

# Information for guided chronic disease self-management in community settings.

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#### researchers



#### reform agenda

Illness to wellness

reactive to prevention

traditional to evidence-based

fragmented to integrated

late stage to early intervention

provider driven to consumer

## **Reform Commission**

#### RECOMMENDATIONS



- 6. healthy communities,
- 7. wellness and health promotion
- 8. health promotion and prevention ...community ownership and commitment
- 10. personal responsibility
- 11. health literacy
- 12. provide access to evidence-based, consumer-friendly information that supports people in making healthy choices and in better understanding and making decisions about their use of health services.
- 13. to support people's decision making and management of their own health we recommend that, by 2012, every Australian should be able to have a personal electronic health record that will at all times be owned and controlled by that person
- 14. support for carers
- 18. care coordination
- eHealth, EPR, telehealth
- 53. better and innovative use of technology and communication...older people, and their carers, to activate and access...their own person-controlled electronic health record;..improved access to e-health, online and telephonic health advice for older people and their carers and home and personal security technology;
- 123. Greater patient involvement in their own health care, that governments collaborate to resource a national health knowledge web portal (comprising e-tools for self-help) for the public as well as for providers.

## Challenge

- poor integration/coordination
- disease management
- need for care plans for CD patients
- little case management
- little consumer partnership
- little guidance on www

## Chronic disease

 CD – leading cause health burden AIHW, 2008

**Diabetes** 

**Asthma** 

Dementia

COPD

hypertension

## Ageing & Chronic illness

- declining health status, and increased costs of care
- 23% of +65 years have a profound or severe core activity limitation and chronic illness
- >15M Australians are directly affected by at least on chronic disease
- lead to acute care episodes and poor outcomes

# challenges in ageing



- care workforce
- family carers
- longer "aged" period
- chronic illness
- support and care needs
- consumers prefer home

## Self-management

WHO framework for innovative care of chronic diseases - self-management support for effective health care organisations (World Health Organisation, 2002).

Patient self-management (Australian Department of Health and Ageing, 2008)

 interest for its potential to help people who are aged 65+ with chronic illness to manage more effectively in the community settings.

#### Literature

Evidence on effectiveness of self-management (Handley, Shumway, and Schillinger, 2008) providing better disease management (JansÃ, et al., 2006) enhancing quality of care as well as reduce hospital admissions (Coye, Haselkorn, and DeMello, 2009) providing better psychosocial support (Weinert, Cudney, and Hill, 2008).

Needs to be guided

## CDM self-management

#### Anticipated benefits:

- Better partnerships b/n patients, carers and clinicians
- Better guidance
- Ensuring right information at the right time and place
- Better compliance
- Slowing of the advance of chronic conditions
- Earlier and more timely interventions
- reduction in hospital attendances and admissions
- clinical and economic benefits

## Self-management

- Historic model (and in developing world)
- Current clinician provides advice for patients to follow
- Internet and OTC
- Disease-specific associations and programmes

#### Consumer disease associations

Cancer **Arthritis Alzheimers Asthma Diabetes** Pain other



Advocacy
Advice
Peer-support
Research

rarely in information strategy

### UK

- Expert Patients Program
- lay-led self-management programme
- people living with long-term conditions.
- aims:
  - support
  - increase their confidence
  - improve their quality of life
  - better manage their conditions.

## Impacts of Technology

- safety/quality
- reduce duplication
- efficiency
- disintermediation
- volumes ^
- standards
- consumer control







# Potential of technology

- independence
- access to care from home
- education
- remain in own homes
- reduce travel
- monitor activity
- self-management
- early warnings
- safety and security
- alerts
- support for carers
- social networking





#### Pilots/trials/research

USA - CAST Center for Aging Services Technologies <a href="https://www.agingtech.com">www.agingtech.com</a>

Ireland - TRIL (Technology Research for Independent Living)

EU – SOPRANO collaboration

Scotland - West Lothian, 4000 homes

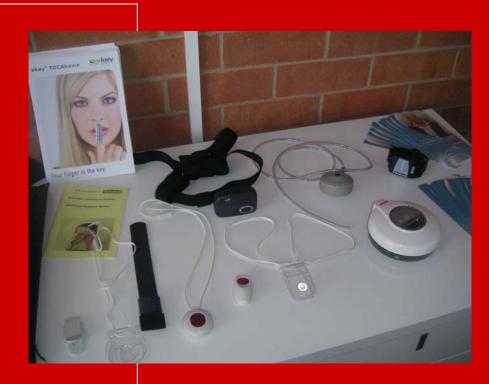
Italy - Tuscany; telecare - 5,000 homes

- Lombardy - telecare

Australia – Queensland Smart Home Initiative; Swan Care WA, Baptist Care NSW; CAAIR, EHRC, Centre for Health Innovation (Vic)

## Assistive technology

- resistance
- stigma
- control
- abandonment 40%



new developments in intelligent AT, wearables, smart homes, robotics

## Technology for aged care staff

# Nurses and information technology







#### Survey of 10,000 nurses 2006 (Hegney et al)

- Access to and use of IT lowest in aged care

#### Barriers (Yu and Comensoli 2004):

- lack of management/stakeholder support
- cultural resistance
- cost
- staffing
- work practices
- change management

#### Research

2009 semi-structured interviews managers aged & community care services in regional Qld:

- 50 invited 30 participated
- h/w and s/w changes 28 (5 iCare, 1 Skype for residents, cctv, other)
- internet 9 all staff, 12 mgt only
- care plans 28 only 2 manual
- clinical use 25, eMIMS, incontinence, research

#### Research

#### Current research:

#### senior managers, community aged care

- in-depth semi-structured interviews on attitudes to GCDSM
- strong support for GCDSM amongst managers in the care provider community who were consulted.
- Internet is a major source of information and has a plethora of health-related information however some of this can be confusing, inaccurate
- There was a sentiment that we enjoy on-line control over many aspects of our lives including ready access to other databases that assist us but little access to our own information

### **GCDSM**

#### **Discussion**

- guide patients in accessing both evidence-based information about their condition as well as aspects of their own health history so that they can develop targets and monitor indicators such as weight, exercise, blood sugar levels and spirometry.
- self-management needs to be guided as a partnership between patients and their care team members.
- little infrastructure to support case management or collaboration between providers and with consumers
- little means for electronic referrals or ensuring a carer receives all relevant details to plan and deliver appropriate care.

## Hervey Bay e-community of care

#### **Functionality:**

Alerts

E-referrals

Discharge referrals

Waiting lists – EACH etc

Further - consumer access

#### Infrastructure:

Provider directory

Telecommunications, software, interfaces

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