Working in Partnership to Deliver Patient-Centred

Adrian Sieff
2 March 2012
Our Mission

*The Health Foundation* is an independent charity working to continuously improve the quality of healthcare in the UK.
Our Approach

Inspiring Improvement in Healthcare

We commission R&D to *identify* problems and solutions in healthcare

We *innovate* to test new ideas in practice

We *demonstrate* to turn what works into accepted practice

We *encourage* to inspire and create advocates at all levels
Changing Relationships

Shifting from an orientation in which the habits and rules of providers and professions come first, to one in which the world is seen through the eyes of the person: felt experience and authority
A new paradigm
From patient to partnership

- Expert
- Carer
- Object
- Indifference
- Passive

- Enabler
- Supporter
- Subject
- Compassion
- Activated
People’s perspective?

- Life with a long term condition: the person’s perspective
- Interactions with the service: planned or unplanned
  - Scheduled follow up appointments, providing motivational support
  - Shared decision making
    - Decision aids
  - Scheduled care planning appointments, providing proactive, structured support
  - Scheduled care pathway, providing specific interventions

the person living their life with a LTC
 episodic consultations
What is supported self-management?

“Self management support can be viewed in two ways: as a portfolio of techniques and tools that help patients choose healthy behaviours; and a fundamental transformation of the patient-caregiver relationship into a collaborative partnership.”

Co-creating Health

Achieve measurable improvements in the quality of life of people living with long term conditions and improve their experience of health services by embedding self management support within mainstream health services.
An ambitious approach...

Complex, multi-level programmes which in combination and sometimes individually new to LTCs

• application of QI methods
• behaviour change techniques
• co-delivery of training
• primary and secondary care
• multi-professional
• etc ...
The Chronic Care Model

The problems:
- Lack of care coordination
- Lack of active follow-up
- Patients inadequately trained to manage their illnesses

‘Overcoming these deficiencies will require nothing less than a transformation of health care, from a system that is reactive - reacting mainly when a person is sick - to one that is proactive and focused on keeping a person well and healthy as possible.’

Understanding have role; confident and capable in role

Supporting people on their journey of activation
The evidence

Evidence for supporting self management grows every year.

• Research is up to date
• Internationally, studies are consistently positive
• Research has used a range of methodologies.
• Studies are from small to large scale.

It shows that supporting self-management can improve:

• self confidence / self efficacy
• self management behaviours
• quality of life
• clinical outcomes
• patterns of healthcare use
Active support works best

Research shows that more active support focused on self-efficacy (confidence) and behaviour works best to improve outcomes. Information and knowledge alone are not enough.

Source: Prof Judy Hibbard, University of Oregon
The Co-creating Health model
The Three Enablers

Becoming an active partner

Agenda setting
- Identifying issues and problems
- Preparing in advance
- Agreeing a joint agenda

Goal setting
- Small and achievable goals
- Builds confidence and momentum

Goal follow-up
- Proactive – instigated by the system
- Soon – within 14 days
- Encouragement and reinforcement

Making change

Maintaining change
## An Integrated Approach

<table>
<thead>
<tr>
<th>Programme</th>
<th>Who</th>
<th>Role change</th>
<th>Focus</th>
</tr>
</thead>
<tbody>
<tr>
<td>Self-management Programme</td>
<td>Patient</td>
<td>From passive patient to self-management</td>
<td>Activation and partnership: confidence and skills</td>
</tr>
<tr>
<td>Advanced Development Programme</td>
<td>Clinician</td>
<td>From expert who cares to enabler who supports self-management</td>
<td>Building the knowledge, skills and attitudes needed to provide effective self-management support</td>
</tr>
<tr>
<td>Service Improvement Programme</td>
<td>Service</td>
<td>From clinician-centred services to services that have self-management support as their organising principle</td>
<td>Embedding the 3 enablers into everyday practice by building them into systems and care pathways</td>
</tr>
</tbody>
</table>
Some high level findings

Delivering ...  
• Engagement of clinicians in self-management  
• Patients with significant potential to gain  
• Improvement in health and well-being, activation and quality of life, condition specific health indicators  
• Clinicians with prior training, more time in LTCs gained more

... and building  
• Integration – or white light  
• Link better with other initiatives (QIPP, personalisation, mutuality) at site level  
• Target ADP on teams to avoid isolation
Self-management Programme – activation

There were more patients at the highest activation stage (4) and fewer at the lowest activation stage (1) after attending the SMP.
Self-management Programme – conditions

- **Depression** – significant improvements in depression, anxiety, health status, quality of life

- **Pain** – improvements in symptoms, confidence to manage their pain, health status, anxiety and depression

- **COPD** – significantly improved mastery of their condition

- **Diabetes** – significantly improved their diabetes specific quality of life

“I used to go to the doctor only when they summoned me, and then say ‘What are you going to do to fix my problem?’. But now I’m saying like, ‘I’m not sure these particular painkillers are working the way we hoped, can we try something else? What could I do myself?’ “

Person living with a long-term condition
Patients use self-management skills

hei-q skills and acquisition technique scores before SMP and 6 months follow-

Pacing activity, working out what you can do even on your worst day was very useful”.

SMP completer interviewed by Bristol Site Reporter

The skills that I learnt, especially on the SMP—that was the real key for me’

Tell Me More Interview participant, Depression site

hei-q self-management scale (1-4, ↑ =better). **P<.001, t-test; ES= Effect Size: small (0.2), moderate (0.5), large (0.8).
Self-management Programme – content and approach

Goal setting in particular was an important technique which participants found useful for initiating self-management behaviours.

Participants valued the input from both the clinician and lay tutors with the former providing the clinical knowledge and reassurance and the latter the inspirational role modelling.

Limited content in the SMP manual relating specifically to applying the three enablers within a clinical consultation.
Clinicians responded more positively to training by further increasing their practices in self-management after attending the ADP if they

- had previously attended training similar to the ADP
- spend more than a half of their working week in direct care and contact with patients with long term conditions
- were more confident and value self-management support

“"It’s a change from the traditional approach where you say ‘You need to do this’, and the patient says “you’re the boss”, but doesn’t actually do it. We used to wonder why that wasn’t working”

Community matron
Clinicin use of the 3 enablers

Self reported changes in practicing the 3 enablers pre and post ADP - paired data

**3P<.0001 (Q2 Appendix Table 17)**
Did patients notice the difference?

Patients who consulted clinicians after they completed the ADP programme were significantly more satisfied with the consultation, felt well supported in their efforts to self manage their condition and confident they can carry out an agreed care plan.

BUT

Open to bias from the strong possibility that clinicians who asked their patients to complete the PPiC after the clinician had attended the ADP were those most committed to the course and so more likely to administer the PPiC to their patients.
Did clinicians change?

Clinicians attitude towards self-management changed and they became more aware of its value and meaning. For some clinicians attending the training helped them move from a traditional role of advice giving and being in control of the consultation to one of supporting patients to make decisions and take shared control.

We conclude that clinicians sampled for their opinions, via research interviews and discussions with site reporters, felt they gained from attending the ADP in both improved practices, and confidence to use them. But they often voiced concern about the lack of sustained impact on their everyday clinical practice.
making good decisions
in collaboration
Shared decision making....

- Recognises and utilises the expertise in the room

- Supports people when there is more than one feasible option

- Leads to:
  - Greater knowledge/ health literacy
  - More accurate perceptions of risk
  - More appropriate decisions
  - Fewer unwanted treatments
Is it happening?

Wanted more involvement in treatment decisions

Source: NHS inpatient surveys
Why isn’t it happening?

- Attitudes
- Skills
- Infrastructure
Shared decision making: a model for clinical practice
Ask 3 Questions: Get 3 Answers
Ask 3 Questions

Sometimes there will be choices to make about your healthcare. If you are asked to make a choice, make sure you get the answers to these 3 questions:

- What are my options?
- What are the possible benefits and risks of those options?
- How likely are the benefits and risks of each option to occur?

We want to know what’s important to you.
<table>
<thead>
<tr>
<th></th>
<th><strong>Lumpectomy with Radiotherapy</strong></th>
<th><strong>Mastectomy</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Which surgery is best for long term survival?</strong></td>
<td>There is no difference between surgery options.</td>
<td>There is no difference between surgery options.</td>
</tr>
<tr>
<td><strong>What are the chances of cancer coming back?</strong></td>
<td>Breast cancer will come back in the breast in about 10 in 100 women in the 10 years after a lumpectomy.</td>
<td>Breast cancer will come back in the area of the scar in about 5 in 100 women in the 10 years after a mastectomy.</td>
</tr>
<tr>
<td><strong>What is removed?</strong></td>
<td>The cancer lump is removed with a margin of tissue.</td>
<td>The whole breast is removed.</td>
</tr>
<tr>
<td><strong>Will I need more than one operation?</strong></td>
<td>Possibly, if cancer cells remain in the breast after the lumpectomy. This can occur in up to 5 in 100 women.</td>
<td>No, unless you choose breast reconstruction.</td>
</tr>
<tr>
<td><strong>How long will it take to recover?</strong></td>
<td>Most women are home 24 hours after surgery</td>
<td>Most women spend a few nights in hospital.</td>
</tr>
<tr>
<td><strong>Will I need radiotherapy?</strong></td>
<td>Yes, for up to 6 weeks after surgery.</td>
<td>Unlikely, radiotherapy is not routine after mastectomy.</td>
</tr>
<tr>
<td><strong>Will I need to have my lymph glands removed?</strong></td>
<td>Some or all of the lymph glands in the armpit are usually removed.</td>
<td>Some or all of the lymph glands in the armpit are usually removed.</td>
</tr>
<tr>
<td><strong>Will I need chemotherapy?</strong></td>
<td>Yes, you may be offered chemotherapy as well, usually given after surgery and before radiotherapy.</td>
<td>Yes, you may be offered chemotherapy as well, usually given after surgery and before radiotherapy.</td>
</tr>
<tr>
<td><strong>Will I lose my hair?</strong></td>
<td>Hair loss is common after chemotherapy.</td>
<td>Hair loss is common after chemotherapy.</td>
</tr>
</tbody>
</table>
What needs to be done?

- There needs to be a compelling narrative
- Everyone needs to play their part
- We need meaningful measures of shared decision making
- There needs to be accompanying service change
THE PATIENT WILL SEE YOU NOW
REBALANCING RELATIONSHIPS BETWEEN PEOPLE WHO USE SERVICES AND THOSE WHO PROVIDE THEM
A few publications
Changing Relationships
what have king Solomon and the Beckhams to say?
Transforming the dynamic king Solomon and the Beckhams

Song of Songs

I am my beloved’s and my beloved is mine