Undermining patient and public engagement and limiting its impact: *The consequences of the Health and Social Care Act 2012* on collective patient and public involvement

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Abstract

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Patient and public involvement has been at the heart of UK health policy for more than two decades. This commitment to putting patients at the heart of the British National Health Service (NHS) has become a central principle helping to ensure equity, patient safety and effectiveness in the health system. The recent Health and Social Care Act 2012 is the most significant reform of the NHS since its foundation in 1948. More radically, this legislation undermines the principle of patient and public involvement, public accountability and returns the power for prioritisation of health services to an unaccountable medical elite. This legislation marks a sea-change in the approach to patient and public involvement in the UK and signals a shift in the commitment of the UK government to patient-centred care.

The UK has been in the vanguard of the promotion of patient and public involvement (PPI) internationally. Nationally, there has been a long history of this agenda which is often traced to the founding of Community Health Councils in 1973.¹ This changed dramatically and accelerated following the Health and Social Care Act 2001 that created new statutory duties on NHS organizations to demonstrate engagement with patients and the public in services evaluation, development and delivery. Successive legislation has elaborated the specification and responsibilities of NHS providers and created different local mechanisms to enable involvement; PPI forums (2003) replaced by local involvement networks (2008)

and now replaced by local Healthwatch (2012). The recent Health and Social Care Act 2012 is a retrograde step in the opportunity for patients and the public to hold accountable those who plan and deliver health services in England.

Does patient and public involvement make a difference?

There is an extensive literature documenting particular patient and public involvement (PPI) projects but far less evidence of the impact of PPI on prioritization or commissioning of services. Recently, the UK Department of Health (DH) has published a spread

sheet to support organizations to present a 'Business Case' for public and patient engagement.² This approach assumes that the costs of PPI will be recovered based on money that is saved through suggestions identified in involvement exercises. This may well be the case but many of the benefits of involvement – increased trust, greater understanding of the health system and condition, improved self-management, accountability for clinical and managerial decisions – do not bring explicitly identifiable financial benefits. Indeed, many of the benefits are likely to be realized in the future or in relation to reputation and knowledge and are likely to go beyond particular individuals. A different way of conceptualizing PPI is to consider it a mechanism to identify and generate public value and legitimacy.^{3,4}

Patient and public involvement: moving from local involvement networks to healthwatch

Local involvement networks (LINKs) were created under the *Local Government and Public Involvement in Health Act 2007* in each of the 152 local authority areas across England. This new model for involvement was based on the interaction between networks of local community and voluntary organizations and interested people within a defined local authority area; involving people based on localities rather than National Health Service organizations. LINKs were charged with bringing together the experiences and expectations of local people to evaluate and improve local health and social care services. They were not an inspectorate but a source of intelligence about what the experience of service users, and what the priorities for health and social care services should be. Most importantly, all those responsible for commissioning – prioritizing and contracting – services were required to engage with patients and the public and their local LINK when arriving at decisions. The new commissioning arrangements make no mention of local Healthwatch organization and the requirement

to involve patients and the public in commissioning NHS services is vague.

The Health and Social Care Act 2012 transforms the process for commissioning health and social care services. Framed as promoting local determination, social care services will be commissioned by local authority Health and Wellbeing Boards. These boards will include a representative of the local Healthwatch and normally be chaired by the Director of Public Health (DPH) who is now appointed by the local authority; it appears that DPHs will be 'performance' managed by both Local Authority Chief Executives and Public Health England. Health and Wellbeing Boards are required to have at least one representative from the local Healthwatch and are responsible for overseeing both the joint strategic needs assessment (192) and the Joint health and well-being strategy (193) the latter prepared with the local clinical commissioning groups (CCG). In the development of both the assessment and the strategy the local authority must 'involve the local Healthwatch organization for the areas...involve the people who live or work in the area'.⁵ The process of these two will be supported by a representative of the NHS Commissioning Board.

Local Healthwatch organizations will be performance managed by Healthwatch England which is a committee of the Care Quality Commission. It remains unclear who will make up Healthwatch England but they will give general advice and assistance to local authorities, the Secretary of State and the NHS Commissioning Board on 'the views of people who use health or social care services and of other members of the public on their needs for and experiences of health and social care services'.⁶ In fact the Act goes further, turning a body which in previous incarnations had sought to influence the provision of health and social care services for the local population through those responsible for planning and commissioning services in to a body that now is intended to promote choice. All local Healthwatch organizations are responsible for 'providing advice and information about access to

local care services and about choices that may be made with respect to aspects of those services'.⁷ The voice of the local community is further stifled as the legislation prohibits local Healthwatch organizations from 'the promotion of, or opposition to, changes in—(i) any law applicable in the United Kingdom or elsewhere; or (ii) the policy adopted by any governmental or public authority in relation to any matter'.⁸ More recently this has been clarified by the DH who now suggest that local Healthwatch organizations will not be prohibited from 'advocating a change in the law or policy, provided it is based on evidence, is genuinely in connection with its community benefit activities; and that such campaigning or activities do not become the organization's main focus or activity'.⁹

Patient and public involvement and clinical commissioning groups

Public and patient involvement in relation to health services now becomes the responsibility of clinical commissioning groups (CCGs). Equally emphasized is the importance to involve individual patients and even more to promote patient choice. Indeed, CCGs have a duty to 'act with a view to enabling patients to make choices with respect to aspects of health services provided to them'.¹⁰ But individual choice is different from involvement. Patient choice is constrained by information and most importantly what options are available; under the new commissioning arrangements options will be more varied at local level. Collective involvement in commissioning should be about applying common priorities to define those options, which are different from the aggregation of individual choices.

Local Healthwatch organizations have an established footprint and typically local people who have been actively involved in Community Health Councils, Patient Forums and LINKs are still involved. But, the input of local Healthwatch organizations is mostly circumscribed; any observations on NHS services must be fed to Healthwatch England. By

choosing not to specify that involvement mechanisms in CCGs should incorporate local Healthwatch organizations, the Act undermines the existing mechanisms for collective action and requires each CCG to develop their own model of involvement.

Those developing involvement in health services in the CCGs are clinicians and predominantly GPs and are likely to have only limited expertise in PPI. Indeed, a survey by the National Association for Patient Participation reported that only 38% of GP practices had any organized patient involvement.¹¹ Similarly, a Picker Europe survey of PCTs exploring PPI in commissioning found that involvement was primarily used to collect data for commissioning using surveys and one-off consultations, rather than to influence what services should be commissioned.¹²

Accountability to patients and the public

There appears little local accountability for the commissioning decisions made by CCGs. Instead, while commissioning decisions are supposed to be justified on the basis of the joint strategic needs assessment, the accountability for the actual commissioning is only upwards to the NHS Commissioning Board (now renamed NHS England) not outward to local people. Health and Wellbeing boards can give NHS England its opinion of whether a CCG commissioning plan takes 'proper account of the health and well-being strategy',¹³ but this is a very weak and indirect form of accountability. Each CCG's Constitution must include a statement on arrangements for involvement and principles underpinning implementation. It is unclear how or if CCG's duty to involve patients and the public will be monitored or evaluated.

In some ways, this misses the point of patient and public involvement. PPI is not simply about a mechanism for those who pay and receive health and social care services but is also a way to exercise accountability – to create a dialogue between the different kinds of knowledge that are relevant to identifying health-care needs and expectations. The biggest

challenge to the NHS in the next 20 years is the increase the population where multiple morbidities are the norm.¹⁴ This is a challenge that we – the public and the NHS – must face together. PPI creates a way for us to have a dialogue about what we want and need to promote well-being and to hold to account the politicians, health-care provider organizations and patients. The Health and Social Care Bill erodes public ownership of the NHS, a key mechanism that drives the coproduction of well-being now and in the future by weakening PPI and strengthening individual patient choice. We may be all in this together, but the model of the NHS presented in the Health and Social Care Bill makes it more difficult to think of the ‘we’.

The Health and Social Care Act 2012 dilutes PPI, renames and weakens LINKs and reasserts a separation between health and social care. Those with the responsibility for commissioning NHS services, the CCGs, have a statutory power to ‘do’ PPI as part of discharging their commissioning functions but have no requirement to involve the Local Healthwatch, little experience and no accountability to local people for how they will do this directly or through the local authority Health and Wellbeing Boards. The Secretary of State for Health has pledged ‘First, that patients must be at the heart of everything we do, not just as beneficiaries of care, but as participants, in shared decision making. As patients, there should be no decision about us, without us,’¹⁵ the question remains whether such statements are merely rhetoric or will be made a reality and more importantly how will we know.

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