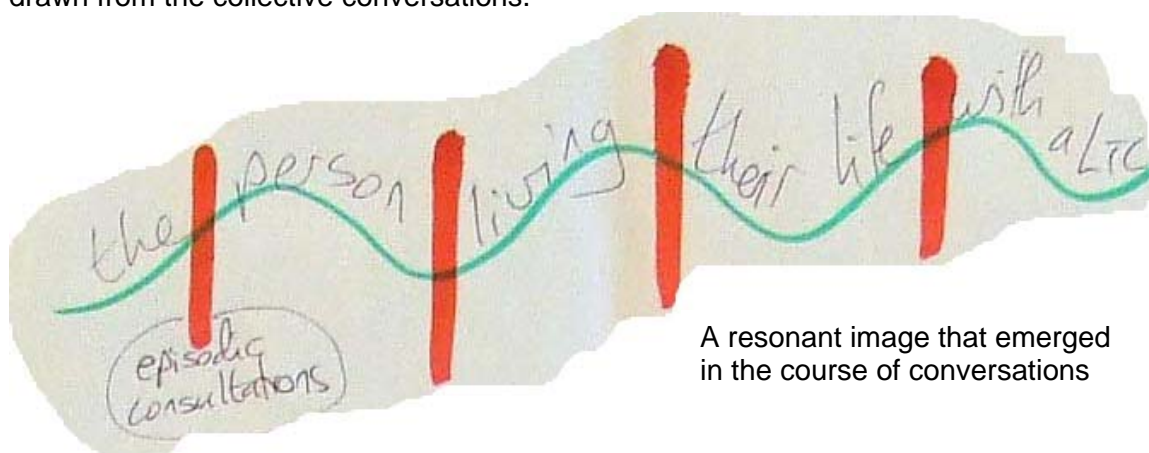


## ***Supporting people who live with long term conditions - patient-centeredness is not enough***

### **Report of workshop held on 11<sup>th</sup> and 12<sup>th</sup> December 2008**

When reading through this report, we invite you to spend time actively looking at the attached graphics and do some sense-making of your own, not simply take this offered but partial compression. This summary is inherently incomplete. The richness of the learning comes from the hundreds of interactions that led people to articulate ideas drawn from the collective conversations.



A resonant image that emerged in the course of conversations

'Patient Centred' has increasingly become an NHS mantra to focus attention on what matters. One would then expect particular attention to be placed on the 30% of all people who identify as living with a long term condition (LTC). LTCs account for 69% of the total health and social care expenditure in England. If you have a LTC it can be more difficult to live the life you would want to. Good support, (appropriate, personalised information and working in partnership with health and social care professionals) and shared decision making can help people get nearer their aspirations.

Unfortunately, in the UK, shared decision making between people with LTCs and clinicians is worse than most other countries, and has not improved over the past 5 years (2008 Commonwealth Fund International Health Policy Survey of Sicker Adults).

For diabetes, the evidence is that whilst 95% of patients are seen annually, less than 50 % discuss their care plan (Healthcare Commission). This matters. Approaches that "activate" the patient are more consistently associated with good physical health outcomes than those that limit focus on the patient's perspective (Mitchie, Miles, Weinman *Patient-centredness in chronic illness: what is it and does it matter? Patient Educ Counseling* 2003). Despite many efforts to promote patient and public involvement, there has been a failure to tackle the most important issue, namely the quality of conversations between patients and clinicians (Hibbard, Collins. *The Clinician*

Activation Measure, Commonwealth Fund 2008). The evidence is strong that the best intervention for the best outcome is a collaborative interaction between patient and care giver (Bodenheimer T, MacGregor K and Sharifi C. Oakland: California Healthcare Foundation, 2005).

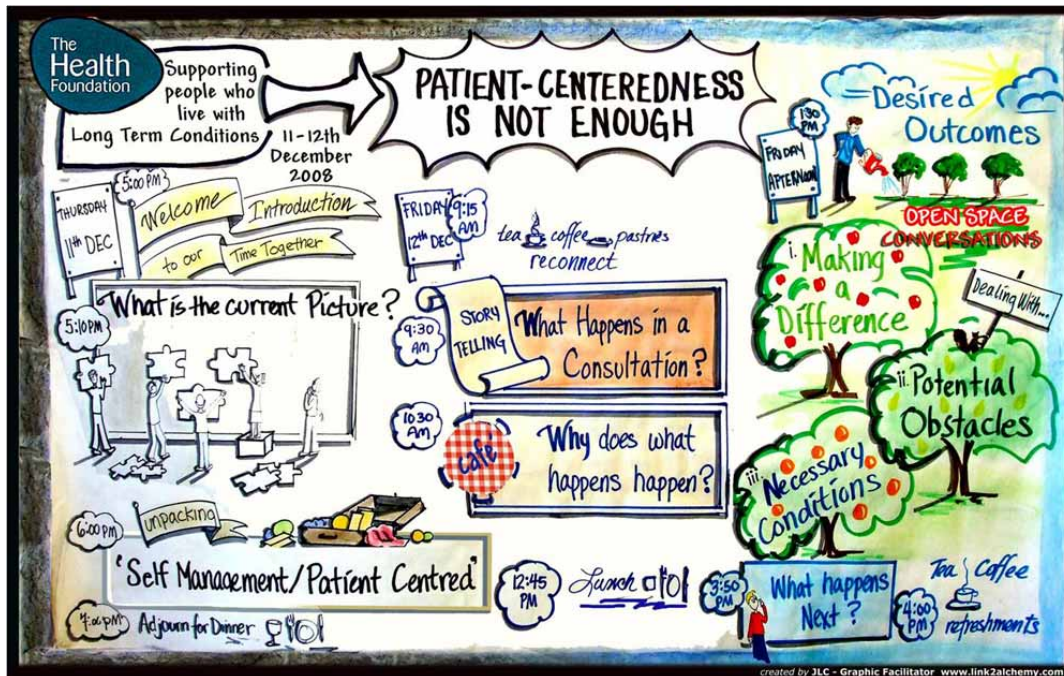
A mutual curiosity as to why, despite the evidence and the rhetoric, so little had improved across the UK is what brought the event hosts together. They were aware that Care Planning is a national initiative to improve quality of life for people with LTCs, but were experienced enough to know that depending on how it was enacted, it could help or hinder the outcome. They invited a wide range of people who had a stake in the question – bringing with them a rich mix of backgrounds, experiences and current roles (see appendices 1 & 2). Everyone was invited in their personal capacity, not to be a representative. They all had some level of disgruntlement with the current support offered to people with LTCs.

The design of the workshop was based on the belief that:

- All systems produce outcomes that are an inevitable consequence of the processes it follows
- Unless you understand what really guides the current attitudes and behaviours, you can't know what interventions will change them
- If you bring the right mix of perspectives together with the right information and relationships, the group will be able to work out what needs to be done

The workshop endeavoured to be congruent with many of the principles of co-production. There was no outcome towards which the participants were being steered. The event was an offer of space, time and interesting people to be curious together. Participants incorporating the learning into their existing work or coming up with new collective initiatives would be equally desirable outcomes.

## **Agenda**



## Context

We started by sharing some context - in particular the recognition that what we are trying to do is difficult in the current system, which is dominated by an acute model of care. Long term conditions (never fixed, go up and down, never go away) require different relationships between them and the clinician and also between the different organisations sharing the care. There is national and international evidence that, at a population level, the impact of having a LTC could be lessened with good support. However it is not obvious what the best interventions are. There are a lot of initiatives:- access to information, skills development, technology, self-care networks – all trying to address the issue. There is also the belief, one that helped shape this event, that the patient - clinician relationship is pivotal.

## The current picture

The work started with an attempt to build a shared picture of what we are talking about. Working in groups of 5/6 they were given piles of 'factoids' (appendix 3) - selected facts about some aspect of the system. Each person chose a couple that really appealed to them and shared it with their group. Everyone was invited to add additional factoids they knew. Then collectively across the whole room, we built up a shared picture of the current situation.

### Sample factoids (see appendix 3)

**60% of primary care clinicians do not endorse:**

- **patients making independent judgments**
- **patients acting as independent information seekers.**

Hibbard, Collins Commonwealth Fund 2008

**'The most significant problem is the failure of clinical staff to provide active support for patient engagement'**

Picker 2007

- **> 90% interested in being more active self carers**
- **> 75% would feel more confident about taking care of their own health if they had guidance or support from a professional or peer**
- **>50% who had seen a care professional in previous 6 months had not often been encouraged to self care**
- **30% had never been encouraged by the professionals to self care**

DH/MORI survey 2005 "public views on self care"

**In practice, the introduction of a focus on self-management tended to be interpreted within the consultation as meaning compliance with medical instructions..**

Rogers A, Kennedy A, Nelson E, Robinson A. Uncovering the Limits of Patient-Centeredness: Implementing a Self-Management Trial for Chronic Illness. Qualitative Health Research 2005, Vol. 15, 224-239

**People with LTCs only take between 1/3 and 2/3 of prescribed medication. This equates to a waste £0.5 billion worth of prescription drugs per annum'**

A question of choice: — compliance in medicine taking: The Medicines Partnership 2005

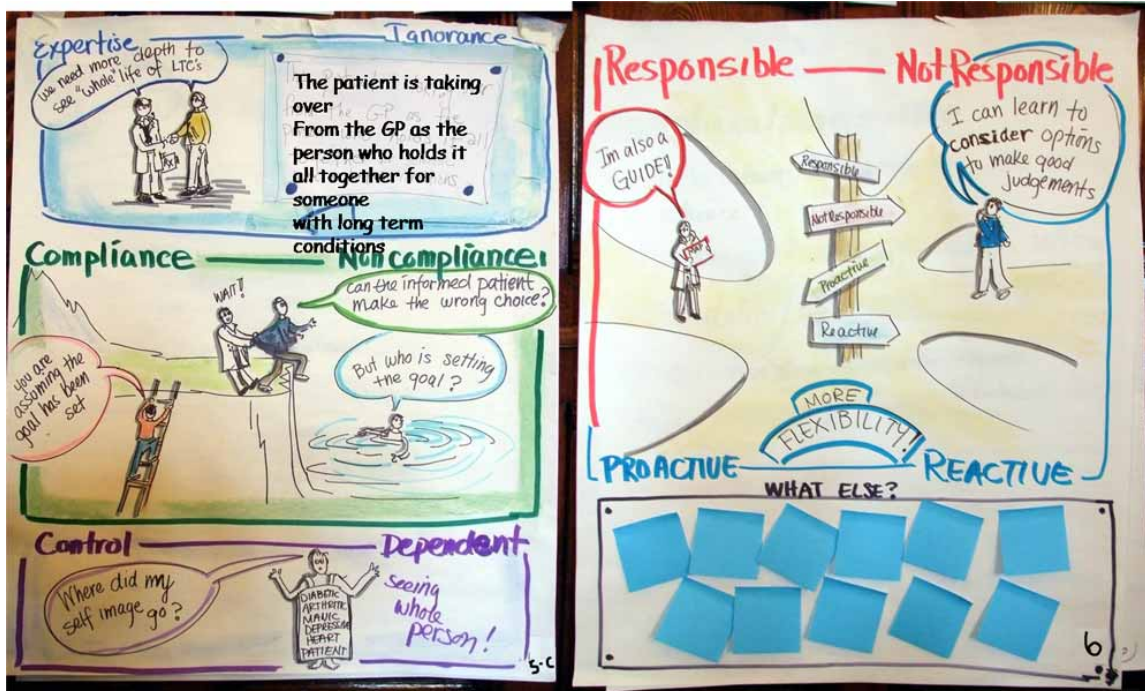
**Professionals too busy to talk...don't want to share information/control ... don't hear me...don't believe me'**

Quote from Diabetes NSF Supplementary material 2002

- What is the role of the clinician?
- When does 'illness' become a category? Whose condition is it?
- What role does expertise have in decisions about health?
- What does mass personalisation look like?
- What counts as a direction when you genuinely believe in multiple perspectives?

These uncertainties were seen by many in the room as reflecting the early stages of a transition in/battle for the values, roles and power relationships of the players in the system.





Whilst there was not enough time to explore the complex relationships between the different dimensions, two themes seemed to cross them all:

- Fit for purpose: each dimension had to be co-created in real time for specific circumstances (continuous creativity)

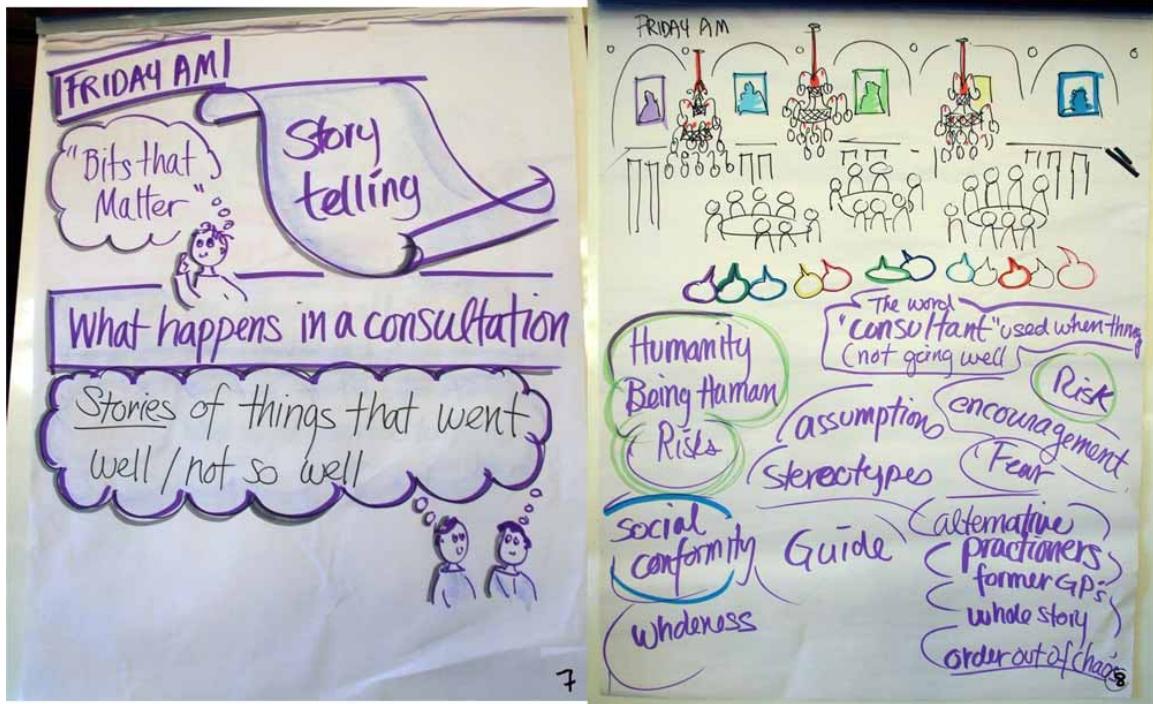
And

- The importance of both patient and clinician being able to “hold on their sense of self” throughout the interaction”

We then adjourned for dinner and conversation.

### Stories

After a recap of our work the previous evening, we grounded ourselves in our lived experience of expert interactions. In small groups we told stories about a time when we had consulted/been consulted and it had gone either extremely well or extremely badly. These could have been patient-clinician interactions, or in very different contexts (e.g. parent/teenager). The groups were looking to uncover the detail that made what happened happen (no generalisations like ‘good communication’ were allowed). This exercise both grounded us and allowed us to share in hypotheses about what made this relationship work/fail. Participants took the learning into the next stage, but shared some reflections as the image below shows:



We now moved to the heart of our time together: Could we collectively build a hypothesis that explained why we had the system we currently have i.e. why patients are so little involved in decision making about their LTCs?

We had 3 rounds of conversation, with participants capturing their learning on sheets of paper during each round, and then moving to different tables to disseminate and engage with the collective learning at that table.

In the first round they focussed on the question: 'Why are patients so little involved in decision making about their LTCs?'

In the second round (now with a representative from 5 other tables) they looked for commonalities and patterns.

In the third round they looked for what lay beneath the patterns i.e. what might have given rise to the current system?

Whilst you almost certainly have your own views on the question, we would encourage you to look at the images below and explore their links.



The whole group conversation at the end of these rounds raised these issues:

- What you pay attention to shapes the outcome you get.
- The current system values the providers, not the users.
- It focuses on parts (the consultation), not the whole life of the person with a LTC.
- The current culture has been co-created.
- One aspect that has contributed has been a model of illness as a solvable problem, not an infinitely variable continuous process.
- Not talking about roles and power relationships contributes to non-compliance.
- There was a shared belief in the room that the traditional roles are no longer valuable or sustainable.
- We need both patients and clinicians to be comfortable in a new relationship, both valuing each other's expertise and willing, when appropriate to concede priority.
- We were curious as to "what would give permission for both sides to break out" – there was a belief that both sides held back through a mutual "fear of what they might lose if the relationship changed".
- A person with a LTC can use a rich mix of resources, only one of which is NHS/social care system, to shape their life.

### Action

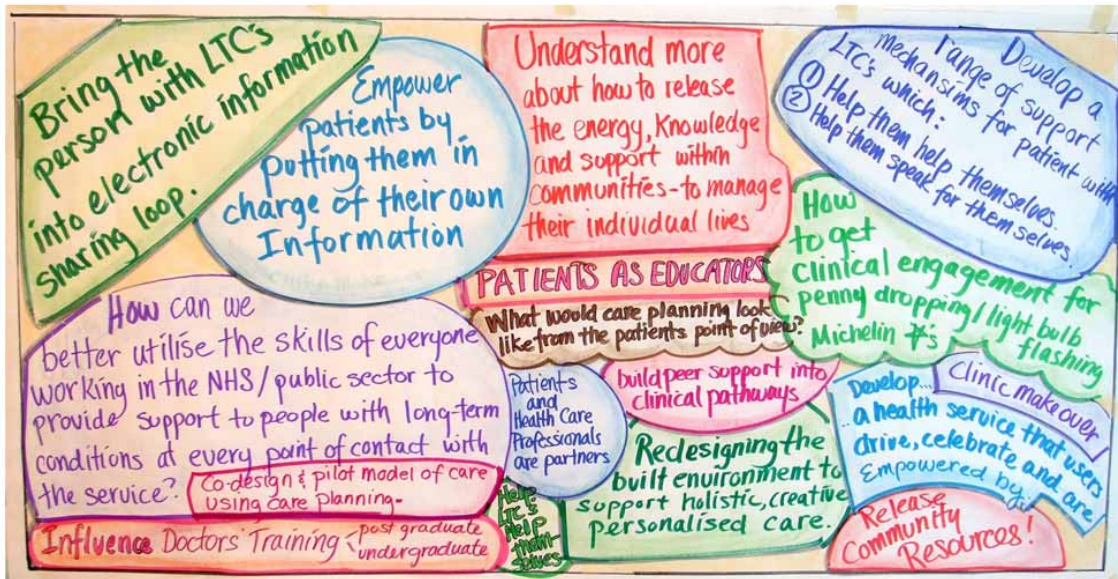
After lunch participants paired up and talked about what success would look like for them. Then after being reminded once again that we are after large-scale systemic change (and heroes either burn out or are eaten up by the system), participants were invited to suggest work they were interested in doing that could potentially change the system. Many suggestions were put forward and informally linked, grouped and connected. The list below is the record of these suggestions:



- Empower patients by putting them in charge of their information - bring the person with LTC into the electronic information sharing loop
- Design and pilot a generic LTC model of care using care planning
- Influence doctors' training – postgraduate as well as undergraduate
- Care planning is happening – what is needed to ensure it becomes fit for purpose to support people with long term conditions
- LTC needs a POETIC vision! (**P**atient Centred Professional Inspired, **O**utcome based, **E**vidence based, **T**eam oriented, **I**ntegrated (Primary, secondary, employers etc), **C**ost-effective but clinically governed
- “Clinic makeover” – overhaul a whole clinic or practice so it is based around the real lives and needs of people with LTCs
- Develop and test better ways of having patients as teachers in medical education, both undergraduate and postgraduate
- Develop a programme where patients and health care professionals work together to develop the “ideal” consultation
- Clinical engagement – how to get penny dropping/light bulb moments for more clinicians so that they “get” this? Could we award Michelin stars?
- A consensus/writing group to identify what “good” care planning look like from the patient’s point of view
- Develop a microcosm health system that as an end product is the users’ to celebrate, drive and be empowered by.
- We would like to understand more about how we release the energy, knowledge and support within communities to manage their individual lives.
- Redesigning the built environment to support holistic, creative, personalised care.
- Develop a range of support mechanisms for people with LTCs which help them help themselves and help them speak for themselves.
- We need experiments to learn how to build peer support into clinical pathways

Participants worked together to flesh out action plans for those ideas that most attracted their interest.

# Results of our time together...



# ...springboards for our actions

Implicit in these interventions are different models of change. We did not have time to explore our beliefs as to why, and under what conditions, they would make a systemic difference.

We finished our time together by pairing up and rehearsing how we would describe what we had learned and how we would take our proposed actions forward. We invite you to do the same.

## Appendices

- 1 Letter of invitation
- 2 Attendance list
- 3 Factoids

## Appendix 1 – Letter of Invitation



The Health Foundation  
90 Long Acre  
London WC2E 9RA

Telephone  
020 7257 8000  
Facsimile  
020 7257 8001

[www.health.org.uk](http://www.health.org.uk)

12 January 2009

Dear,

***Supporting people who live with long term conditions - patient-centeredness is not enough***  
**11<sup>th</sup> and 12<sup>th</sup> December 2008, Covent Garden, London**

We are pleased to be writing to confirm our invitation to you to participate in this event.

We enclose an explanatory statement which we hope will stimulate thought and promote debate and will be explored further during the event.

The event, supported by The Health Foundation, and facilitated by Martin Fischer, will be held in Central London. We are encouraging attendance to the entire event which will start with an opening session from 5.00pm followed by dinner on **11<sup>th</sup> December**, continuing with a full-day of discussions between 9.30am and 4.00pm on **12<sup>th</sup> December**.

There will be around 30 participants and a full agenda and venue map will be provided closer to the time. Costs of travel and accommodation will be met by The Health Foundation.

If you are able to attend, could you please advise Emma Harvey on 020 7257 8057 or [emma.harvey@health.org.uk](mailto:emma.harvey@health.org.uk) by **Monday 24<sup>th</sup> November**. Please advise Emma as to whether you would like accommodation to be arranged for you for 11<sup>th</sup> December. Please also contact Emma if you need any further information about the meeting.

Kind regards,

A handwritten signature in black ink, appearing to read "Alf Collins".

**Dr. Alf Collins**  
**Chair of DH/SHA Self Care Network**  
**& National Clinical Lead,**  
**Co-Creating Health Initiative**

A handwritten signature in black ink, appearing to read "Simon Eaton".

**Dr. Simon Eaton**  
**National Care Planning Lead for Diabetes**

A handwritten signature in black ink, appearing to read "N. Grazin".

**Natalie Grazin**  
**Assistant Director**  
**The Health Foundation**

A handwritten signature in black ink, appearing to read "Sue Roberts".

**Dr. Sue Roberts**  
**Programme Chair, Year of Care**

Registered company  
1714937  
Registered charity no.  
286967

## ***Supporting people who live with long term conditions – patient-centeredness is not enough***

11<sup>th</sup> and 12<sup>th</sup> December 2008

**The event will be participatory and based around the participants' consideration of the following statement:**

*In recognition of the opportunity provided by the renewed emphasis on personalised care within government policy and as a response to the commitment to make care planning universally available to people with Long Term Conditions (LTCs) in the NHS Next Stage Review;*

*and, recognising that despite many initiatives to increase the involvement of individuals in decision-making about their own care, the UK remains amongst the lowest achieving countries with developed health systems, and unchanged over the last 5 years;*

*... we argue that there is a fundamental need to reappraise the nature of the dialogue and behaviours of health care professionals working with people with long term conditions.*

**The purpose of the event is:**

to bring together the main stakeholders – people with long term conditions, academics, clinicians, practitioners and policy makers to identify:

- the nature of the challenge
- what needs to change within routine consultations to enable better support for patients with LTCs, especially in relation to support for self management
- what changes are needed to the capacity and capability of the workforce and the nature and provision of health service infrastructure to enable the NHS to rise to the challenge

**... and then to identify:**

what needs to be done practically in research, teaching, training, practice and service infrastructure, including the development of metrics, to enable widespread implementation across the NHS.

**... and finally, to make recommendations about:**

how the care planning policy commitments should be implemented in order to catalyse the proposed transformations most efficiently.

**The event has been organised by:**

Alf Collins: Chair of DH/SHA Self Care Network and National Clinical Lead, Co-Creating Health Initiative

Simon Eaton: National Care Planning Lead for Diabetes

Natalie Grazin, Assistant Director, The Health Foundation

Sue Roberts: Programme Chair, Year of Care

**...and is supported by The Health Foundation**

## Appendix 2 – Attendance List

***‘Supporting people who live with long term conditions - patient-centeredness is not enough’***

**11<sup>th</sup> and 12<sup>th</sup> December 2008**

<b>Kate</b>	<b>Ansell</b>	Patient Representative	NHS West Midlands
<b>Neil</b>	<b>Betteridge</b>	Chief Executive	Arthritis Care
<b>Jo</b>	<b>Bibby</b>	Director of Improvement Programmes	The Health Foundation
<b>Tom</b>	<b>Blakeman</b>	Clinical Research Fellow	National Primary Care R&D Centre, University of Manchester
<b>Dr Kate</b>	<b>Briggs</b>	Patient Representative	
<b>Dr Alf</b>	<b>Collins</b>	Chair of DH/SHA Self Care Network & National Clinical Lead	Co-creating Health Initiative
<b>Dr Simon</b>	<b>Eaton</b>	National Care Planning Lead for Diabetes	Northumbria Healthcare NHS Foundation Trust
<b>Dr Benjamin</b>	<b>Ellis</b>	Clinical Advisor	World Alliance for Patient Safety
<b>Professor Glyn</b>	<b>Elwyn</b>	Clinical Epidemiology Interdisciplinary Research Group	Department of Primary Care and Public Health, Cardiff University
<b>Martin</b>	<b>Fischer</b>	Facilitator	Fischer Associates
<b>Dr Jonathan</b>	<b>Fuld</b>	Consultant Physician, Acute and Respiratory Medicine	Addenbrooke's Hospital
<b>Margaret</b>	<b>Goose</b>	Clinical Standards Executive	Royal College of Physicians
<b>Natalie</b>	<b>Grazin</b>	Assistant Director	The Health Foundation
<b>Trisha</b>	<b>Greenhalgh</b>	Professor of Primary Health Care	Department of Primary Care & Population Health, Royal Free & University College Medical School
<b>Emma</b>	<b>Harvey</b>	Programme Co-ordinator	The Health Foundation
<b>Dr Patrick</b>	<b>Hill</b>	Consultant Clinical Health Psychologist	British Psychological Society
<b>Christine</b>	<b>Hoy</b>	Senior Programme Manager Self Care	The Scottish Government
<b>Dr Tom</b>	<b>Humphries</b>	GP Clinical Lead Diabetes	Derbyshire County PCT
<b>Stephen</b>	<b>Johnson</b>	Deputy Director - Long Term Condition	Department of Health
<b>Helena</b>	<b>Jordan</b>	Independent Consultant	Self Care Solutions
<b>Paul</b>	<b>Kinnersley</b>	Reader, Dept of Primary Care and Public Health Director, Communication Skills Teaching	Cardiff University
<b>Jeraldine</b>	<b>Lovell</b>	Graphic Facilitator	
<b>Helen</b>	<b>Magee</b>	Senior Research Associate	Picker Institute Europe
<b>Tracy</b>	<b>Morton</b>	Long Term Conditions, Directorate of Commissioning and System Management	Department of Health
<b>Dr Vinod</b>	<b>Patel</b>	Associate Professor (Reader) in Clinical Skills Hon. Consultant in Endocrinology and Diabetes	Warwick Medical School George Eliot Hospital NHS Trust
<b>Jim</b>	<b>Phillips</b>	Director	EPP CIC
<b>David</b>	<b>Pink</b>	Chief Executive	National Voices
<b>Mary</b>	<b>Price</b>	Long Term Conditions Coordinator	Islington PCT

<b>Sue</b>	<b>Roberts</b>	Programme Chair	Year of Care
<b>Caroline</b>	<b>Rollings</b>	Lead Nurse	Newport Pagnell Medical Centre
<b>Jonathan</b>	<b>Stead</b>	GP and Lead Researcher MDPCRG	South West
<b>Stephen</b>	<b>Thornton</b>	Chief Executive	The Health Foundation
<b>Alex</b>	<b>Tobin</b>	Programme Director	Co-creating Health Initiative
<b>Bridget</b>	<b>Turner</b>	Head of Healthcare Policy	Diabetes UK
<b>Professor Craig</b>	<b>White</b>	Clinical Lead, Self Management	The Scottish Government
<b>Marlene</b>	<b>Winfield OBE</b>	Director for Patients and Public	NHS Connecting for Health

# NHS Operating Framework 2009-10

*Over the next two years, to ensure that those living with a long-term condition receive a high quality service and help to manage their condition, everyone with a long-term condition should be offered a personalised care plan.*

**Department of Health  
December 8<sup>th</sup> 2008**

- **85% of clinicians believe they share decisions about treatment with patients**
- **50% of patients believe this is the case**

References include:

Hibbard et al 2008, DH Mori 2005 Healthcare Commission 2004 /2008, Picker 2007



# A clinician's perspective

When you ask patients for the first time about what self-management goal they want to work on, they're so surprised. They say, "*Why are you asking me? You're the nurse. You tell me what I have to do*". I always thought I was doing a good job, but I realise now how inbuilt it was that I tried to solve patients' problems for them. That's the way we were taught and that's the way we've always acted."

Carol Nixon, COPD Specialist Nurse,  
NHS Ayrshire and Arran, Sept 2008

# The experience of someone living with COPD

When I was first diagnosed with COPD\*, I asked what the cure was and they said 'there's no cure' and then they give you a magazine and you say, you know, "What can I do?" "Well, the information's in the magazine." I mean, when I left that hospital, my wife and I sat dumbstruck. There was no information anywhere and it was only in the second consultation six months later that I had with the consultant then that I said, "Look, there must be something that I can do to help it?". But the first consultation is just - it's a collapse. It's a magazine you're handed and you're out the door.

**Donald, living with COPD in Ayr, Scotland,  
Interviewed June 2008**

\* Chronic Obstructive Pulmonary Disease – a serious lung condition

# **The experience of someone living with Diabetes**

The longer I have diabetes, the more I feel like I live somewhere in between. In between how the world defines sickness and health...It seems the world sees people as either sick or well and what I'm realising is that I'm neither, and both.... Good days and bad ones. In control and not. Up and down. With diabetes it's never static and so the usual definitions of health don't really describe my life."

**“Health in between” posting, 2008**  
**At the *Aiming for Grace* blog**

# A young GP's perspective on the internet

Q: For doctors?

A: Fantastic. I'm on Google all day. Any medical questions I have, just type them and up it comes, before you see a patient...

Q: And what about for patients?

A: We'd rather the internet didn't exist. They look up some really scary stuff.

**Extract from Young GP Focus Group, November 2007**

**Cited in The Talking Cure, Stilgoe and Farouk, 2008**

# Reasons people look at consumer-created healthcare content on the web

- 37% To discuss their condition
- 39% To discuss their medication
- 41% To see how others are coping

**Four out of five people who look at consumer-created web content change their behaviour after doing so.**

John Coulthard, Director, Microsoft UK Healthcare,  
*The Patient of the Future*  
in *Engaging Patients in their Health*,  
The Kings Fund, 2008

# Trends from the national surveys 2002-07

- **Access has improved dramatically**
- **Trust in doctors remains high**
- **Knowledge about medicines has deteriorated**
- **Shared decision-making was low and stayed low**

# The Clinician Activation Measure

**60% of primary care clinicians do not endorse:**

- **patients making independent judgments**
- **patients acting as independent information seekers.**

Hibbard, Collins  
Commonwealth Fund, 2008

# People who live with long term conditions face 3 challenges:

- **medical management**
- **emotional management**
- **role management**

A large literature



**Despite many efforts to promote patient and public involvement, there has been a failure to tackle the most important issue, namely the quality of interactions between patients and clinicians**

Hibbard, Collins. The Clinician Activation Measure  
Commonwealth Fund 2008

# Royal College of Physicians

*‘The purpose of medicine is clear. It is to care for the sick always and to cure patients where possible; it is to prevent ill health and to treat disease; it is to promote well-being and to create healing environments.’*

Medical professionalism in a changing world  
Report of a Working Party, December 2005

# Royal College of Physicians

**The practice of medicine is distinguished by the need for judgment in the face of uncertainty. Doctors take responsibility for these judgments and their consequences.**

Medical professionalism in a changing world  
Report of a Working Party, December 2005

# Helping patients manage their chronic conditions

The self management support intervention for which the evidence is strongest is a collaborative interaction between care-giver and patient

Bodenheimer T, MacGregor K and Sharifi C  
Oakland: California Healthcare Foundation, 2005.

# A consultant reflects.....

*‘... I suppose if I’m honest I think probably myself and probably my colleagues felt that things like sitting down with another colleague and practicing interviewing a patient was..... I suppose we felt we’d really passed that stage.... we like to think of ourselves rightly or wrongly as fairly experienced in that respect. So I didn’t really think I’d gained much from that ..... might be something that would have been more valuable perhaps for a more junior person.....’*

Rogers A, Kennedy A, Nelson E, Robinson A. Uncovering the Limits of Patient-Centeredness: Implementing a Self-Management Trial for Chronic Illness. Qualitative Health Research 2005, Vol. 15, 224-239

# Public views on self care

- **> 90% interested in being more active self carers**
- **> 75% would feel more confident about taking care of their own health if they had guidance or support from a professional or peer**
- **>50% who had seen a care professional in previous 6 months had not often been encouraged to self care**
- **30% had never been encouraged by the professionals to self care**

# An unresolved tension?

**Although GPs valued increased patient involvement in their health care, this was in conflict with other values concerning professional responsibility.**

*Blakeman et al. A qualitative study of GPs' attitudes to self-management of chronic disease., BJGP 2006*

# The definition of good practice

## Supporting self-care

You should encourage patients and the public to take an interest in their health and to take action to improve and maintain it. This may include advising patients on the effects of their life choices on their health and well-being and the possible outcomes of their treatments

**Paragraph 4,  
GMC Good Medical Practice  
(2006)**



**In practice, the introduction of a focus on self-management tended to be interpreted within the consultation as meaning compliance with medical instructions.**

Rogers A, Kennedy A, Nelson E, Robinson A. Uncovering the Limits of Patient-Centeredness: Implementing a Self-Management Trial for Chronic Illness. *Qualitative Health Research* 2005, Vol. 15, 224-239

**... patients' practices were frequently effectively excluded from the “negotiation” of the written self-management plan.**

**Patients attributed considerably greater importance to diet as a means of managing illness than was recognized by treating doctors.**

Rogers A, Kennedy A, Nelson E, Robinson A. Uncovering the Limits of Patient-Centeredness: Implementing a Self-Management Trial for Chronic Illness. *Qualitative Health Research* 2005, Vol. 15, 224-239

# Long Term Conditions

Over 30% of all people say that they suffer from a LTC. This group accounts for:

- 52% of all GP appointments
- 65% of all outpatient appointments
- 72% of all inpatient bed days

LTCs account for 69% of the total health and social care spend in England

# Achieving a shared understanding: incorporating the patient illness framework

**Definitions used within the Cambridge Calgary framework –  
widely used to train medical students in communication skills**

Silverman JD, Kurtz SM, Draper J (1998) Skills for Communicating with Patients.

Radcliffe Medical Press (Oxford)

# Managing diabetes; England 2007

## **Of those known to have diabetes**

- **95% had check up in previous year**

## **At check up**

- **50% discussed ideas to manage diabetes**
- **50% discussed a plan to manage diabetes**
- **40% discussed personal goals for managing diabetes**

**... Common place?**

**The health and social care system must be shaped around the needs of the patient, not the other way round**

**Step by step over the next ten years the NHS must be redesigned to be patient centred – to offer a personalised service.**

**.... by 2010 it will be common place.**

**NHS National Plan,**

**27<sup>th</sup> July 2000**

# **‘High Quality Care for All’**

**The fundamental solution to the rise of lifestyle diseases is to change our lifestyles. While the NHS can support and encourage change, ultimately, these are decisions that can only be made by us as individuals...**

**NHS Next Stage  
Review Final Report**

**June 2008**

# People with Long Term Conditions

- **Only take between 1/3 and 2/3 of prescribed medication**
- **This equates to a waste £0.5 billion worth of prescription drugs per annum'**

From....information in A question of choice: —  
compliance in medicine taking: The Medicines  
Partnership 2005



*‘professionals [are] too busy to talk...don’t want to share information/control ... don’t hear me...don’t believe me’*

Quote from patient,

cited in Diabetes NSF Supplementary Material, 2002

## **Investing in self care will reduce**

- **GP visits by between 24% and 69%**
- **Hospitalisation by 50%.**

**Raising the Profile of Long Term Conditions Care**  
A Compendium of Information DH 2008

**Nearly a third of people visiting GPs said they were not involved as much as they wanted to be in decisions about their care and treatment**

Healthcare Commission, Autumn 2004

# Barriers to patient involvement and self-management

- The lack of effective consultation skills to facilitate patient involvement
- Conflict between values of professional responsibility and increased patient control
- Contextual barriers, such as incentive schemes, that focus on biomedical care

*Blakeman et al. A qualitative study of GPs' attitudes to self-management of chronic disease., BJGP 2006*

# Patient activation

Approaches to “activate” the patient were more consistently associated with good physical health outcomes than those that limited focus on the patient’s perspective

**Systematic Review of 30 papers relating to patient-centredness**

Mitchie, Miles, Weinman *Patient-centredness in chronic illness: what is it and does it matter? Patient Educ Counseling* 2003

# Shared Decision Making

The three most often reported barriers were:

- time constraints
- lack of applicability due to patient characteristics
- lack of applicability due to the clinical situation

The three most often reported facilitators were:

- provider motivation
- positive impact on the clinical process
- positive impact on patient outcomes

Gravel, Légaré, Graham *Barriers and facilitators to implementing shared decision-making in clinical practice: a systematic review of health professionals' perceptions*. Implementation Science 2006

# Wanless (2002)

**Self care is one of the best examples of how partnership between the public and the health service can work.....**

**for every £100 spent on encouraging self care, around £150 worth of benefits can be delivered in return**



.... "I hope these are easier to flush away  
than the last lot" ....



'the clinicians role when working with people with Long Term Conditions:

- 'doing to, doing for or doing with?'

# Long Term Conditions.....

..most people cannot expect full recovery and need to acknowledge, understand, incorporate, accommodate and adapt to and come into a relationship with their conditions before they can truly 'move on' to a successful 'outcome'.

They are then in a position to make the best possibly decisions about their own life, as active participants in their own care, and to determine their own priorities and goals for management itself (ref).

# The challenge for clinicians

- to move beyond listening to and valuing patients' insights as the key to finding 'common ground' in a 'joint' management plan which they will ultimately 'approve'.
- to become comfortable with using their sophisticated expertise to support the individual to develop their own goals and action plans, which is the foundation of successful self management