

# Changing Outcomes through a Knowledge Network

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# What is a Knowledge Network?

- Network effect is a characteristic that causes a good or service to have a value to a potential customer dependent on the number of customers already owning that good or using that service.
- Network as much about connectivity as dissemination of information

# What is a Knowledge Network?

## Knowledge concepts:

- information of which a person, organization or other entity is aware.
- gained either by experience, learning and perception or through association and reasoning.
- confident understanding of a subject

# Whose outcomes?

- Target Population (End-Users)
  - Health planners and managers
  - Health Professionals
  - Patients and carers
  - General community
  - Local, State and Commonwealth government

# Current Status of Project

- One aspect well established
  - [www.caresearch.com.au](http://www.caresearch.com.au)
- Clear governance structure
- Established methodology for content review
- On-going Commonwealth funding (3 years)
- Executive Officer Appointed
- Large stakeholder engagement already

# Main Issues & Challenges

- The Palliative Approach is delivered by a range of HPs in a diverse range of settings
  - GPs, nursing and Allied HPs in community
  - Residential Aged Care sector
  - Acute and sub-acute
- Specialist Palliative Care
  - Inpatient Palliative Care Units
  - Specialist community providers
  - Consultative Teams supporting other treating teams in acute and sub-acute settings (growing & significant role, large numbers)
- Making the network evidence based
  - **Best available** important in this field
  - *Identifying & prioritising* evidence needs
  - Developing & translating evidence that **changes** outcomes

Knowledge Network Consultation

# Success - “End-User benefits”

- Need utilization to improve outcomes
- Good evidence base that without perceived end-user benefit
  - Close to 50% “failure” rate
    - Passive resistance to use
      - Also if ‘imposed’ literature showing active resistance
- The graphical-user-interface must allow rapid access to the knowledge desired

# Benefits and Outcomes

- End-user benefit may range from:
  - SPC HPs finding all the literature regarding symptom control for a rare condition
  - An organisation benchmarking its psycho-social assessment outcomes in order to compete for funding
  - A pt / carer from CALD background downloading info on opioid analgesia in their first language
  - Enabling remote CPD opportunities for range of HP
  - Developing research capacity
  - A patient presenting a list of questions along with a symptom inventory to a HP
    - This could include a QOL or “distress” screening tool to ensure the psycho-social-spiritual domains are addressed

# Patient / Carer Empowerment

- Could this KN target those who do not avail themselves of same degree of support
  - CALD
    - Many resources already translated
    - Many tools validated in other languages
- Simple tools could allow pts to track aspects of their care over time
  - If this was collated would focus
    - Education, quality improvement and research priorities
- Online bereavement support?
  - Carer support in general needs developing

# Evaluation

- Formative evaluation is vital in identifying needs of EU and thus ensuring endorsement
  - Beta testing functional aspects
  - Design graphical-user-interface(GUI) to be user friendly
  - Discovering what may bring benefit to **each** group of end-users in order to achieve common outcome improvements across settings
    - Will be difficult to generate population level outcomes without individual buy in from all the groups and settings
- Identify training needs for utilisation of KN
- Implementation impact on clinical care
- Direct and *indirect* measures of changed outcomes
- Evaluation methodology new and evolving
  - Another challenge and opportunity

# Outcomes

- Developing methodology demonstrating that a knowledge resource directly changed outcome is not straightforward
  - It is a relatively new field of academia
  - Many large PAS systems costing big \$s have not good evidence to show better outcomes
- Smaller EU groups will be easier to assess
- Some outcomes will be simple to show

# Linkages & Partnerships

- National PC Program Initiatives:
  - Palliative Care Outcome Collaboration(PCOC)
    - The network working with and assisting organisations to collect (& interpret?) data
  - Palliative Medicines Working Group
    - Building population level data to gain access to medications that are listed for other indications
- Strategic relationships:
  - Palliative Care Australia
    - Enable standards and policies to be adopted early
  - Consumer Health Forum
- Ensure no duplication & link with other resources
  - Clinicians Health Channel
    - About **distribution pathways** & content
      - Particularly for large groups in primary and sub-acute care

# Choices- Vortals & Portals

- Does the network channel the user based on who they are?
  - Or on what they want to know?
- Badged portals may make architecture of knowledge easier?
- A vortal may facilitate better cross consistency
- Differential access may limit utility?
- Search vs. navigation
- How do we make sure we do not fall behind in such a rapidly evolving field?

# What it might look like?

- The “one-stop shop” to navigate to
  - Disease & symptom specific information for all EU
    - This will allow some users to move up and down “levels” or granularity of knowledge depending on their needs
      - Example may include a HCA in RAC who may want knowledge between that of Health Professional audience and that of patient / carer
        - This also would be true for volunteers
        - Same issue for generalists with a specialist interest
  - All information will be “cleared” by a review process
  - A lot of peer review knowledge is currently not available through channels such as PubMed & Medline but is via *caresearch*

# The rest of the one-stop-shop

- Links to other knowledge & information sites
  - Not re-inventing the wheel
- Research:
  - including informing pts of research they can avail themselves of
- Tools
  - Symptom monitoring(longitudinal data) to empower pts & carers
  - Validated “question prompt sheets” to maximise encounters with clinicians
  - Other media such as videos, information sheets in other languages or graphical explanation for those with limited literacy
- Combined my facilitate “information prescriptions”
  - Either for patient to generate for themselves or HPs to ‘prescribe’?
    - Common information prescriptions could be built over time
      - “Anorexia & weight loss in advanced lung cancer”

# Communities of Practice

- This “network” must represent a critical mass of knowledge for PC practice!
  - Audit resources
    - Sharing specific tools to avoid duplication of effort
  - Service modeling reports & “lessons”
    - Integration with primary care clinicians
    - Day Hospices
    - New or expanding Consultative Services
    - Resource planning (for psycho-social / bereavement care)
  - Capacity to link groups
    - Online journal clubs
    - Online research groups
    - Special interest groups

# Communities of Care

- How may this link with:
  - Tele & Video conferencing:
    - Between pt / carer and HPs
    - Support between non-specialist and SPC
      - Particularly an issue for rural & remote Australia
- How broad to we make the target population?
  - Huge growth in non-cancer palliative care
- What resource implications are involved with web based support groups of potentially vulnerable pts & carers?
  - Costs (facilitation / moderation), protection & liability from predators
- Can we address death normalisation in our society?
- Can this be future proofed for tele / cyber health?