

Making ripples: patient involvement in service planning

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ABSTRACT

Patient involvement in shaping the face of modern medicine is increasing. Patient representatives – local and from the Patient and Carer Network – are now an integral part of shaping the work of the Future Hospital Programme through their direct involvement in the development sites. The path to a successful partnership between clinicians, managers and representatives is not easy but is worthwhile as illustrated in two stories from the Royal College of Physicians' phase 1 development sites in north Wales and Wakefield. Each trust is different, as are the viewpoints of clinicians and representatives. However, shared learning and partnership working is a very powerful catalyst in promoting change for the benefit of both patients and staff.

KEYWORDS: Patient centred, patient involvement, communication, respect, shared learning

Patient involvement at the Royal College of Physicians

Patient involvement within the Royal College of Physicians (RCP) has grown out of recognition that working together can produce better outcomes for patients, carers and clinicians. The setting up in 2003 of the Patient Involvement Unit, and the resourcing and support for the Patient and Carer Network (PCN) was a public statement of the RCP's commitment to integrating patient involvement into its core activities. Over the past 12 years, the relationship between the RCP and members of the PCN has evolved, with a growing confidence and trust in the expertise, knowledge, talents and commitment of PCN members. The decision to involve PCN members in the Future Hospital Commission (FHC) was a powerful indicator of the 'coming of age' of the PCN.

Patient and carer involvement in the Future Hospital Commission

The work of the FHC took place against a backdrop of considerable concern – at the RCP and nationally – about 'the challenges facing healthcare staff and the hospitals within

which they work, and the potentially catastrophic impact this can have on patient care'.¹ These concerns were reinforced by publication of the Francis inquiry reports (2010 and 2013) with the clarion call to 'foster a common culture shared by all in putting the patient first'.² The government's response confirmed that 'listening to patients and the public and responding to what they say is at the heart of a compassionate healthcare system. Patients must be involved and given a say at every level of the system'.³ PCN members were involved in all aspects of FHC work 'informing and developing its recommendations'.¹ The Future Hospital Programme (FHP) was set up by the RCP in 2014 following the launch of the FHC report, with the aim of supporting the implementation of the report's recommendations. This activity includes the work being undertaken by the FHP development sites. The FHC values, and the 11 principles of patient-centred care, provide a benchmark against which to evaluate the patient experience.

Patient involvement in the Future Hospital Programme development sites

Patients and carers can offer a constructive challenge to unpick the rationale behind current systems and to understand better the proposals for doing things differently. The presence of a patient in the room provides opportunities for a more constructive debate. The added value is that this contribution is viewed through the perspective of the patient.

For this reason, patient involvement has been fundamental to the FHP development site projects. Each development site was expected to have at least one local patient representative within their team. This was to ensure a patient perspective was present throughout the life of the project, offering a 'reality check' for clinical colleagues, being an integral part of decision making and being able to participate actively as the project evolved.

The involvement of PCN members in the service design and implementation activity within FHP development sites has been a new experience for both the RCP and the PCN. Expressions of interest were invited from PCN members, initially in the autumn of 2014, and by July 2015 all four development sites were benefitting from PCN involvement. One of the key roles for the PCN member attached to the individual development sites was to 'support local patient leads to contribute effectively and strategically to local plans'.

The experience of each of the local patient and PCN representatives, as well as the clinicians at each of the sites, has been different. To give a sense of what it has meant in practise to be involved, and what has been learnt through this

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experience, two stories of patient involvement are shared by the PCN member linked to the Betsi Cadwaladr University Health Board (BCUHB) and a clinician at Mid Yorkshire Hospitals NHS Trust.

C@rtref: CARE delivered with Telemedicine to support Rural Elderly and Frail patients

Making connections

The C@rtref project at BCUHC is focused on responding to the chronic health needs of older people living in rural and remote areas in north Wales by bringing specialist care closer to home. The team is using online virtual consultations to treat patients in their own community settings and avoid the need to travel to hospital.

The introductory phone conversation between the PCN representative and the clinical project lead was crucial as a first step towards involvement through information gathering and sharing. On reflection, the onus was on the PCN representative to identify information and documentation to ensure smooth integration into the project team. Nonetheless, this information provided the opportunity to learn more about C@rtref, to ask for a copy of the project bid papers and to request any supporting materials; for example, a copy of the frailty assessment document being used to select patients for inclusion in the project. There was also the opportunity to address any curiosity the team might have about who they had assigned to them, through a sharing of personal and professional connections with north Wales. Initial email contact was also made with the local patient representative.

The project documentation was essential background reading. The statement that 'patient experience is valued as much as clinical effectiveness' was supported by the intention 'to use co-production methodology where ever possible to improve the patient experience'. BCUHB provided a summary of the considerable work that had been undertaken to engage with, and listen to patients and other interested partners. This had included seeking views on the introduction of virtual consultations. The RCP Wales paper, *Rising to the challenge*, published in 2015, sets the Future Hospital aspirations into a Wales context and promotes the use of telecare and teleconsultations to improve care and support for people with chronic conditions.⁴

Furthermore, attendance at the Future Hospital Symposium (Acute Medicine Study Day) in north Wales in February 2015 was a chance to get a broader overview of acute medicine in the region, to hear more about the C@rtref project and to meet the project manager and clinical leads. Most importantly, it also provided an opportunity for conversations with the local patient representative and the digital inclusion officer (DIO).

BCUHB was fortunate to have a patient representative with considerable previous experience of involvement in patient-centred initiatives in Wales.⁵ During the setting up phase of the C@rtref project he had visited clinics to assess facilities and piloted the virtual consultation experience. He also co-wrote the bilingual patient satisfaction questionnaire with a clinical colleague. The DIO shared his involvement in supporting patients to use the video link and to gather initial patient experience feedback through the use of the post-consultation questionnaire.

Sustaining patient involvement

The past year has been a time of turbulence for the trust and the project team staff and BCUHB is now in special measures, which adds to the pressures. In conversation with the local patient representative it became apparent that despite his continued enthusiasm and commitment, he was not finding it easy to stay up to date with the rest of the team. His clinical colleagues could interact on a daily basis and could then make ad hoc decisions. Proposals to reintroduce occasional formal briefing sessions were discussed as an essential support to reengagement and support for patient involvement. The local patient's presentation at the learning event hosted in north Wales was a timely reminder of the importance of recognising the skills, experience and wider knowledge that patient representatives can contribute to the team, in addition to their personal experience as a patient and carer.

In recent months, while the C@rtref project has been able to continue, albeit at a slower pace than originally anticipated, sustaining patient involvement has not been easy. The local patient representative and the DIO had worked together to support the introduction of a bilingual patient satisfaction survey for the virtual consultations. When the funding for the DIO post came to an end, the local patient representative strongly advocated a reappointment to this post in order to ensure ongoing support for patients and staff involved in the virtual consultations. He also considered this role essential for maintaining a consistent approach to the administration of the surveys and encouraging patients to share their experiences. BCUHC has now identified people with digital inclusion experience and is in the process of bringing this expertise back into the team.

Sadly for the team, the local patient representative decided to step down. While a new local patient representative was being recruited, the PCN member maintained contact with the clinical team and supported and promoted the search for, and recruitment of, a new local patient representative. The new patient representative has now been welcomed into the team. The PCN member and the RCP FHP coordinator have put together an induction programme of conversations, on-site visits, and background reference material to introduce her to the RCP, the FHP, to C@rtref and to the network of patient representatives who can support her active involvement in the virtual consultation service.

Throughout the project so far, the aim of the PCN member has been to stay in touch with, and offer support to, the local patient representative. Acting as a 'critical friend' for clinical colleagues has included providing honest feedback and asking questions that may cause ripples and give pause for thought and action, described by a team member as an occasional 'nudge'. The relationship is one of mutual respect and a shared determination to make sure C@rtref is a success.

Mid Yorkshire Hospitals NHS Trust – partnership working to achieve a goal with patients

In 2013, the Mid Yorkshire Hospitals NHS Trust announced its plans to reconfigure its services to improve clinical outcomes, save lives and provide high-quality care. As part of these plans, the development of acute services for frail and older people was discussed publicly. Patient experience and public and patient

involvement representation was deemed vital to the Future Hospital project group, in order to ensure ongoing critical review of the project with a patient focus. There was a delay in identifying a suitable local and PCN representative. This meant that, initially, the group was very clinically focused on its objectives, which were to establish a model of care and business plan, given the financial and staffing constraints within the trust.

In creating the new team and look at Future Hospital models of care, the time lapse was useful as it allowed the dynamics within the new team to settle. However, the team lacked the patient focus needed for such a project to succeed and was immersed in facts and figures rather than looking at the impact on individual patients. Patient involvement during this period could have provided the missing link in stabilising the team as well as ensuring better partnership working early on. On the other hand, given the project itself was in a frail position at the start, patient involvement may not have been effectively and successfully supported.

At Mid Yorkshire, the appointment of the local and PCN representative at the same time has been vital in giving the confidence for both to feel at ease within the team and vice versa. They have quickly become integral team members and, in particular, have been key in creating the patient information leaflet and posters (Fig 1) that explain the role of the Rapid Elderly Assessment Care Team. In particular, they shaped the style of the leaflet and gave families and patients ownership of the leaflet by introducing a communication section, which clinical members of the team had not considered.

Recently they have been instrumental in reviewing feedback from patients using the service. They plan to carry out the

feedback themselves in 2016 and speak to patients and their relatives to gain even more insight into the patient journey and thus prompt ongoing improvements to the team.

No acute trusts stand still and at Mid Yorkshire, during this sea of change, organisational pressures have at times resulted in the cancellation of meetings. Indeed, when setting up the links with the patient representatives, it was decided that one of the managers would link the patient representatives with the team and ensure non-biased feedback was obtained. The idea behind this was to ensure its sustainability, particularly at times where organisational pressures are high, especially for clinical staff. However, this role has now been shared between a manager and a clinician as it was soon realised that there was great vulnerability to failure if only one person was the link between the representatives and the team. Plans for the project evolve on a weekly or even daily basis and thus communication is vital to ensure partnership working and the project's momentum. Without this, weaknesses within relationships and partnerships can begin to show and this can quickly lead to disengagement.

Patient involvement: reflections and recommendations

Involving local patients and PCN members in service design, monitoring and evaluation is a new learning experience for the RCP and the PCN. It has been suggested that such activity represents a cultural shift in patient involvement. Patients 'must make the transition from being mere "users and choosers" to being "makers and shapers" of health services'.⁶

Patient involvement, whether for the local representatives or for the PCN members, continues to be a challenge, not only for



Fig 1. Patient information leaflet and information posters co-produced for use at Pinderfields Hospital, Wakefield. Reproduced with permission.

the individuals concerned but also for the RCP and the project teams. Effective patient involvement is best achieved using a four-way collaboration between the RCP, the project teams, the local patient representative and the PCN member. Good public and patient involvement is dependent on there being shared goals, a shared understanding of roles and responsibilities, shared accountability to make things happen and, overall, a supporting of others to make a difference.

Clarity about the expected roles of the patient representatives is essential. It allows sites to have flexibility in supporting patient involvement that best fits their local circumstances. To be effective, clinicians and patient representatives need to build relationships based on trust, mutual respect and openness. Project sites need to give thought to how relationship building can be facilitated, what they expect from the patient representative and how they plan to support and sustain their involvement. In achieving this, helpful practical guidance is available from NHS England.⁷

Informal conversations with local patient representatives and PCN members have provided the chance for reflection on their experiences of involvement. The general view was that support and encouragement for them to become part of the development team has to be considered from the very start of the project and, thereafter, to be kept under review as the project progresses. Where organisational pressures deflect attention to other priorities, it is important to find ways to remain focused on the development project activity and to continue to support the involvement of the patient representative.

When local patient representatives have felt engaged and have a shared sense of purpose, their contribution to the progress of the development projects has been significant (Box 1).

The development sites have benefited from shared learning events where colleagues from the RCP, patient representatives and PCN members have been present alongside the clinical teams. As well as catching up on work in progress in the individual projects, these forums have provided opportunities to encourage informal networking for patient representatives and the PCN members, as well as for the clinicians. They have also provided opportunities for patient representatives, PCN members and members of the clinical teams to hear from experts in relevant fields, including Annie Lavery (director

Box 1. Patient involvement in action at the Future Hospital development sites.

- > Ensuring a 'think patient' perspective is integral to project meetings and Future Hospital Programme learning events.
- > Co-producing project specific information leaflets for patients and families.
- > Co-designing virtual consultations.
- > Recruiting, training and supporting volunteers to pilot the Future Hospital patient experience surveys.
- > Providing feedback on the patient experience surveys and proposing improvements, including site-specific tailored questionnaires.
- > Sharing good practice and ideas across the projects through informal networking and mutual support.

Box 2. Patient leaders.¹¹

'Patient leaders are people who invest their time and resources to influence decision making at a strategic level that improves care experience. They are people with valuable health and care related expertise, with strong empathy created by their own experiences, resources and ideas to make an active contribution to improving the experience of care and the health and well-being of others.'

of patient experience in Northumbria), which has helped to inform the projects.

Professional journals and research papers provide insights into the journey of patient and public involvement in healthcare to date, and seek to understand the dynamics involved.⁸ Recent publications reflect on the changing language of involvement.^{9,10} In particular, NHS England, and others, have promoted the recognition of patients as leaders who, through their involvement in strategic planning and service design, are able to make significant contributions to improving health and social care (Box 2).¹¹ This may well be a role that can evolve from, and be nurtured by, patient involvement in the RCP FHP.

Whatever models of involvement are developed and however the language changes to describe patient involvement, the key message from patients and carers remains constant: the purpose of involvement is to improve services and the patient's experience of care.

Recommendations

The inclusion of PCN members in the selection process for the second phase of Future Hospital development sites has provided an opportunity to share our learning and to enable an improvement in the patient involvement experience. We encourage readers embarking on projects involving patients to ensure the following steps are taken:

- > Ensure patient representatives receive an effective induction to their role, the team, the project and the organisation. This information must be provided in a way that is accessible and suits the needs of patient representatives.
- > The onus should not be on the patient representative to identify relevant information or people; this delays effective relationships from being formed and consequently delays meaningful involvement.
- > Project teams must agree on who can take decisions and when. 'Corridor conversations' between clinicians, leading to ad hoc decisions being taken, risk isolating patient representatives and may lead to decisions that are not sufficiently informed by the needs of patients using the services.
- > Patient representatives must be involved from the start of projects to ensure that the aims of the work align with the real needs of people using the services and patient representatives are truly equal partners in the project.
- > Patient representatives must be kept informed like any other member of the team through, for example, inclusion in email circulation lists and meeting invitations. Their inclusion in project meetings is vital to ensure the project remains faithful to the underpinning principles of patient care and that communication is maintained with the team.

- > Clinicians and patient representatives must both take responsibility for building trusting relationships. Careful thought needs to be given to how relationship building can be facilitated. Without trust and open engagement, patient involvement will not be effective.
- > Clinicians must be flexible in their approach with patient representatives; this means considering the technical language they use and how to make people feel welcome and at ease in clinical environments.
- > Where organisational pressures deflect attention to other priorities, it is important to find ways to remain focused on the development project activity and to continue to support the involvement of the patient representative. ■

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