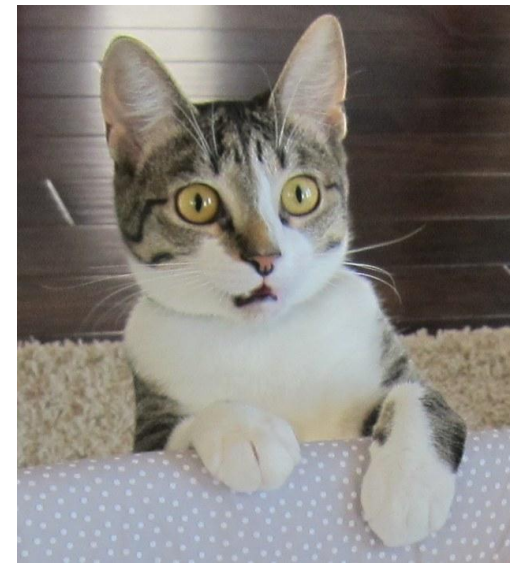# PANNING FOR GOLD: CONSUMERS + DATA = A CHANGE FOR THE BETTER

Jacqui Gibson-Roos

DATA WE FEAR…

"Google given access to healthcare data of up to 1.6 million patients"

Artificial intelligence firm DeepMind provided with patient information as part of agreement with Royal Free NHS trust"

"It includes information about people who are HIV-positive as well as details of drug overdoses, abortions and patient data from the past five years, according to a report by the New Scientist

A spokesperson for the Royal Free said **patients would not be aware** that data was being made available but it was encrypted and such an arrangement was standard practice"

The Guardian, 4th May 2016

OBSERVATIONS AND COMMENTS FROM DAY ONE

- Catherine Katz -Patients driving patient experience including surveys development. She explained how Australian Commission for Safety and Quality in Health Care are using focus groups to develop survey questions such as " Did you see anything dangerous or harmful during your stay" and how administrators tried to change the question to 'Did you report any harmful or dangerous practices'

- Nick Bush – There are 212 areas of reporting currently being undertaken. What is meaningful data for a CEO, a Board member and a member of Community Advisory Committee (CAC)? Could CAC be the training area for future Board Members?

- Too much self assessment is currently being undertaken in hospitals and the likelihood rise of internal audits using KMPG (and alike companies) to employ clinicians to review departments were there are issues. Why not train consumers to be part of the internal audit?

- Data collection such as surveys. Multi options are better than one and need to be tailored to suit your local setting. Nurses for the People Matter surveys preferred to have a paper option to complete.

MY EXPERIENCE WITH VICTORIAN HEALTH EXPERIENCE SURVEY DATA

- A brief personal history with VHES
  - Completed 1 survey
  - Member of the DHSS VHES reference group meeting as a consumer
  - Access to data – a privileged positon

  - Member of Austin Health Community Advisory Committee
  - VHES data has been presented to the committee about 3 times

NOISE AT NIGHT PROJECT

CAC members and Austin staff noted that VHES data results in Oct to Dec 2014 and 2015 showed that noise at night was an area of concern for patients

A collaborative approach was undertaken to ensure that consumers including CAC member could be active contributors to the project this included:

- Survey questions development

- Surveying patients about the noise at night – total of 76 responses from across all Austin campus wards

- Input into where to complete a noise audit

NOISE AT NIGHT - PATIENT SURVEY RESULTS
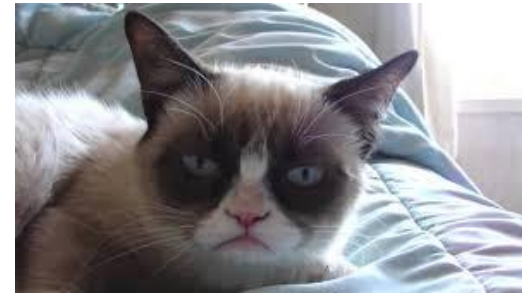
68% of patients in 4 bed rooms, 22% in single rooms

74% of patients felt the noise level overnight didn't disrupt their sleep (score b/w 1-5)

Things patients identified as creating the most noise at night:

- Other patients – 53%
- Pumps beeping – 29%
- Staff undertaking duties in their room or talking outside their room – 36%
- Other noises mentioned often: TVs being on too late, patients on phones up until midnight, doors banging, Public Announcement (only 6 responses), cleaners after 8pm in Olive Newton John wards

NOISE AT NIGHT - PATIENT SURVEY RESULTS

Between what hours do patients think it's reasonable for the hospital to be quieter:

- Majority either between 10pm – 6am or 12am – 7am

Comments:

- *When the buzzer is rung it keeps ringing until attended to. A pager or just a light flashing would be much better*

- *Put distressed patients in single rooms*

- *Create guidelines about use of radio, TV and telephones and what hours they can be used. Other patients in my room were still having telephone conversations at midnight and radios and televisions were also noisy*

THE SOLUTION

A new Noise at Night policy has been produced, reviewed/edited/pulled apart by the CAC and soon to be implemented after approval has been sought

OTHER CO-DESIGN PROJECTS

Southern Metro Primary Care Partnership

- Consumers involved in ambitious project of preparing for Statewide Health Catchment Plan 2017-2022

- by building the capacity of consumers in the region to understanding the co-design process, current relevant health population data and improving health literacy