NSW FALLS PREVENTION NETWORK FORUM

Patients as active partners in their healthcare

Patient Experience and Consumer Engagement (PEACE) Team

Friday 22 May 2015
ACI State of Play

- PEACE Team.
- Consumer Council reporting to the Board.
- 40 Clinical Networks, Taskforces & Institutes.
  - Over 70 individual patients & carers involved.
  - Relationships with 30 community based organisations/ NGOs.
PEACE Framework

Aims to:

- Develop a ‘person-centred’ vision for the ACI and NSW Health system.
- Provide information, advice, resources & tools to support the ACI to:
  - Capture and apply patient, carer and staff experience.
  - Meaningfully engage consumers.
- Outline what the PEACE team does, who we partner with, and how to engage us.

Consumer Engagement

- **Consumer engagement**: process for incorporating consumer & community interests/needs into decision making and service planning, delivery & evaluation.\(^2\)
- Consumers can be engaged at the inform, consult, collaborate & empower level.
- ACI aiming to move from consult/ collaborate to empower with **co-design**.

Patient Experience

- **Patient Experience** is the interpretation & evaluation of everything a patient sees, feels, & hears while receiving health care.
- **Patient Experience** impacts the whole journey, from pre-care to clinical care to follow up care & everything that happens in between.
- Provides valuable insight into how well our systems are working & what we can do to improve.
What do Patients & Carers Value?

- Access to care
- Respect for patients’ values, preferences & expressed needs
- Coordination & integration of care
- Information, communication & education
- Physical comfort
- Emotional support & alleviation of fear & anxiety
- Involvement of family & friends
- Transition & continuity

Picker Institute. (1993). Principles of Person-Centred Care
Consumer Engagement - Matching

Project Initiation

Consumer engagement approach
- Regular advice and input
  - Appointing a consumer to the project governance group
  - Developing relationships with relevant NGOs including those representing vulnerable groups
    - Working with relevant LHD groups example: LHD Consumer & Community Participation Managers & Multicultural Health Managers

Patient experience approach
- Obtaining a range of consumer perspectives
- In-depth information about patient experience
  - Patient Interviews
    - Focus Groups
    - Observation/Shadowing
  - Surveys
  - Patient Experience Trackers
- General indication of patient experience
<table>
<thead>
<tr>
<th>What PEACE does</th>
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<tbody>
<tr>
<td><strong>Strategy</strong></td>
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<tr>
<td>• Support the ACI Consumer Council.</td>
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<td>• Develop relationships across NSW Health.</td>
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<td>• Access emerging evidence and innovation.</td>
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<td><strong>Product and service development</strong></td>
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<td>• Embed consumer engagement &amp; patient experience at all stages of ACI product and service development, including new models of care, informed by the redesign methodology.</td>
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<td><strong>Capability development</strong></td>
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<td>• Encourage wide-ranging &amp; representative consumer input.</td>
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<td>• Enable &amp; empower consumer participation by providing support, education &amp; training.</td>
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<td><strong>Relationship development</strong></td>
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<td>• Identify and collaborate with consumers, clinicians and managers for cultural and behavioural change.</td>
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Support for ACI Networks, Taskforces & Institutes

- Advice
- Advice & approach
- Advice, approach & tools
- Advice, approach, tools & practical assistance
PEACE Toolkit

- Surveys: paper or electronic including Patient Experience Trackers (PETs)
- Stories: in-depth interviews and videos
- Focus groups: patient and staff
- Observation/ ‘shadowing’
- Rounding
- Experience-Based Co-design
Ethics Approval

• Method is consistent with the NH&MRC guidelines about Quality Improvement projects that do not require HREC review

• NSW Health/Cancer Institute Ethics Committee reviewed method & associated resources in November 2006. **Determination: Ethics approval not required**

• Note: Recently some LHDs have requested a local LNR ethics application - if in doubt CHECK early. A further SSA for projects across multiple sites may also be required.

• Some journals require ethics clearance for publication.
In Focus: Patient Stories

6 steps…

1. Identify & invite individual patients/carers to a discussion
2. Set up discussions
3. Obtain consent & facilitate the discussions
4. Record & analyse patient stories
5. Prioritise opportunities for improvement & high performing areas – thematic analysis
6. Combine the results with other data sources & present to your team & your stakeholders
Begin Packaging the Information

- Write down patient stories **as soon as possible** after the discussion:
  - Narrative format, using story teller alias
  - Send to story teller for validation

- DATA: enter “best & worst” aspects on the patient stories spreadsheet
  - Automatically generates graphs to cut & paste into your report
  - [https://gem.workstar.com.au](https://gem.workstar.com.au) to register
  - 8 digit alphanumeric password

- Use illustrative quotes to add DEPTH & highlight issues
- Full text stories can be included in the report’s appendix as appropriate
## Analysis Spreadsheet

### Patient Background
- **Patient Name**
- **Patient Age**
- **Gender**
- **Storied History**
- **Interviews**
- **Year of Journey**
- **Health Issues**

### Type of Patient Journey
- **Patient has an acute illness**
- **Patient requires surgery, booked or emergency**
- **Patient requires hospital admission**
- **Patient requires discharge planning**
- **Patient requires other care coordination (e.g., physical therapy, social work, etc.)**

### What Patients and Carers Value

<table>
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<tr>
<th>Access to care</th>
<th>Respect for patient values, preferences, and expressed needs</th>
<th>Coordination and integration of care</th>
<th>Information and education</th>
<th>Involvement of family and friends</th>
<th>Emotional support and alleviation of fear and anxiety</th>
<th>Non-medical needs</th>
</tr>
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**PLEASE COMPLETE BELOW:** Choose from a drop-down list when available, and follow the guide given when clicking on a cell.
Data Example: Older Person’s Journey

Positive and negative aspects of patient experience, findings from 79 interviews in Upper Cumpuctal AHS

Access to Care

Respect for patients

Coordination and integration of care

Information and education

Transition and continuity

Physical comfort

Emotional support

Involvement of family and friends

You will have some great quotes to share with staff!
The ambos examined her and put a canular in. Within about 20 minutes we were on our way to hospital.

During the time Jean was in Emergency she complained about being uncomfortable on the trolley and that she was cold.

The ambulance was not ready for her. Jean waited on the trolley for about 40 minutes before she was placed on a bed.

When we saw Jean in another ward she was very upset. In her words she said "they just came and wheeled me off. I didn't know where I was going and I seemed to be moving most of the night. I wanted them to phone you but they said they wouldn't until 9am.

We asked if Jean could be put in a more comfortable bed or at least the rubber underlay taken off. We were told that they wouldn't see if another bed was available. Nothing was done. We realised that Jean had not had a shower or a body wash for the four and half days that she was in hospital.

Our concerns were that Jean got poor nursing care and it was very difficult for us to get information.

We waited for about 2 hours and I finally went to the Nurses station and asked what was happening about the Doctors instructions. I was told that nothing had been written up and they couldn't do anything until the Doctor had written up the notes.

Jean had to visit her GP for treatment of the bed sore she developed in hospital.

Our concerns were that Jean got poor nursing care and it was very difficult for us to get information.
Do the stories reflect issues you already know about from.....

- Patient survey
- Complaints/compliments
- Adverse events
- Staff experience

Prioritise and target most important issues for your project.
In Focus: Patient Experience Trackers (PETs)

- Electronic, mobile device
- Measure patient experiences at the point of care in real time
- Five questions & five options for response
- Every patient/carer can be surveyed every shift/day
- Data helps in identifying priority issues
- De-identified information
- Used for staff experience as well

Avg. 1000 surveys per month
Examples of PEACE Projects

- Broad application of the PEACE methodology (patients as partners in their healthcare) in action:
  - Co-design project: Hospitalisation of people with Intellectual Disability
  - Chronic Pain management in multicultural communities
  - Care of the Confused Hospitalised Older Person (CHOPs)
Experiences based Design is about designing better experiences…

The ACI’s Patient Experience and Consumer Engagement (PEACE) Team is currently piloting Co-Design methodology as another tool by which to better understand, act upon, and empower positive change for patients and consumers across NSW Health.
Example: Patient story and a process map...

Patient arrives at clinic

It took ages to find a car parking space and then I found it was a 15 minute walk to the outpatients clinic. How frustrating!

Patient registers with reception

The room was cluttered with out of date magazines and notices on the walls and I was already feeling really nervous

Patient waits to see consultant

I seem to be waiting a long time, have I been forgotten or missed my name being called out? Feeling anxious

Patient sees consultant

Consultant was really helpful

Patient goes to different department for investigations (X-Ray/Pathology

I wasn’t sure where to go – the signs were difficult to follow

How do I find out where to go...I think I am lost. I am worried that I will be late

frustrating

unsure

nervous

relieved
Intellectual Disability: Hospitalisation

• In partnership with the Metropolitan Regional Intellectual Disability (MRID) Networks (based out of South Eastern Sydney LHD) and the ACI Intellectual Disability Network, the PEACE team are co-designing the experiences of hospitalisation for persons with Intellectual Disability.

• Along with informing the ACI’s overarching strategy on Co-Design, one anticipated outcome of this project will be the development of a MRID Hospitalisation Toolkit.
Early findings…

• Underpinned by communication ++ coordination of care and care transition is key.

• Clear role delineation between acute care and community staff during hospitalisation is essential.

• Care of persons with a disability is a system issue.
Example: Falls and Co-design
Chronic Pain Management in multicultural communities

• Partnering with the ACI Pain Network

• The purpose of the focus groups are to explore the way in which the Arabic, Greek, Chinese and Vietnamese communities understand, manage and access services for chronic pain. The anticipated outcomes of the focus groups will be the development of culturally appropriate chronic pain resources and programs.

• Sydney LHD – Arabic, Vietnamese

• South Eastern Sydney LHD – Greek, Chinese (Mandarin & Cantonese)

• South Western Sydney LHD – Arabic, Vietnamese
Early findings…

• Very positive++ community response.
• Culturally appropriate translation of concepts and information is a major challenge.
• Opportunities for better usage of ethnic radio, newspapers and community gatherings to share information, provide education and market new ideas such as “retraining the brain” for chronic pain.
CHOPs

Care of the Confused Hospitalised Older Person (CHOPs)

- PETs, carer and staff focus groups, patient stories in multiple sites – multimodal approach!!!
Thank you

Any Questions?
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