A long and winding road: Can you predict successful knowledge mobilisation and implementation in advance? Learning from the development and roll out of a social network intervention designed to support long term condition management

Anne Rogers
University of Southampton
UK

Knowledge Mobilisation Translation

- collaboration researchers & decision-makers.
- solution to underuse of research in policy and practice settings.
- engages knowledge users—policymakers, practitioners, patients/consumers members of the wider public—in mutually beneficial research
- joint development of questions data collection, analysis dissemination of findings.
- Knowledge that is co-produced has a better chance of being implemented
Social Policy Structural boost to knowledge mobilisation and translation activities

- National Institute of Health Research
- Collaborations in Leadership for Applied Health Care and Research
- Specifics of one case
Vision

Improve the health of the people of Wessex and quality and cost-effectiveness of health care

- Step change in integration/pathways of care for people with long-term conditions
- Reduce hospital admissions/re-admissions – more appropriate health care utilisation

CLAHRCS Found in Translation

- The second translational 'gap' 2006 Cooksey mending the disconnect between development and implementation of new interventions in practice. (adapting, building, redesign)

The aims of the NIHR CLAHRCs include:

- Develop and conduct applied health research relevant across the NHS, and to translate research findings into improved outcomes for patients;
- Create a distributed model for the conduct and application of applied health research that links those who conduct applied health research with all those who use it in practice across the health community;
- Improve patient outcomes locally and across the wider NHS.
- The role of the NIHR CLAHRCs will be to ensure that applied health research can be effectively taken up in practice across the geographical regions represented.
NIHR Clinical Research Infrastructure

Invention | Evaluation | Adoption
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Biomedical Research Centres | Biomedical Research Units | Clinical Research Facilities
Experimental Cancer Medicine Centres | Translational Research Partnerships and Collaborations | Patient Safety Translational Research Centres
Healthcare Technology Co-operatives | Diagnostic Evidence Co-operatives | Collabs for Leadership in Applied Health Research and Care
Clinical Research Networks

Approach to Implementation

Direct knowledge transfer – building and exploiting things we know work | Mutual knowledge exchange through social interaction | Multi-level implementation encouraging environmental and organisational readiness | Facilitate knowledge translation heuristic tools

Each of our themes combines research with implementation (R&I) to ensure maximum integration and effectiveness of translating research into practice.

Clinical Academics leading R&I themes to enhance capacity improve quality of care
NIHR CLAHRC Wessex

Established in January 2014 for a five year programme of work. We are a Wessex wide partnership of providers, commissioners, patients, the public, clinicians and researchers. We aim to put into practice what we learn from undertaking research. Our focus is on bringing benefits to people living in Wessex through better integration of pathways to care for people with long terms and to reduce hospital admissions through more appropriate use of health care.

1. Integrated Respiratory Care
   - Identify variation in outcomes
   - Improve diagnosis
   - Improve case management, self-management and rehabilitation

2. Ageing and Dementia
   - Identify early cognitive impairment
   - Improve assessment
   - Implement volunteer midtime and mobilisation assistants

3. Fundamental Care in Hospital
   - Identify deficiencies in fundamental care
   - Test strategies to improve safety, nursing capacity and patients physical needs

4. Public Health and Primary Care
   - Reduce antibiotic prescribing
   - Improve early detection and prevention of chronic liver disease and acute kidney injury

5. Self-management long term conditions
   - Create tools to support management of conditions and care pathways
   - Improve commissioning of self-management resources

6. Complexity and end of life care
   - Identify the factors behind complexity of care
   - Develop models for minimally invasive health care

Learning from the natural history of the development and roll out of a social network intervention designed to support long term condition management.
The existing self-management, policy context and the research

- NHS Improvement Plan

**Self Care Support Rapid Expansion over a decade**

1996 Health Futures ideas generated including self care skills training, national telephone helpline & supporting people in the community

1997 the New NHS White Paper commits to supporting people to care better for themselves

1998 NHS Direct helpline launched

2000 NHS Plan cites self care as one of the five key building blocks of the future NHS

2001 Expert Patients Programme initiated by the DH

2002 Wanless Report puts self care at heart of “fully engaged” scenario

2004 NHS Improvement Plan has self care in one of the new National Standards (D10)

2004 “Choosing Health” White Paper plans “health trainers”

2005 “Self Care – A Real Choice” published

2006 “Our health...” White Paper & “Supporting people with long term conditions to self care” published

2006
Summary of main policy Expert Patient Evaluation: Based on Chronic Disease Self Management Support Programme

<table>
<thead>
<tr>
<th>Method</th>
<th>Results</th>
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<tbody>
<tr>
<td>RCT</td>
<td>EPP is effective and cost-effective for patients but with caveats- self efficacy nothing much else (individual)</td>
</tr>
<tr>
<td>Process</td>
<td>Implementation problems due mainly to poor fit with NHS and administrative burden for little public health gain. Reach is limited (system)</td>
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<tr>
<td>Personal experience</td>
<td>Improvements due to support and exchanges in group, behavioural and utilisation changes limited due to existing self-management strategies (networks)</td>
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One size doesn’t fit all

Snakes & Ladders of Relationship between policy makers, research commissioners and researchers

- Working with those closest to implementation of a novel programme as a process evaluation – didn’t work: Temporality – trainers were trying to promote produce gain traction in a SMS free zone… we found the GPs wanted to bin it…
- “bury it moment”
- Positive able to learn from re-design and try a different innovation with buy in from those on the ground
WISE Approach

**Aim**
- Patient: Make better use of self-management support
- Professional: Provide better self-management support
- NHS System: Improve access to self-management support

**Method**
- Relevant Information and Support based on:
  - Current need
  - Personal priorities
  - Negotiated plan
- Changed professional response:
  - Assessment
  - Sharing decisions
  - Supporting change
  - Self-management support options
- Improving:
  - Staff training
  - Data on local resources
  - Patient access to support

**Tools**
- PRISMS Menu of options
- Management plan
- Computer template
- Online Directory of support groups

**Tools**
- Training whole practice teams
- Better patient-centred shared decisions
- Better understanding of patient support needs
- Targeted access to appropriate support
- Better patient self-management
- Healthier patients with lower health costs

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NIHR CLAHRC Wessex
What worked and what did not?

We set out to implement a practice-based training programme to enhance outcomes through enhanced self-management, which involved a number of steps:

1. Engaging a high proportion of practices with the programme - **achieved**
2. Delivering training to a high proportion of clinicians and other staff - **achieved**
3. Ensuring training was relevant and acceptable - **achieved**
4. Encouraging implementation of the training in routine practice – **partially achieved**
5. Enhancing shared decision making and self-management – **not achieved**
6. Improving outcomes – **not achieved**

Continuing policy focus on individual to bring change self-caring patient

- **Active**: (engaged in shared decision making)
- **Expert**: (possesses knowledge and skills for self management)
- **Resourceful**: (willing to minimise the load that they place on health care)
- **Prudent**: (willing to minimise the load they place on the health service)
The newer agenda building on experience

- Increasing the effective targeting and promotion of self-care support for long-term conditions requires more of a focus on patient contexts and networks. Social networks are viewed as being centrally involved in the mobilisation and deployment of resources in the management of a chronic condition. This forms the basis of a novel approach to understanding, designing, and implementing new forms of self-management support.

- The translation and implementation of a self-care agenda in contemporary health and social context needs to acknowledge and incorporate the resources and networks operating in patients' domestic and social environments and everyday lives. The latter compliments the focus on healthcare settings for developing and delivering self-care support by viewing communities and networks, as well as people suffering from long-term conditions, as a key means of support for managing long-term conditions. By focusing on patient work and social-network provision, our aim is to open up a second frontier in implementation research, to translate knowledge into better chronic illness management, and to shift the emphasis towards support that takes place outside formal health services.

The surprising power of networks
Knowledge from Public Health rather than the clinic….

- Behaviour a collective phenomena in adopting health and unhealthy behaviour
- Nicolas Christakis John Fowler - weight gain in one person is associated with weight gain in others in networks.
- Smoking behavior spreads through close and distant social ties, groups of interconnected people stop smoking in concert
- CONTAGION The spread of ideas, attitudes, or behaviour patterns in a group through imitation and conformity.
- Apply to genesis of chronic illness but also management and public health interventions
Network capacity for personal management

- **Capabilities** (Sen) how humans function also having the capability - a practical choice, "to achieve outcomes that they value and have reason to value"
- **Wellbeing**, in a "capability space", in the freedom people have to do or be what they have reason to value (Sen, 1992).
- **Affiliation**: live with and toward others to recognize and show concern for other humans, to engage in various forms of social interaction (connectivity)
- **Relationships** represent sources of support, access to resources (as well as conflict and demand)
- **Relations and interdependency** between social actors can help situate wider contextual influence on illness management (e.g. role of pets, neighbourhood)

Systems of support

- Health professionals
- Non-health professionals with health related and health relevant functions
- People with LTCs
- Voluntary and community groups with health related and health relevant functions
- Personal communities
- Support groups
- GP
- Community matrons
- Psychiatrists
- Pharmacists
- Diabetes specialist nurses
- Social workers
- Legal (crime, justice, state)
- Religious or spiritual leaders
- Supervisors (bosses, managers)
- Community wardens
- GPs
- Nurses
- Community matrons
- Psychologists
- Podiatrists
- Pharmacists
- Diabetologists
- Rheumatologists
- Cardiologists
- Neurologists
- Physiotherapists
- Health trainers
- Social prescribers
- Faith healers
- Spiritual leaders
- Social workers
- Legal (crime, justice, state)
- Religious or spiritual leaders
- Supervisors (bosses, managers)
- Community wardens
- Support groups
- Local/Thames
- Internet based
- Ethnic group
- Religious group
- Ethnic group
- Special interest groups
- Other social groups
Personal Communities & Outcomes

1. Social involvement with a wider variety of people and groups supports personal self-management physical & mental well-being.

2. Support work undertaken by personal networks expands in accordance with health needs, helping people to cope with their condition.

3. Network support substitutes for formal care and can produce substantial saving in traditional health service utilisation costs. Health service costs significantly \( p<0.01 \) reduced for patients receiving greater levels of illness work through their networks.

GENIE – An Online Social Network Intervention

Network Questionnaire

Network Mapping

Local Support Map

Preference Questions

Less or more important

Time 1 GENIE 12 months later
Who is Using GENIE?

- Isle of Wight Integrated care services
- Housing Associations
- Across Europe as part of a study on social networks in self-management support
- In Dorset as an activity in regular community-based self-management support courses
- In Solent, in a study involving people with mental health problems
- In Southampton to transition people with COPD from pulmonary rehab and maintenance classes to community support
- In Canada, GENIE has been used with adults with multi-morbidity, the frail elderly and adults with diabetes and hypertension
- Plans for implementation in Southampton City Council integrated Care. GENIE is being modelled for all Wessex CCGs and health economic outcomes are being evaluated
- Promoted to 15 Vanguards by NHS England

What are the lessons?

- Social structural support for research together with KMI is crucial (thank you NIHR)
- Always try to place one project one effort in broader context of policy and practice, over time
- failure might not be failure – part of journey – look for improvements in translation at the margins
- There is always a tension and gap between ideal type policy rhetoric and practice on the ground
- Identify it, learn from it and look at what that implies for your project
- No theory – however interesting can be more than a set of sensitising concepts – the messiness and chaos of what happens in practice and serendipity of what is taken up in practice can’t be accounted for
- Relational work needs to be at the centre stage of KM
- The knowledge you identify as crucial might require a total change of mind set to get research into practice – pets for patients not professionals!!


http://www.implementationscience.com/content/9/1/19


Contact Genie E: info@genie-net.org
Tel via CLAHRC Wessex: 023 8059 7983

More info at Genie-net.org