

Ramping up patient participation close to home

What do your colleagues think about 8 till 8 access 7 days a week; online registrations, prescriptions and appointment booking; telecare and health apps; electronic media consultations (text, email, Skype); and patient-owned records - not forgetting 24h care continuity for elderly frail patients? More to the point, what do the patients and carers think – and what do they really want? Big changes are heading toward practices and community health services. If you don't know what the users think, waste no time finding out. The best way is to ramp up participation close to home.¹

Primary and community care face challenges and need effective responses. NHS England's *Improving General Practice : Call to Action*² lays out a stark rationale for enabling primary care “to play an even stronger role at the heart of more integrated out-of-hospital services that deliver better outcomes, more personalised care, excellent patient experience and the most efficient possible use of NHS resources.”

Community nurses are key to this transformation. Their “X factor” will be leading change in partnership with patients, carers and the public. Here are some ways to do that.

Embedding participation - a “could do” right now

All practices in England belong to Clinical Commissioning Groups. Nurses should play a big part in their patient and public engagement (PPE) strategies by reflecting user needs, priorities and insights. Patients, carers and the public are already saying what they want: “Be ambitious and not constrained by the past.”³

In late 2012, we asked CCG leaders what should be happening in practices to embed participation. A common response was Patient Participation Groups (PPGs) – but there was a fear that many were not fit for purpose.⁴ A good approach is in the *Smart Guides to Engagement*⁵ on *Practices and Patient Engagement* together with advice on how to *Get off on the right foot with your patient participation group*.⁶

Maximising participation - a “should do” for all services

You can maximise patient participation with conversations between clinicians and patients on the implications of the new “Call to Action”. Doing this with Balham Park Surgery's Patient Liaison Group in Southwest London found enthusiasm for working in partnership to

¹ NHS England (September 2013) *Transforming Participation in Health and Care*
www.england.nhs.uk/2013/09/25/trans-part

² NHS England (July 2013). *Improving General Practice: a call to action*. www.england.nhs.uk/ourwork/com-dev/igp-cta/

³ NHS England (September 2013). “Patients tell 7-day service forum: ‘Be ambitious and not constrained by the past’” www.england.nhs.uk/2013/09/20/patient-7day-service-forum/

⁴ *Embedding Patient and Public Involvement in CCGs*. January 2013. www.networks.nhs.uk/nhs-networks/documents/documents/ppe

⁵ www.networks.nhs.uk/nhs-networks/smart-guides

⁶ <http://bit.ly/KsHAgK>

- address practical issues around 7 day access,
- explore alternatives to individual face to face appointments to free up time for people really needing them, and
- think about patient expectations if federations of practices deliver wider services.

Conversations can be bigger than individual practices. In Croydon a few years back, we worked on a project called '1000s of everyday conversations' with nurses and other staff to gather feedback during consultations with patients. They then discussed in their teams what one thing they would do to improve things the next week.

Efforts to improve information, transparency and choice are all desirable but they don't add up to empowered patients. For patients to help lead primary care changes into a responsive, integrated, and accessible out of hospital service, we need to move into a different league: we need patient leadership.

Enabling patient leadership - the “must do” for future survival

Participation advocates need to face some hard facts. Current engagement structures and systems are not fit for the future. That's because at their heart is a paternalistic model which views patients as providing feedback and professionals as listening attentively and then making the decisions. But having patients as leaders means a lot more than just listening to their views.

Patient leadership is about supporting patients to work as partners for change, alongside professionals. This could be as community leaders, peer to peer support workers and many other roles in the community. But it also means that in the NHS, they must become an equal voice in budget setting, “never event” reviews, specification writing and procurement, service monitoring – everything that affects the patient experience.

This is more than having a few “patient representatives” on narrowly-defined and institutionally-led structures. It is about working with patient leaders to identify and develop a range of opportunities for dialogue and influence. It also means providing the right kind of development and support.

The key to distinguishing patient leadership from medical/clinical/managerial leadership is the mindset that comes with it. This emerges from living with illness, injury or disability and the life experiences that this generates, including interacting with health and social care structures and systems. This creates a lens through which patient leaders make choices and decisions, relate to others and engage as leaders. The experience of patients becomes not a weakness but a strength on which to build – a radical concept for many healthcare professionals. As Dr Spock of Star Trek might have said to Capt Kirk, “It's leadership, Jim, but not as we know it”.⁷

This should not be threatening to nurses. Patient leadership could be transformational not confrontational. It thrives in a climate of collaboration, where there is joint work towards solutions, innovative ways of dealing with challenges, patient engagement in tough decisions on planning and policy and continuous

⁷ <http://centreforpatientleadership.com/>

improvement in the quality of patient care and experience. These are just the things that primary and community health care and its practitioners need to prosper in the present as well as the future. Patient leaders could aid the transformation of primary and community healthcare services. It's clear to us that the changes needed won't happen without them.

Nurses can help make this happen. If you want to see the future of working in partnership with patient leaders, then dip into the new resources specially designed to support patient leadership.⁸ Once you do, you will realise that keeping patients on the outside looking in and with no developmental support is a fatal flaw in the well-intentioned rhetoric to "place patients at the centre of care".

The challenge is to ensure patient leaders have the skills and share of the power to activate their potential. Just as people with long-term conditions are beginning to be seen as part of the solution to the care crisis, so patient leaders could be their equivalent at decision-making level. At both levels, patients are the greatest untapped asset in healthcare and their value cannot be ignored.

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⁸ *Bring it On: 40 ways to support Patient Leadership* April 2013. <http://centreforpatientleadership.com/wp-content/uploads/2013/04/Bring-it-on-40-ways-to-support-Patient-Leadership-FINAL-V-APRIL-2013.pdf>