

Catalysts for Change

Catalysts for Change - a personal viewpoint on User Involvement by Derek C Stewart for Diabetes Research Network Patient Involvement Conference, Dec 4th, 2008

(The following notes were written following the presentation)

The themes of this presentation are:

- Acknowledging the Journey
- The Relevance of Transferable Skills
- Clarifying Our Role
- Being Effective
- Leadership for Change

Acknowledging the Journey

The past isn't that long ago. So for a moment let us just consider how far we have travelled.

I got involved in 1999 when I was asked to take part in a local health service forum. The group was made up of patients, professionals and was the beginning of Involvement. Before that time as a patient trying to engage just meant exclusion – excluded by language, excluded from meetings, excluded from giving ideas.

Inclusion would now be more an appropriate watch word.

In 1999 there were only a handful of patients and now there are hundreds. Then it seemed as if the impact we might make would be single voice and now it seems more like a choir.

We do, however, need to get better at **acknowledging and marking the progress made** so that we can learn from history and apply it in the future. We need to learn from people who made a difference in other areas: Mental Health, HIV Community, Women with Breast Cancer.

We should also be looking to the future regarding new treatments and approaches to service delivery. We need to hear from current patients rather than relying on our own experience.

We must develop our thinking to be broader than the continuum of engagement and **consider the aspects of advocacy and change agents.**

Catalysts for Change

The Relevance of Transferable skills

We are More than our Patient Experience

Perhaps we should give more recognition to the fact that we are more than just the experience of our illness, disease, condition and treatment/s though these are the pivotal and central reference points for our involvement.

The purpose of our involvement is always about improving services and research. The nature of that improvement is change, whether in culture, climate, theory or practice.

So, what other skills, knowledge and experience can we bring to the topics that are at the heart of change?

For example, think about your experience of the following...

- *Working Together*: Have you been involved in relationship building, team work, dealing with staff, mergers
- *Problem Solving*: Do you have any experience of quality circles and assurance, resolving difficulties, changing practice
- *Customer Focus*: have you worked in selling, marketing, publicity, dealing with enquiries and complaints
- *Finance*: What knowledge of family budgeting, household bills, business accounts.

These experiences may have been gained at home, work or recreation.

So, what skills and knowledge have you developed as a result of your experience?

As teacher I was involved with learning: lesson planning & preparation, aims, objectives and outcomes. I was specifically working with pupils with challenging behaviour and using the arts as a learning medium. It is as much those experiences that I draw upon and then **apply the skills in a transferable manner**.

I see my patient experience as the fulcrum, a reference point for a role that enables me to converse with other patients and with healthcare professionals.

The experience becomes a reflection - a shaving mirror which can be used with either the standard or close-up lens to learn from others and effect change. **Telling your story does not effect change in itself.**

My cancer led me to national participation and involvement becoming a member of a national Board, chair of a PCT, and a journey travelling through Education, Health to Home Office & Local Authority. I have moved beyond cancer patient and taken on new roles but each stems as a direct result of having had the cancer and the change made to my life through the disease and its treatment.

This has then become about the patient experience in change management subsequently taking on roles in leadership and identifying what makes the voice of patient experience so effective.

Catalysts for Change

Our Role

Presence:

Of course, we should be present in order to make a difference although it is worth noting that absent friends who are no longer with us can continue to illuminate experience.

This is now referred to as the Cialdini Effect (1) – This is based on people's tendency to reason "if a lot of people are doing this, it's probably a wise thing to do" and therefore do what they observe others are doing.

The thinking behind patient and public engagement and active involvement ranges across different theories:

These include filling what was the missing chair at most tables; a 'reminder of purpose', the 'end user' of service planning, citizens with a right in democracy, observers on public money, etc.. We may simply bring a renewed focus from the customer, client, and patient perspective.

The Cialdini effect would suggest that the more we have been present then the more it becomes the norm and therefore less threatening to some professionals. Yet, **presence in itself is not necessarily effective involvement.**

The Role:

I don't think it necessarily matters whether you see yourself as an individual, a representative, as long as there is agreed **clarity of the role in explicit, defined terms** and the participants understand what that role is, any responsibilities and what efforts are made to inform that opinion and communicate.

The Place:

As far as I am concerned patient involvement can take place at any level and in almost every aspect of research with the appropriate support/ training (e.g. some oncologists had cancer as a child which subsequently propelled them into medicine and research).

People affected by cancer are involved on Government Advisory Boards, the governance of research, too numerous committees, throughout the research cycle, on various operational steering groups as well as trial management processes.

They are engaged and involved locally, regionally, nationally and internationally.

It helps beyond measure if there is **a solid infrastructure with identified resources to cover expenses, support, training and review.**

The Task:

Over the years I have developed my own phrases to capture the essence of the task. I therefore see us as an **Active Presence, Vigilant Watchers, Contributors to the Dialogue and Challenging Partner.**

Catalysts for Change

Our role, as patients taking a positive role in cancer research user involvement, is developing into one of active presence, vigilant watcher, contributor to the dialogue, challenging partners and participants in a shared decision making (2).

- As *active presence* we have an expectation of being asked to participate, sitting at the table and act as a physical reminder of the purpose.
- As *vigilant watcher* we are able to witness that the patients' interests are being considered but we must make sure that people continue working together and make maximum use of resources.
- As a *contributor to the dialogue* it is about having a right to add our voice to the dialogue with a responsibility to gain an understanding of the wider issues.
- As *challenging partners* we should all be encouraged to ask awkward questions. We, as patients, need to spend time listening to different patient communities to gather their views. We might as a by-product become ambassadors for research in general and some may want to be involved in our own research
- As *participants in a shared decision making* where our experiences, values and preferences are equated with the treatment options, potential benefits, harms, outcomes of clinical trials and the organisation of research for patient gain.

Each of these shifts the role into advocacy – speaking up and out on issues which are central to our experience.

User involvement is not about having patients attending every imaginable meeting and group but about ensuring that change is matched with improvement.

By-products of personal development

There are a number of aspects of involvement that lead to you contributing again in society, building confidence, identifying transferable skills, earning new information and you may even find activity in a voluntary or paid capacity.

Although I note these as by-products they are fundamental to self-worth and self-esteem and probably have an increased value in terms of coping with ill health yet they are not the key focus of activity. However they may help make you more effective catalysts for change.

Being Effective – Some Examples

Significant improvement has taken place. It is difficult to trace a direct link or causality between patient involvement and change but tangentially it is curious that many of the things I will mention were less evident before we became involved.

Attitude and Culture - We have moved from exclusion to inclusion. The organisations that provided strategic direction did not involve any patients. Now we sit on almost every Board, Committee, Steering Groups and it would seem odd if we were not present.

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Research itself - There is now a broader portfolio in most areas of research that takes account of the whole trajectory of the illness and includes Supportive & Palliative Care, Quality of Life, Primary Care. There is also the User Led Research Competition run annually by Macmillan which encourages and develops service users actively taking up research ideas.

Specific changes Many patients/carers have taken part in the prioritisation of research topics, improving trial leaflets and videos. We have helped crafting better questions and given views on the manner of approach. Increasingly people are taking part in discussion around validation and relevance of certain trials along with helping disseminate results.

In General - There has been more *publicity* (recent articles on experimental cancer medicines in the Observer and on the ONE Show.) More Research Open Days have taken place.

Presence – This is now in all aspects of Policy Making, Membership on Boards, Most conferences and events, and we are making improvements in service delivery

Service Improvements

For many years the worlds of Research and Service Delivery appeared at times to be completely separate. The publication of Research for Patient Benefit marked a significant moment of tying research and service together. The Cancer Reform Strategy has highlighted new areas of research in areas of particular interest to patient experience for Public Awareness, Living with Beyond Cancer, etc.

Lord Darzi's report talks about measuring the quality of service and the new NHS Constitution talks about patients being given information about trials.

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It is for all these reasons that I increasingly see our role as **catalysts for change, advocates and leaders of the patient/carer voice.**

Becoming leaders

Leadership is not necessarily always about being in charge, taking responsibility or giving orders. **By speaking up and out we can help focus discussion** and lead the way forward from an independent perspective.

It is about raising issues and providing focus that help shape the research that then helps improve patient experience.

In a recent article about leadership Armistead, Pettigrew and Aves speak about 4 challenges to partnership working: Resolving differing expectations, Building a consensus, Managing conflict, Performance management (2)

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The suggestions I have made earlier around our presence and our roles help to address the issues around differing expectations and the examples illustrate how we have worked to gain consensus around certain common purposes.

Yet, to effect behavioural change you need to consider the following:

- Separate the person from their behaviour
- Empower individuals by starting from what they can do
- Set new goals in small steps
- Offer support and coaching
- Acknowledge failure as learning opportunity
- Recognise the achievement
- Offer praise with new challenges

For performance management we need to be relentless in our pursuit of quality and this includes:

Tough truth-telling

Our experience combined with the extensive evidence and intelligence that exists on local and national research offers great potential for us to ask more effective questions; we can be more than our single voice, not just dropping a problem in middle of room but being solution focused. Creating an 'us' rather than you and me

Targeted Activities

Identifying a specific issue

- What is the problem?
- Where is the problem?
- Who are the key people?
- How can we reach an acceptable response?
- What can each of us do to help?
- Where is the Action Plan?
- Who will provide follow up and feedback

Agents for Improvement

First of all it is about understanding that **change is constant**, that we need to be working to drive policy. We need to identify and overcome any obstacles.

Catalysts unite and unify by offering a future picture.

We can achieve this by identifying what is common between us, encouraging and praising, helping create the linkages that bond together.

We need to watch the horizon – what is happening, what is coming up to inform and form policy and alter practice.

We need to plan, prepare and work together across disease sites as that is how we live.

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“It is not enough to say we are doing something; but to be clear about the progress we are making” (4).

1. Psychometrica - R B Cialdini (2007)
2. Consumer Involvement in Cancer Research in the United Kingdom: The Benefits and Challenges – Stevens and Wilde (Kirby, Stewart, Ahmedzai, Cunningham & Darbyshire)
3. Exploring Leadership in Multi-sectoral Partnerships – Armistead, Pettigrew and Aves, Centre for Organisational Effectiveness, Bournemouth Univ. (2007)
4. Report from The Advisory Council Misuse of Drugs (2006)