How and why self-management support has failed in primary care and what can be done about it?

Anne Kennedy AND Anne Rogers
University of Southampton
University of Manchester
Keele University
York University

University New South Wales, November 29th 2013
WISE Approach

To make self-management support part of every day routine in primary care

Focus on areas of high deprivation

Whole System Informing Self-management Engagement
Why Primary Care?

• GPs reluctant to refer to external self-management education programmes because of a fear of a further fragmentation of care and ambiguity over how patients would benefit.
• Chronic Care Model Wagner et al takes a systems view of primary care seeing it as offering ready access, clinical information systems, decision support and continuity of care. Primary care identified as a key provider SMS because of its reach and increasingly central role in chronic disease management
• Dennis et al (2008) identified primary care as being well placed to provide education and support for self-management practices and a systematic review of quality improvement strategies found that targeting the system of chronic disease management along with patient-mediated strategies should be an important component of interventions aimed at improving diabetes management.
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**
- **Patient**
  - Relevant Information and Support based on:
    - Current need
    - Personal priorities
    - Negotiated plan

- **Professional**
  - Changed professional response:
    - Assessment
    - Sharing decisions
    - Supporting change
    - Self-management support options

- **NHS System**
  - Improving:
    - Staff training
    - Data on local resources
    - Patient access to support

**Tools**
- **PRISMS**
  - Menu of options
  - Management plan
- **Online Directory of support groups**
- **Computer template**
  - Menu of options
  - Explanatory model
Implementation Approach

Normalisation Process Theory (NPT)* used to explain the way new or modified practices of thinking, enacting, and organising work associated with WISE are operationalised in healthcare.

What are the Merits of NPT?

• Allows for temporality –
  – ‘thinking about the doing’
  – ‘doing the doing’
  – Continuous investment

• Focus on work
  – What is it?
  – Who does it?
  – How does it get done?
  – Why did it happen like that?

• Focus on tools and technologies
Tools to Implement in WISE RCT

WISE is a generic approach to self-management support, tools capture two elements:

- Education (guidebooks for patients)
- Forming collaborative partnerships (Shared-decision making tool PRISMS)
Context for WISE

• Accommodating QoF – pay for performance
• Increased role for practice nurses in providing chronic care
• Guideline focussed = biomedical care
• Professional role conflicts – behaviour change
• National change and dismantling of PCTs
Training

• Two sessions
  1. Whole practice
  2. Clinicians only
• Delivered by lay trainers
• Supported financially by Primary Care Trust
Forms at Desk/ Clinician Nurse.

Forms collected

Analysed by staff

Minor/Neurosis. (Frequent Attenders)
Worried well
Multiple pathologies.
Elderly.
'Heart-sinks'
Young mums.
Polypharmacy.

Give Status leaflet for staff help.
CONSORT

32/51 practices in Salford
12 added from Bury

22 practices in intervention
3 dropped out

2295 (41%) patients with diabetes, COPD, IBS
80% at 6 months
72% at 12 months

22 practices in control

3304 (44%) patients with diabetes, COPD, IBS
81% at 6 months
74% at 12 months
Training Implementation

Attendance at training sessions
  – 90% (n=179) session 1
  – 82% (n=85) session 2

Training rated positively
  – Mean > 2.5 out of 5 point by 76% session 1 and 89% session 2
Minimal Clinically Important Differences

- Shared decision making
- Self-efficacy
- Health-related Quality of Life
- General Health
- Social/Role Limitations
- Energy/Vitality
- Self-care activity
- Wellbeing

- Shared decision making at 6 mths
- Self-efficacy at 6 mths
- Health-related Quality of Life at 6 mths
- Self-care activity at 6 mths
Forest plot of standardised effect sizes by outcome measures (vertical dotted bars show minimally important differences)

- Shared decision making
- Self efficacy
- Health related Quality of Life
- General health
- Social or role limitations
- Energy/vitality
- Self care activity
- Wellbeing
- Enablement
- Shared decision making at 6 months
- Self efficacy at 6 months
- Health related Quality of Life at 6 months
- Self care activity at 6 months

Effect

Usual care better | Intervention better

-0.2 | -0.1 | 0 | 0.1 | 0.2
Summary Over-Arching Analysis

- **Context differed**

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Practitioners</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aligned with policy, easy buy-in</td>
<td>No alignment with practice priorities (QoF), no relevance or use in SMS as biomedical focus</td>
<td>No change, context remained the same</td>
</tr>
</tbody>
</table>

- **Expectations**

<table>
<thead>
<tr>
<th>Organisation</th>
<th>Practitioners</th>
<th>Patients</th>
</tr>
</thead>
<tbody>
<tr>
<td>High, reduced costs healthier self-managing population</td>
<td>Low, lot of work, no gain</td>
<td>Low, SMS from others not primary care. Poor prior experiences</td>
</tr>
</tbody>
</table>
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
Process Evaluation Methods

Use of NPT to help explain why WISE did not embed in everyday practice
<table>
<thead>
<tr>
<th>NPT</th>
<th>Component</th>
<th>Questions to consider</th>
<th>Findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cohere nce: Sense-making work</td>
<td>Differentiation</td>
<td>Does participant recognise WISE tools different from existing ways of working?</td>
<td>Difficulty differentiating WISE principles from those existing practice undermined embedding of intervention. SMS not seen as different to how they already work.</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Does the pp. understand purpose of tools and techniques?</td>
<td></td>
</tr>
<tr>
<td>Communal Specification</td>
<td></td>
<td>Does the pp. recognise the steps needed to take as part of practice team to assist tool integration?</td>
<td>Ltd communication in practices post-training stifled discussion abt WISE potential benefits.</td>
</tr>
<tr>
<td>Individual Specification</td>
<td></td>
<td>Does the pp. identify their personal role and responsibilities with the use of the tools?</td>
<td>Variation in nurses’ opinion re fit of WISE tools in current practice: guidebooks fitted well PRISMS not.</td>
</tr>
<tr>
<td>Internalisation</td>
<td></td>
<td>Does the pp. identify any benefit in adopting the WISE tools, and for whom?</td>
<td>Familiarity with established information and services undermined efforts to identify the benefits and value of the WISE guidebooks.</td>
</tr>
</tbody>
</table>
Use of Tools

Self reported implementation (response rate 48%)

– Guidebooks (88% clinicians used, 51% ‘regularly’)

– Shared decision-making PRISMS tool (42% reporting *no use*)
PCT Level

• Fed into aim of PCT to be innovative and research active. SMS good for patients and may reduce costs
• PCT supports SMS from top-down
• Managed through professional directorate NOT commissioning
• Middle managers did not buy-in to WISE – no means of measuring impact
Health Care Professional Level

- GP’s abandoned/delegated work of CDM – anti-patient need
- Little engagement - WISE not seen as different to existing work- exception enlightened
- Scepticism of will of patients to take responsibility for health-low expectations of
- CDM done by nurses, but task-driven work bio med monitoring hinders incorporation of SMS
- Guidebook fits education role, PRISMS disrupts relationships Generates the articulation of need
- Not measured audited by QoF, not worth the effort
Reluctance to elicit more SMS related need

• Focus on shared decision making in consultations designed facilitate opportunities for people to bring up more than one concern, and for clinicians to elicit more tangential information from patients in an encounter

• “So I tend to fiddle with their blood pressure pills and the diabetic pills and their insulin doses and cope with crises when they come along….The lifestyle type things, which I know are important, tend to get delegated to the nursing staff to do……you know, beyond me being very basic and saying to them well, you need to try and lose weight or you need to try and eat more healthily or you need to do more exercise, that’s almost as much as I can do, really, because of time limitations. (Dr X, Practice 22)
Narrow Format of Consultations

- QOF Computer guided template- Prescribed medication, routine spirometry,- tasks not global health.
- “the underlying technical and fragmented nature of the tasks they were required to perform had the effect of reducing opportunities for patients to offer symptoms following an oblique trajectory. We found only two examples where the interactional environment allowed the patient to utilise this formulation to indicate a concern with their nurse”. Chatwin et al SSM in press
Professionals Cynical about Patients
Openness to Change

• We can point … take a horse to water but I can’t make him drink. I can give them all these things, but I can’t make them access them. But I can do my best and… that’s all.”

• (Nurse E P12)
Institutionalisation of practices

• “I know it sounds awful, it was, like, it was teaching us to suck eggs!... Because, we’ve all been clinicians for a long time, I know it gives you another way of looking at things, but, it’s, like, we already know what the patients are going through, we’ve all been experienced clinicians, it’s not, like, we’re new to the post and the fact that, it’s, like, we have a limited amount of time, in a consultation, we’ve not got an hour, per patient, I wish we did, …. we have ten minutes and you try and get everything done in them ten minutes and, then, somebody is coming along and telling you, oh, this is what you should be doing and this is this and this and this and it’s, like, and where are we supposed to fit everything in, in ten minutes.”
Patient Level

• Saw no change
• No benefit in seeking or getting SMS from HCP
• Do not perceive GP practice as where SMS happens – low expectations
• Develop SM skills for self – experience, trial and error
• Guidebooks useful – what others are doing
• No recall/use of PRISMS - don’t want to disrupt relationship
Lack of engagement in consultation (Protheroe et al 2012)

• ‘an interaction, or series of interactions between a patient and the healthcare system or health care professional in which the patient is active in providing information to aid diagnosis and problem–solving, sharing his/her preferences and priorities for treatment or management, asking questions and/or contributing to the identification of management approaches that best meet his/her needs, preferences of priorities.’ (Haywood et al., 2006)
‘... maybe if he said to me first, you know, “you’re not sorting, you’re not getting this sorted out very well are you and what can we do extra?”
Pt ID 21 (male, 72y, CHD and COPD; low SES).

R: ‘I’m not seeing the doctor, but then if everything is ticking over with the nurse maybe I don’t need to see the doctor, but I just feel that, you know, you should see a doctor.’
Q: Have you mentioned that to...
R: No, I haven’t actually. No. I’ll ask her next time I go. “How come I’ve not seen the doctor?” you know, but then she could say “but what do you want to see the doctor for?” and I’d say, “well, I don’t know”.
Pt ID 25 (female, 66yrs, diabetes, low SES)

‘No. They want to do their own job, I’m only a layman, I don’t know what they’re doing. They know better than me, so leave them and let them get on with it’
Pt ID 23 (male, 74yrs, CHD and COPD; low SES)

‘well they’re supposed to be in a position what they should know right away and people like us, well common people, you can’t ask a bloke who’s been trained all them years, its rude.’
Pt ID 20 (male, 75yrs, CHD and COPD; low SES)

‘I’m monitoring my blood pressure myself and I took the readings to him. I also requested, I said, “why don’t we do some, you know, the whole gamut of tests”........he gave me a copy there and then [the test results] and we both had a look at them together, he said, “you’ve nothing to worry about..but you should go on medication”. He wanted to put me on 5mg [Blood pressure medication] and I said “no, let me monitor my blood pressure and find out if I’ve got it under control . . I’m not a great believer in overdosing if you don’t need to” So the last time he said “well I think I should put you on 5mg, that’s the recommendation.” So I said, “No, lets keep it at 2.5”
Pt ID 1 (male, 80yrs, stroke; high SES)

‘I’m interested you know, I want to know what’s happening in my body . .what do these tablets do, why
Health Related Phenomena Spread through Personal Networks

- A person's chances of becoming obese increased by over half if he or she had a friend who became obese in a given time. Among adult siblings, if one sibling became obese, the chance that the other would become obese increased by 40%. If one spouse became obese, the likelihood that the other spouse would become obese increased by 37%.

Persons of the same sex had relatively greater influence on each other than those of the opposite sex. Health improvements in one person might spread to others.

The Spread of Obesity in a Large Social Network over 32 Years
Nicholas A. Christakis, M.D., Ph.D., M.P.H., and James H. Fowler, Ph.D.
July 26, 2007
DOI: 10.1056/NEJMsa066082
Under focus on mobilisation of resources in personal communities for SMS

- It has been suggested that more distal elements related to social relationships and the availability of social capital at the community level may be key to the mobilisation of resources needed to take self-management action.
- A network perspective offers an opportunity to redress the balance of an exclusively individual focus on self-management because it addresses the broader set of contributions and resources available to people in need of chronic illness management and support.
PRIMARY CARE CONTRIBUTIONS COMPARED TO OTHERS

- *Emotional work*. Health professionals did significantly lower amounts of emotional work than partners/spouses, close family members, other family members, friends, pets, groups.

- *Illness specific work*. Health professionals undertook significantly less illness specific work than partner/spouses and close family members (p<.001) but significantly more than friends, pets, groups and other relationships (all p<.001).

- *Everyday work*. Health professionals performed significantly less everyday work than partners and spouses (p<0.001), close family (p<0.001) and pets (p<.05).
### Mean emotional, practical, biographical and negative work scores for different relationship categories

<table>
<thead>
<tr>
<th></th>
<th>Partner or spouse</th>
<th>Close family</th>
<th>Pets</th>
<th>Other family</th>
<th>Friends or colleagues</th>
<th>Groups</th>
<th>Other relationships a</th>
<th>Medical Professionals</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Emotional work</strong></td>
<td>167</td>
<td>600</td>
<td>54</td>
<td>171</td>
<td>433</td>
<td>146</td>
<td>69</td>
<td>600</td>
<td>2240</td>
</tr>
<tr>
<td><strong>Illness specific work</strong></td>
<td>167</td>
<td>600</td>
<td>600</td>
<td>171</td>
<td>433</td>
<td>146</td>
<td>69</td>
<td>600</td>
<td>2240</td>
</tr>
<tr>
<td><strong>Everyday work</strong></td>
<td>167</td>
<td>600</td>
<td>54</td>
<td>171</td>
<td>433</td>
<td>146</td>
<td>69</td>
<td>600</td>
<td>2240</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>8.02 (.19)</th>
<th>5.07 (.17)</th>
<th>4.24 (.38)</th>
<th>3.91 (.23)</th>
<th>3.50 (.17)</th>
<th>2.75 (.23)</th>
<th>1.94 (.29)</th>
<th>1.56 (.12)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>6.54 (.24)</td>
<td>2.80 (.14)</td>
<td>2.25 (.010)</td>
<td>1.99 (.19)</td>
<td>1.62 (.11)</td>
<td>1.52 (.19)</td>
<td>.94 (.11)</td>
<td>.69 (.15)</td>
</tr>
<tr>
<td></td>
<td>6.41 (.23)</td>
<td>1.88 (.13)</td>
<td>1.40 (.22)</td>
<td>1.12 (.17)</td>
<td>.93 (.10)</td>
<td>.90 (.16)</td>
<td>.87 (.15)</td>
<td>.85 (.08)</td>
</tr>
</tbody>
</table>

p<0.001
Key Findings

(1) social involvement with a wider variety of people and groups supports personal self-management and physical and 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 were significantly (p<0.01) reduced for patients receiving greater levels of illness work through their networks.
Need to Consider the Weak Ties as well as Close Ties

- 16.1% of network membership involved in chronic illness work.
- Amount of work undertaken similar but less than that of stronger ties.
- More durable and less liable to loss over time than stronger ties.
- Enabled the moral positioning of the self-managing self.
- Act as an acceptable bridge and mediator between a sense of personal agency and control to self-manage and the need for external support because it is possible to construct more of a sense of reciprocal exchange than is the case with other health related relationships.
Implications

• Self-management support is not currently doable in primary care UK
  – Does not account for patient priorities
  – Unless professional priorities and ethos change

• Presumptions of policy makers misplaced

• Growing evidence of difficulties in achieving effective outcomes through self-management

• Evidence of the relative importance of social capital and networks points to other foci of interventions
Publications

- **Background** *BMJ* 2007;335:968–70.
- **Formative evaluation** *Imp Science* 2010 5:7
- **Protocol** *Imp Science* 2012 7:7
- **Baseline** *Med Decis Making* 2013 33: 26
- **Baseline Consultations**-SSM *inpress*
- **RCT** *BMJ* 2013;346:f2882
- **Process evaluation** – IJNS in revision + Imp Sci in submission