Changing Outcomes through a Knowledge Network

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What is a Knowledge Network?

Knowledge is information of which a person, organization or other entity is aware. Knowledge is gained either by experience, learning and perception or through association and reasoning. The term knowledge is also used to mean the confident understanding of a subject, potentially with the ability to use it for a specific purpose.

  - The 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.
  - One consequence of a network effect is that the purchase of a good by one individual indirectly benefits others who own the good.
  - The network may be as much about connectivity as dissemination of information.
Whose outcomes?

- Target Population (End-Users (EU))
  - Health planners and managers
  - Health Professionals (HPs)
    - Palliative Approach
    - Specialist Palliative Care (SPC)
      - Specifically to include volunteers
  - Patients and carers
  - The community at large
  - Local, State and Commonwealth government

Current Status of Project

- One aspect well established
  - www.caresearch.com.au
    - Predominantly aimed at health professionals in SPC
- Clear governance structure
  - Management Group
  - National Advisory Group
  - Task Based Working Groups
- Established methodology for literature 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

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
    - 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)
  - 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

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

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?

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
  - 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 do 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?