

Coordinated care: a patient perspective on the impact of a fragmented system of care on experiences and outcomes, drawing on practical examples

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ABSTRACT

The NHS has been on a journey of major structural change since its first significant reorganisation in 1974. In recent times, the emphasis has been on developing the market philosophy first introduced by Margaret Thatcher in 1989. As service commissioning develops, and more providers join the market, many patients find the system difficult to navigate and complain of fragmentation in the delivery of care and of new services failing to provide the high quality of care they expect. This article examines the impact on patients of a fragmented system of care, drawing on some practical examples. If person-centred care is to become a reality across the NHS then collaborative approaches to commissioning and delivering care must be developed.

KEYWORDS: outcomes, clinical commissioning, person-centred, involvement and integrated

Organisational change and patient involvement

The NHS has seen significant organisational change over the past 40 years. The first major reorganisation in its history was in 1974 and ever since politicians have continued to introduce top-down reorganisations in the belief that the right structure and systems will deliver high-quality cost-effective care.

Because of unacceptably long waiting lists for treatment, a number of initiatives were introduced by the Blair Government in an attempt to alleviate the situation. In implementing these initiatives, it became clear to many that the lay patient input was needed if the delivery of high-quality safe care was to be achieved.

Importantly, the traditional system of ensuring good public consultation around service change was weakened by the abolition of community health councils (CHC) in England in 2003. Patients no longer had the option of seeking independent professional advice about healthcare services, including help in making complaints about poor standards of care. The abolition of CHCs marked a step change in how service reconfiguration was communicated to patients and created a vacuum in terms of giving patients a voice in how services were developed and

reconfigured at a time when more independent providers were entering the health market.

In 2011, the government produced a national document called *Working together for a stronger NHS*.¹ This document advocated giving greater power to healthcare professionals rather than NHS managers. It proposed opening up the NHS to qualified providers and giving local communities a greater say in plans for service change. Many organisations had realised that a consistent approach to person-centred care was required.

Surprisingly, successive governments have pursued the market philosophy and the reforms introduced by Andrew Lansley were, to say the least, the most controversial since the introduction of the internal market by Margaret Thatcher. These reforms were seen by many as removing the ability of the NHS to plan strategically and the transfer of public health to local government is in great danger of marginalising public health physicians at a time when 'healthy living' has never been more important. Many recall the 1974 NHS reforms, when public health was brought into the NHS, as it was not able to influence wider health policy from its position within local government.

In recent years, politicians from all parties have stressed the need for patient, carer and public involvement in all aspects of care delivery. The focus has been on shared care, with patients having a greater say in the direction of their personal care plans. Encouragingly, many services are responding well to greater patient involvement; unfortunately, the policy agenda seems heavily focused on cost reduction and market principles, which often make the delivery of person-centred care difficult. Continuity of care, especially for those with long-term conditions, is a major concern for patients but, again, this becomes difficult to achieve under the current organisational arrangements.

Implications for patients of fragmented systems and services

Although the health policy focus is on person-centred care, the fragmented nature of current service commissioning and delivery often leads to problems for patients in practice, as the following case studies demonstrate.

The attempt to reduce waiting lists for joint replacement surgery led to very different approaches to service delivery.

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In some areas of the UK, private surgical teams were brought in from other countries, performing joint replacement surgery in mobile theatres. Initially, this did help to reduce the waiting lists but did it benefit patients and was it more cost-effective? It came to light that some of the surgical teams were unfamiliar with the prosthetics used in the UK. Many prosthetic hips were fitted incorrectly and some patients were left unable to walk and needing NHS treatment to put things right. Quality and safety standards had been lowered and patients had suffered. Even when the surgery went well, the surgical teams went back to their home countries before adequate post-surgery follow-up had been completed.²⁻⁴ The concept of having whole person-centred care and ensuring that patient care was seamless was denied to many patients by this model of service provision.

A second example of a fragmented system of care concerns a patient with long-term care needs who, in 2004, went to see a new GP at her surgery complaining of symptoms of a urinary tract infection. As this patient was new to this GP, he referred her for diagnostic tests even though she was known to suffer from systemic lupus erythematosus (SLE). The referral was made to a privately commissioned service over 10 miles away from her home. Following a cystoscopy and other tests, this patient received a letter from the session physician explaining that all was fine. The physician had no access to her hospital file. The contract had been fulfilled, he had done the tests and, for an average patient, the service had been delivered. However, this patient continued to have problems and at her regular SLE review she was informed that she should have been seen by the multidisciplinary team, which includes a renal specialist. The patient was treated immediately and things started to settle. This situation occurred because all patients were viewed in the same way when diagnostic services were being commissioned from external providers. This example highlights the need for continuity of whole person-centred care for those patients with long-term conditions.

The following contrasting stories demonstrate how fragmented services and breaking down care to a level that deals with people in episodes of care creates an obstacle to the delivery of person-centred care.

- In 2012, a rheumatology patient receiving immunosuppression therapy for sinusitis was referred to ear, nose and throat services (ENT) at her preferred NHS Trust. All of her care was delivered within the trust. The ENT diagnostics were performed and her sinusitis was believed to be caused by her immunosuppression. The patient was treated appropriately and her rheumatologist, immunologist and ENT specialist were communicated with as a team.
- In 2015, the ENT problem returned and a new ENT referral was made. However, the commissioning of this service had changed and a different NHS trust was responsible for delivering ENT clinics at four health centres. The patient asked about the commissioning process but couldn't get any information. After weeks of investigation, she was informed that a junior doctor now ran the clinic surgery for new referrals. The doctor worked for a neighbouring trust while the patient's care had in the past been provided elsewhere. This doctor did not have direct access to the patient's hospital record or diagnostic results and the patient was extremely worried by the splintered approach to her care. The patient

asked the question 'when a new referral is made does the choose and book lead consider existing long-term conditions before arranging care and does the patient have any choice?' The outcome was that this patient was placed on the ENT waiting list at the original hospital of treatment after already waiting 6 weeks.

The fragmentation of public health

The 2012 NHS reforms transferred responsibility for public health to local authorities, despite public health being unable to influence wider health policy when it was last part of local government pre-1974. The transfer to local authorities has raised significant concerns about the capacity of public health services to meet future demand for treatment and provide adequate training in the specialty to deliver high-quality care in the long term.

Treatment services for sexually transmitted diseases moved with public health to local government and most services have been subject to market testing with many being transferred to new providers. Local authorities have been, or are in the process of, rationalising many of these services and within genitourinary medicine there are real concerns about meeting future demand for treatment and providing adequate training in the specialty to deliver high-quality care in the longer term.

Some local authorities have limited access to testing and treatment for sexual transmitted infections by age; particularly worrying is the split from specialist HIV services and the danger of patients being denied comprehensive and integrated care across the NHS and public health services. The links between services, such as those between genitourinary medicine and HIV testing/treatment are in danger of being broken with serious consequences for patients. In addition, access to HIV prevention services is threatened by loss of support grants to local community and voluntary sector organisations, while the reorganisation of public health has created uncertainty and disruption to training, recruitment and retention of skilled public health staff.

Conclusion

Is this really what clinical commissioning is trying to achieve? A system that is so fractured and where payments are based on outputs ('bottoms on chairs/beds') and not on whole person-centred care aimed at driving quality and safety. Surely we should be moving to a system of commissioning outcomes that are not only relevant to clinical conditions but also to factors of importance to the patient?

One member of the Royal College of Physicians Patient and Carer Network explained that 'it feels as though commissioners look at people as if they are made up of a number of parts that can be isolated, repaired, put back and the case is complete'.

There is an impact on the whole person and a price to pay if attention is not paid to the whole person during service provision. As the focus moves towards whole person-centred care, quality and safety, there are a number of implications for commissioners to consider. There needs to be emphasis on training and continued professional development and this requires the ability of clinicians to share and learn together across physical and professional boundaries.

The Francis report⁵ following the Mid Staffordshire NHS Foundation Trust Inquiry made over 200 recommendations with much focus on splintered systems, staffing levels, leadership and personal/professional development. It posed the question ‘how do we start to include the softer patient information and feedback’ in future planning and how do we measure compassion, empathy, and going the extra mile?

When commissioning and designing services, we frequently ask the question ‘what do we need and what are the essentials’? Perhaps the question we should ask patients is ‘what don’t we need’? In response, countless patients would say that they don’t wish to feel as if a door slams and you are locked out of care at the point of transfer, unfortunately still called discharge. As a patient, it is very frightening to sit in a waiting room knowing the staff are no longer responsible for your care. The gap between monitoring and receiving ongoing care is life in a wilderness. Falling between health and social care organisations is worrying to say the least.

Having to re-enter the fractured system is daunting. Having to repeat history and teach clinicians about how your condition impacts on your life is tedious. A seamless commissioning and service delivery with access to the patient’s records and the patient having in their possession their summary health record would be life changing for all.

It is time to really involve and understand the needs of the whole patient. My ankle bone remains attached to my leg

bone, as it should be. Here’s to whole person-centred care and patient involvement in commissioning and redesign of services. ■

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