction when presenting with an acute condition. This was evident right from the Emergency Department to admission on a ward. Satisfaction was generally higher with all aspects of the experience from Emergency Department waiting times, care and treatment provided, and discharge processes. Conversely when patients presented with an existing chronic illness or with complex care needs, their satisfaction levels (and the carers) were much lower. This was reflected right through from waiting times in the Emergency Department, the care and treatment provided, discharge processes, and particularly for carers, their lack of inclusion in care planning and acknowledgment of the role of carers.

5.2 Perceptions of Staff

Older people and carers tended to have a belief that the role of nurses had changed over time. Perhaps having had experience of hospital systems in earlier days, there was much discussion around how the nurses had become ‘less hands on’. The perception was that that nursing staff were spending a lot of their time on ‘paperwork’ and at the nurses stations, not on basic patient care. There was also a belief there are often staff shortages on wards and this can contribute to difficulty in providing adequate supervision and care, particularly to high needs patients e.g. people with dementia. There was a perception that staff had too many patients in the ward to look after. For carers particularly these situations often led to them to spending quite significant periods of time in the ward with the patient assisting in basic care needs e.g. meals and toileting. This was particularly the case with longer term carers of people with high or complex care needs.

Despite this perception that there are not enough staff or staff are overworked (both nursing and medical), there were a number of very positive comments by both patients and carers of the care and treatment provided. One carer stated that he thought his wife had been treated ‘like a queen’ at Wollongong Hospital. Conversely there was also a perception that staffing issues led to an attitude of ‘not caring’ and poor treatment for the patient including lack of dignity. An example was given of a patient at Shellharbour Hospital who had dementia and because of a lack of staff to assist with his toileting, he was placed in incontinence pads. Incontinence was not an issue prior to this.

5.3 Communication

Communication between patients, carers and health professionals was an area highlighted as being problematic. The patient concerns related to when they were not consulted or kept informed about their diagnosis and treatment options and care plans, and not being able to ask questions or give input into their own health care. Similarly carers related greater dissatisfaction when they were not included, consulted or given information about treatment and care plans particularly when they were longer term carers who had significant expertise in the patients medical history, care needs, behaviours etc.
Patients related that they were not always listened to and that they had valuable information to give staff that could affect their care and treatment. One participant related that they had an iodine allergy but when they told staff this, they were ignored. Iodine was then put on their leg causing a large reaction. Another participant related that their operation was delayed as staff did not know about their heart medication.

Carers related that their knowledge and experience about the patient is often ignored by staff. Carers can be a valuable source of information for health professionals to draw on when making a diagnosis, assessing treatment plans and understanding changes in a person’s condition. This related to both nursing and medical staff although the carers felt that nursing staff were better at communicating with them than medical staff.

When patients and carers felt they were listened to, given opportunities to ask questions, included in consultations about their health care treatment, options and discharge they universally related the overall hospital experience as more positive.

A factor that both patients and carers felt impeded communication was the lack of understanding of the roles of staff and how wards functioned etc. Often people did not know who the different staff were and who to approach to ask for information. Further, some participants reported instances where staff did not introduce themselves. These situations led to a general reluctance to seek out information or speak out, and a feeling that staff were too busy, their own concerns may not be ‘important enough’, or not wanting to ‘rock the boat’.

Lack of information about what was happening in the Emergency Department was an area of frustration for some participants. There was a perception that that some people “jumped the queue” that had not waited as long as others (this was not related to the triage categories).

5.4 Discharge Planning

Problems with the discharge planning process were commented on quite frequently. Very few of the patients and carers received discharge summaries and often their GP’s also did not receive them.

Greater levels of satisfaction were reported when a discharge planner or social worker was involved in discharge planning and subsequently referrals made to community support services. In the majority of cases for the patients and carers this did not occur and very few carers actually received information on relevant support services available. This tended to happen more frequently in an acute hospital setting, with sub-acute areas generally better at focusing on carer needs.

The process to be discharged was identified by many participants as problematic. The wait to be discharged and the time of discharge were the main areas of concern. Patients related that their discharge was delayed due to lost paperwork, waiting for signatures on paperwork, and waiting for doctors and pharmacy. Those who were delayed in this way reported high levels of frustration with the system. In some cases, this was further exacerbated by the problems experienced with parking. One participant reported that his son incurred a parking fine because discharge had been delayed. When patients and carers did not have to wait long to be discharged, they were much happier with the process.
5.5 Provision of Care

Acknowledgement was made by both patients and carers on the difficulties in providing care to people with significant cognitive impairment or behavioural disturbances in the same ward areas as alert and oriented patients. In fact for some of the patients and carers there was significant distress felt when they were cared for in the same ward. The participants cited examples of being in the same ward as patients screaming, witnessing patients taking off their clothes or being restrained by staff. Similar observations were made regarding the Emergency Department setting particularly in relation to patients with mental health problems or drug and/or alcohol problems.

There were also concerns expressed about the lack of understanding of or adequate care for patients with very high support needs or complex disabilities. This included a patient with quadriplegia where the carer felt that staff did not understand his care needs e.g. need to turn, lift, support needed. Contributing to the poor hospital experience of this patient and carer was the lack of dignity experienced as a result of having to be cared for in a ward with others when care required a number of intimate procedures or use of aids e.g. enemas, use of commodes and hoists.

While some participants found ward moves were not a problem, a number did who then highlighted a number of problems that need to be addressed. The main issue here was the loss of possessions (e.g. clothing) and the inability to have staff follow up and address the issue. This would indicate that a better system needs to be put in place to secure patient belongings and ensure they moved safely when the patient is moved between wards.

5.6 Other Issues

5.6.1 Transport and Car Parking

Transport to Wollongong Hospital and car parking was raised as an area of concern by a number of carers, particularly carers who were visiting Wollongong Hospital frequently or staying for long periods. For those carers the hospital car park became too expensive to use and lack of adequate street parking and public transport was also mentioned.

5.6.2 Shellharbour Hospital

A number of problems were identified at Shellharbour Hospital specifically by both patients and carers. These included the hospital being noisy at night, the quality of care provided and poor communication.
6. **RECOMMENDATIONS**

This section outlines the recommendations based on the information obtained in the focus groups, that is, the perceptions of both patients and carers of the hospital setting. Four key areas of concern have been identified – communication, participation, environment and discharge planning – and the recommendations have been organised into these categories.

Further, where possible, policy documents which support the implementation of these recommendations have been cited. Recommendations have also been made regarding on-going monitoring and implementation.

6.1 **Communication**

1. Improve staff awareness of the needs of older patients and carers by ensuring hospital health professionals, including nursing and medical staff, are provided with education in the following areas:
   - Awareness of the needs of the older person as a patient.
   - Working with patients with chronic or complex conditions including people with disabilities.
   - Carer awareness and the availability of carer services.

   Consideration should also be given to including such education as part of mandatory education for health professionals.

2. Enhance the understanding of the older patient and carer on how the ward functions by providing information and/or orientation about the health services they will be using e.g. information on the role of a particular ward, the role of the staff, who to approach, how to access staff, what to expect.

3. Ensure older patients and carers are informed about what is happening at the ward level, by implementing strategies to encourage them to approach staff with questions and to ask for further information, and to be able to easily identify the staff that they should be approaching.

4. Ensure that older patients and carers are informed about what is happening while waiting in the Emergency Department and its surrounds, by implementing strategies to regularly inform those waiting of reasons for waiting times and why others may have “jumped the queue”.

Standard 2 - Leadership and management structures - contained in the “the Framework” outlines criteria Area Health Services are to meet regarding training and attitudes (2.11 and 2.12). This includes:

- AHSs establish systems for the provision and monitoring of necessary training and continuing professional development of all clinical and non-clinical staff involved in the support and management of older people and their families/carers.
- The Department and AHSs actively promote more positive attitudes towards older people at all levels in the NSW Health system.
  - Older people and their families/carers are treated with dignity and respect at all times.
  - Services are provided to older people and their families/carers, regardless of age, on the basis of assessed need.
  - In the delivery of health services, all staff considers the range of needs of older people and not exclusively at their clinical condition.


6.2 Participation

5. Improve participation of older patients in their care and treatment by ensuring that they are kept informed about their illness/diagnosis, treatment options and plans. Older patients should be encouraged as far as possible to take an active role by asking questions, expressing their preferences and providing information to health professionals.

6. Improve participation of carers of older patients in the care and treatment of the person they are caring for by ensuring they are kept informed about the illness, treatment and care options and be included in decision making. Carers should be encouraged to share their knowledge and expertise about the patient with health professionals.

Standard 1 - Care and support of older people and their families/carers - contained in the “the Framework” outlines criteria Area Health Services are to meet regarding inclusion in decision making (1.12). This includes:

- AHSs provide older people and their families/carers with encouragement and opportunity to participate in decision making related to their health management and quality of life.

6.3 Environment

7. Better meet the needs of the older patient and carer while in hospital by improving ward layouts and designs e.g. older patients be cared for in an area separate from more challenging patients to minimise distress; possessions are secured and are moved safely when the patient is transferred to another ward.

8. Improve privacy and retain dignity by giving consideration to the provision of care of patients with high or complex care needs in single rooms wherever possible.

9. Minimise distress, for patients with challenging behaviours and their carers e.g. with dementia, by caring for them in a specialised ward area with appropriate staffing levels.

10. Provide car parking concessions at Wollongong Hospital car park for carers who may be visiting frequently or spending long periods in the hospital, to enable them to utilise the car park at a subsidised cost.


Standard 1 - Care and support of older people and their families/carers - contained in the “the Framework” outlines criteria Area Health Services are to meet regarding physical access to services (1.11). This includes:

- Provision of a safe physical environment and access to appropriate aids.
- Aged-friendly building design, interior fittings, ward or unit structure and design, including clear signs and directions, and disabled access to facilities.
- Range of available transport options.
- Adequate disabled parking spaces in close proximity to service providers.
- Inclusive and supportive environment for families/carers.

6.4 Discharge Planning

11. Discharge planning for older patients, particularly those with chronic or complex conditions and disabilities, is commenced on admission to hospital and includes the discharge planner.

12. Carers should be included in the discharge planning processes, particularly around being kept informed when the patient is being discharged and their need for support in their caring role, as well as ensuring carers have access to information on community supports available.

13. Discharge should occur in a timely fashion with all discharge information and scripts available.

14. GPs should receive discharge summaries within 48 hours of their patient being discharged from hospital.

15. Older patients are educated about their medications on discharge and kept informed about any changes to their medication regime.
Standard 2 - Leadership and management structures - contained in the “the Framework” outlines criteria Area Health Services are to meet regarding effective communication and connections between different care and service providers (2.6). This includes:

- Identify existing mechanisms such as use of personal health records, care coordinators, discharge planners, specialist teams, general practitioners and an area service directory.


The following recommendations are underpinned by the NSW Health Policy Directive on Discharge Planning which includes the following underlying principles:

- The patient and their family/carers are the centre of care and are partners in care.
- Responsive, effective discharge planning starts before the patient is admitted to hospital.
- Admission and discharge are part of a continuum.

Reference: NSW Health Policy Directive PD 2006_054 Discharge Planning Responsive Standards p.6

6.5 Monitoring and Implementation

16. The recommendations contained in this Report will be implemented by requiring each Stream within the Southern Hospital Network (with the exception of the Child and Adolescent and Women and Babies Streams) to develop and implement an Action Plan based on these recommendations. Each Stream will then be required to report yearly to the Network Executive on the progress in implementation.
Appendices
Appendix 1: Letter of Invitation

Focus Groups for People 65 years and over, and carers

Dear name,

I write to invite you to participate in a focus group for people who are over the age of 65 and have who been a patient in Kiama, Shellharbour, Wollongong or Bulli hospitals in the last 12 months. We are also keen to talk with carers who might want to be part of this process.

Our Area Health Service would like to hear about your experiences of being a patient or a carer of a patient. We have contacted you using information from your patient record, however, the information has been used solely for the purpose of inviting you to join a consumer focus group to provide your feedback on our services. We would like to know what can we do to improve your experience? Also, are there things we do well?

Attached is some information to explain what is involved and how to contact us if you are interested in participating in these groups. (SEE FLYER – APPENDIX 3)

The focus groups will not be large. We want to create groups that will facilitate participation and dialogue. Due to limited numbers, your early response to this invitation is encouraged.

We would appreciate your participation in this important project and hope you will find the time to get involved.

Mrs Susan Browbank
General Manager
Northern Illawarra Hospitals Group

1. In accordance with requirements of the Health Records and Information privacy Act 2002 (NSW) Handbook item 2.3, Use and disclosure for secondary information p27, your information has been used solely for the purpose of evaluating the effectiveness of a particular service for the purpose of ongoing quality improvement to that service for clients and carers.
Appendix 2: Advertisement

SOUTH EASTERN SYDNEY ILLAWARRA NSW HEALTH

Hospital focus groups

If you are over 65 years of age and have been a patient at Kiama, Shellharbour, Wollongong or Bulli hospitals over the past 12 months, you are invited to join one of our focus groups.

Southern Wollongong focus group:
10.30am at Kiama Hospital on Wed 19 May.

Northern Wollongong focus group:
10.30am at Bulli Hospital on Fri 12 May.

These groups will meet to give their feedback on our hospital care for people over 65 years. To register your interest, please call Gai Janssen ph 42534404.
“Help us to understand what is important to you”

The Northern Illawarra Hospitals of our Area Health Service need your help. If you are over 65 years of age and have been a patient of Kiama, Shellharbour, Wollongong or Bulli hospitals in the last 12 months, you may be able to help us.

Likewise, if you are a carer of a person aged 65 years or over, who has received any inpatient or outpatient services at the above hospitals during the last year, we would like to hear your perspective.

We are inviting previous patients and/or their carers to be part of four structured focus groups. These groups will be held at:

- Kiama Hospital on the 19 May at 10.30 am, for people in the south,
- Bulli Hospital on the 12 May at 10.30 am for people in the north.

The purpose of the focus groups is to get your perspective on the way services are delivered. We want to know about your “experience of being a patient or carer”. What can we do to improve that experience? Tell us what you think we do well? We estimate each focus group will take approximately 3 hours (including lunch).

If you are interested in being part of a focus group, please call Gai Janssen on 42534404 and register your interest:

- If you require transport?
- If a carer, do you require respite?
- If you have any special dietary needs?

We hope to hear from you.

Mrs Susan Browbank
General Manager
Northern Illawarra Hospitals Group
Appendix 4: Criteria for Selection

Focus Groups for People 65 years and over and carers

Criteria for selection of participants

1. Have they been a patient or carer of a patient of a NIGH hospital ie Wollongong, Shellharbour, Kiama, Bulli?
   
   Yes □    No □

   If no, explain that at this time we are focussing on the acute hospital system and older peoples experiences

2. Was it since March 2005? (last 12 months)
   
   Yes □   No □

   If not, when was it? ____________________________

3. Are they a  Patient □
   Carer  □

4. If a patient, are they aged over 65 years
   
   Yes □    No □

   If not, how old are they? _______________________________

5. Which hospital did they attend?
   Wollongong □
   Bulli □
   Shellharbour □
   Kiama □

6. What service/ward did they use or if they do not know, what was the reason they were there?
   __________________________________________________________
   __________________________________________________________

7. Who wishes to attend?
   Patient and carer □
   Patient only □
   Carer only □
8. Which focus group?

Kiama Hospital  □  19 May 10.30am to 1.30pm?
Bulli Hospital   □  12 May 10.30am to 1.30pm?

Check that they can attend the dates/times of the group
Need to explain that the carer and the patient focus groups will be separate, but
held at the same time

9. Contact details:

**Patient** Name: __________________________________________________________
Address: ________________________________________________________________
______________________________________________________________________
Contact: ________________________________________________________________

**Carer** Name: _________________________________________________________
Carers Address (if different):______________________________________________
______________________________________________________________________
Contact: ________________________________________________________________

10. Do they need transport provided?

   Yes □       No □

11. If a carer, do they require respite care?

   Yes □       No □

12. Do they have any dietary requirements?

   Yes □       No □

Details: ________________________________________________________________

Explain that a letter will be sent with confirmation and all necessary details if
chosen
Appendix 5: Follow-up Letter Confirming Details

12th May 2006

Dear

I am writing to confirm your appointment to participate in the Focus Groups for people who are over the age of 65 years of age and have been an inpatient within the hospital system within the last 12 months and their carers.

The Focus Group will be held in the Physiotherapy Department at Kiama Hospital, on 19th May 2006 starting at 10.30am.

If you have requested transport you will be phoned on Thursday night regarding what time you will be picked up.

If you have any queries regarding the Focus Group or transport, please do not hesitate to contact me.

Looking forward to seeing you and getting your input on the day.

Yours sincerely,

PAULA BLANCH
SENIOR NURSE MANAGER
ACUTE GERIATRIC MEDICINE
Appendix 6: Questions to Guide Focus Group Discussions

Focus Group Questions - Consumers

Start by explaining how focus group will run, cover group rules, time frame, note taking, and introduce the facilitator.

- Ask group to introduce themselves first, and what hospital service they recently used.
- Ask them to think of a recent hospital experience that was positive and what was it about the experience that made it positive.
- Ask them to think of a recent experience that was negative and what made it a negative experience.
- What factors made it positive, what do you believe is good patient care
- What did you find could have been done better
- What was the best aspects, worst aspects of your recent hospital experience
- Were your expectations for care met – in what way were they or weren’t they?
- What made you satisfied or dissatisfied with a service/provider and what did you do when not satisfied
- What made you trust or not trust a service/provider and what did you do when you did not trust a service

The following are some of the areas to cover if need to prompt:

- Admission/pre-admission phase – did they receive enough information, understanding
- Inpatient/outpatient care - assessment, treatment, physical environment, food, being consulted, informed, treated with respect, staff skills
- D/C planning – ongoing needs for further care, links to community services, involvement of their family/carer

Focus group questions - Carers

Start by explaining how focus group will run – that we are really looking at the hospital experience through the carers eyes, cover group rules, time frame, note taking, and the introduction of the facilitator.

- Ask group to introduce themselves first, who they care for, and how long they have been doing this, and what hospital service the person they care for recently used.
- Ask them to think of a recent hospital experience that was positive and what was it about the experience that made it positive for them as a carer.
• Ask them to think of a recent experience that was negative and what made it a negative experience for them as a carer.

• What factors made it positive, what do you believe is good carer friendly practice

• What did you find could have been done better

• What was the best aspects, worst aspects of the recent hospital experience for you as a carer

• Were your expectations for your needs as a carer met and why or why not

• What made you satisfied or dissatisfied with a service/provider and what did you do when not satisfied

• What made you trust or not trust a service/provider and what did you do when you did not trust a service

The following are some of the areas to cover if need to prompt:

• Being consulted and included in decisions about treatment, and care and discharge

• Recognition of their role as carer

• Education and information to care post discharge e.g. on carer services, and the illness and care requirements