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

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<th>Reform Agenda</th>
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<td><strong>Illness</strong></td>
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<td><strong>provider driven</strong></td>
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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 one 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

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.
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
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
- 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
• 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
www.agingtech.com

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
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
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
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
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.
Functionality:
Alerts
E-referrals
Discharge referrals
Waiting lists – EACH etc
Further - consumer access

Infrastructure:
Provider directory
Telecommunications, software, interfaces
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