

Changing Outcomes through a Knowledge Network

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What is a Knowledge Network?

- Definitions: Wikipedia (open-source encyclopedia):
 - 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

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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**.

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Knowledge

- Knowledge is "information combined with **experience**, **context**, interpretation, and **reflection**. It is a high-value form of information that is **ready to apply to decisions and actions**." T. Davenport et al., 1998.
- "Explicit or codified knowledge refers to knowledge that is **transmittable in formal, systematic language**. On the other hand, tacit knowledge has a personal quality, which makes it **hard to formalize and communicate**." I. Nonaka, 1994.
- "knowledge as the **human expertise stored in a person's mind**, gained through experience, and interaction with the person's environment." Sunasee and Sewery, 2002.
- "Knowledge is a physical, mental or electronic record of **relationships** believed to exist between real or imaginary entities, forces and phenomena." Worthington, 2005.
- "the **insights**, understandings, and **practical know-how** that we all possess is a fundamental resource that allows us to function intelligently." Wiig, 1996.
- "knowledge is information **evaluated** and **organized** by the human mind so that it can be **used purposefully**, e.g., **conclusions or explanations**." Rousa, 2002.

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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

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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

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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

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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

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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

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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

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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

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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

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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

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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?

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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*

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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 may 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”

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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

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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?

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