

"I have trawled through and captured what was said explicitly about HW or patient involvement.

Please understand that there were hours of debate and I have merely extracted these bits in the order they came along.

Apologies to their Lordships for any apparent dislocations.

Regards,

*Ruth Marsden
National Association of LINK Members (NALM)"*

Email: Friday, 14 October 2011

Earl Howe: Real accountability to the patient will be achieved in a number of ways. It will be achieved by empowering patients with information and involving them in decisions around their care. But it will also be achieved by empowering local groups of patient representatives to be involved in how services are commissioned, provided and scrutinised. Clauses 178 to 186 propose the creation of HealthWatch. Local HealthWatch will be based on the existing local involvement networks, or LINKs, but with added clout. Funded through local authorities, they will act as the independent eyes, ears and voice of patients and service users in a local area. At the national level, a new body, HealthWatch England, will be established to support local HealthWatch and to act as the national care watchdog wherever quality of care is called into serious question. By making HealthWatch England a committee of the Care Quality Commission, as is proposed in the Bill, we will enable the voice of patients and the public to be heard at the very heart of health and social care regulation.

Baroness Anelay of St Johns: My Lords, it may be helpful to the House if at this stage I give some guidance on an advisory speaking time. There are 100 speakers signed up for the whole of the debate, including the Front Bench spokespersons. If Back-Bench contributions were kept hereafter to eight minutes, the House should today be able to rise at about 11.30 pm.

Baroness Jolly: There are three distinct areas for patient involvement. First, at the time of a consultation with a professional they need to be involved in their care plan and look at any options. There is evidence—there has been a lot said today about evidence—that 75 per cent want involvement and that if they become involved they do better. Incidentally, that goes some way towards reducing health inequalities. This needs to start upstream and it needs to be built into commissioning.

Secondly, we can look at a patient as an expert patient, offering insight and reflection in how their experiences can help the care of others, as can patient organisations. Again this needs to be built into the commissioning process, into senates and into local networks. Finally, as a member of a local healthwatch or HealthWatch England, these replaced the old LINKs groups and, as yet, do not have a sufficiently robust structure with the ability to challenge. Here I disagree with the Minister. They do need more clout.

The Lord Bishop of Bristol: I have an anxiety about the complexity of the NHS structures that will be created by the Bill. Part of the rationale for reconfiguring the NHS was to simplify its structures and management. At present, the Bill envisages a health service that has a much more complex structure and a greater array of interlocking organisations than before. In addition to the Secretary of State, whose function is to become one of oversight rather than of direct involvement, the new look NHS will encompass the NHS Commissioning Board, clinical commissioning groups, health and well-being boards, Monitor, the Care Quality Commission, the National Institute for Health and Care Excellence,

HealthWatch England, Public Health England, clinical networks and clinical senates. In addition, local authorities will have direct input into both public health and the proposed health and well-being boards.

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Baroness Thornton So we are keen to scrutinise this Bill: we support the greater involvement of clinicians in commissioning; we support the devolvement of public health to local authorities with the right safeguards and financial support, and independence at a national level; and we support the creation of health and well-being boards and local accountability. We believe that the Bill needs to enhance the patient's voice because we think that that is very inadequate at the moment. We believe that accountability and transparency need to be addressed from top to bottom of this Bill.

Baroness Jolly: I must have sat through hundreds of board meetings, not to mention audit committees, clinical governance groups and remuneration committees. They were all about the structure of the NHS. There were times, as we discussed systems and processes, that the patient never got a mention and was certainly rarely there at the table.

By their own admission, the Government want to put the patient at the centre of the NHS-"No decision about me without me" is a laudable and catchy strap line. We welcome that, but I fear that at times this patient is still sidelined.

We can look at a patient as an expert patient, offering insight and reflection in how their experiences can help the care of others, as can patient organisations. Again this needs to be built into the commissioning process, into senates and into local networks. Finally, as a member of a local healthwatch or HealthWatch England, these replaced the old LINKs groups and, as yet, do not have a sufficiently robust structure with the ability to challenge. Here I disagree with the Minister. They do need more clout.

Bishop of Bristol The whole needs of patients and others must be met through the provision of comprehensive services. This includes, among other things, meeting their spiritual needs. For many people, spiritual needs may be met only through the provision of religious care. Chaplains are uniquely trained and qualified to provide both religious and spiritual care and, as such, it ought to be explicitly understood that both commissioners and providers should take into account the need for spiritual care where appropriate.

Baroness Bottomley of Nettlestone: Patients are not mild, obedient, good and kind and are not as deferential as they were in the past. There are more hits on the internet on health than on any other subject. Patients are experts. They go to see their doctors and say, "I have looked you up on the internet and these are the research papers I have seen. Why haven't you produced this or that?". It is a totally different relationship-a partnership. It is a good relationship but it is a very different world, particularly if you are a clinician. The development of HealthWatch and the information available for patients has got the balance right.

Baroness Billingham I have no competence compared to them, but I can and will speak on behalf of those who have no voice here and who have written to me in their dozens, and on behalf of those who will rely on the NHS for their health provision in the future.

At the end of my tenure as chair of the Mental Health Act Commission, I was responsible for seeing it merge into what is now the Care Quality Commission. I continue to watch the CQC closely. The merger was designed to simplify the regulatory landscape, but the Bill seems to create yet more complication. Under the Bill, Monitor and the Care Quality Commission have oversight over service providers, but responsibility for overseeing commissioning will lie with the newly created NHS Commissioning Board. So we are back to having different bodies monitoring different aspects of health and social care.

In the case of the CQC, the Bill further reduces its independence: Clause 287 requires the Secretary of State's permission for the CQC to conduct special reviews. The Health Service Journal reported, on 6 October, that according to the CQC's own internal review, doubts have been expressed that it can sustain its current workload.

The CQC has a third less funding than those bodies it replaced and has had to cut generic inspections by around 70 per cent last year because of pressures in registering services. It is currently being asked to cover 18,000 care homes and 400 NHS trusts and will now be asked to take on responsibility for GP practices and the yet-to-be-determined number of "any qualified providers" who may be pressing for registration, all of which will once again distract the CQC from its vital inspection role.

Lord Patel of Bradford I am pleased to see that, so far, the CQC has not reduced its visits to detained patients. It must be congratulated on that, but I question how that can be sustained, given the immense additional pressures to be produced under the current proposals in the Bill. I would like to be assured, if the Minister can, that the gains envisaged in the merger of the Mental Health Act Commission, the Healthcare Commission and the Commission for Social Care Inspection will be realised. We do not want any more horrors like Winterbourne View in mental health services. I hope that noble Lords will recognise the immense amount of work that is still to be done, and that the Government will concede that we must take the appropriate time to do that. Failure to take that time will risk lasting and, most importantly, irreversible damage to one of our greatest post-war achievements: a National Health Service that works in the interests of patients and the public, not in the interests of ideology.

The only barometer I need to test the benefits of the Bill is whether it makes a difference to patients. Like others, I have had the opportunity to speak to the Minister about my anxieties and expectations over the way forward, and like others, I was treated with warmth and politeness. However, we need action now. I have received lots of correspondence, as have most other noble Lords, from all kinds of organisations and individuals. I am not sure whether I am unique, but I was privileged to have discussions with groups of staff and patients from my hospital when I advised them that I intended to speak in this debate. They asked for a meeting and I was delighted to provide it. They told me that they had some worries about parts of the Bill.

They were not sure what the new structures that they were required to work in meant but thought that they looked complicated. They said that they had just got used to the reorganisation of commissioners, which seems to be working well. What does this mean in the new regime that is proposed by the Bill?

Baroness Wall of New Barnet More than anything, what they want from the Government is clarity about the importance of patient experience and the emphasis on whether patients should come into hospital or be treated in the community. That emphasis is not as good and deep in the Bill as it should be. I am sure that the Government are concerned about patients' experience. I urge all of us to use the time that we have not only to persuade the noble Earl, Lord Howe, that we believe that he cares and wants better healthcare, but to listen further to suggestions to improve the Bill. What everybody said to me was,

"Please, Baroness Wall, whatever you do, don't kick this into the long grass". We do not need to do that, and I have no intention of voting to do so.

Baroness Masham of Ilton How is the patient voice to be heard? It is important for special groups such as Diabetes UK, and patients' groups such as the Spinal Injuries Association, the Patients Association and hundreds more, to speak out and be heard. The Government are setting up HealthWatch. It would have been helpful if Governments had built on community health councils, but this was not to be. Health forums were set up and then closed down. Then came LINKs, which few people have heard of and are not well supported. It is felt that HealthWatch should be independent of local authorities and the CQC if it is to be an effective body representing the public's interest in the NHS and social care. HealthWatch England must be an accountable and democratic body, and some of its members should be elected from local HealthWatch bodies. Local HealthWatch must be seen by patients and the public-and particularly by users of social care services-as being independent and serving their needs. If local HealthWatch is made accountable to its local authority the public will have no confidence that it will stand up for and represent them when things go wrong.

The lessons should be learnt from Mid Staffordshire NHS Foundation Trust and the numerous care homes that have become places of oppression and agony for the residents. HealthWatch cannot be both champion of the public and poodle of the local authority. It is essential that primary and secondary health work is done in co-operation, and that pharmacists are involved. They are concerned that currently in the legislation provision for clinical commissioning groups to obtain appropriate advice is too vague. I hope that your Lordships will be able to do what the House of Lords is good at, which is to improve this mammoth Bill for the good of the NHS and of those who serve in it and who use it.

Countess of Mar I will not say much about my concerns about the proposals for HealthWatch at this stage, except to say that there should be a smooth transition from LINKs and that it should be totally independent of local authorities and the Care Quality Commission. I know that noble Lords, including the noble Lord, Lord Patel, will be tabling amendments to that effect. Is the Minister aware that there is a long-standing charity of the same name? I fear that NHS patients may be confused and possibly disadvantaged. Can that conundrum be solved?

Baroness Hollins Enhancing patient choice is not quite the right answer in mental health, unless by choice we mean involving service users in designing and managing their own care pathways. Indeed, choice is often rather a hollow concept in mental health services, with so many patients being treated against their will. Mental health services work closely with local GPs and other agencies in the community. Increasing choice for our patients could actually hamper access to an integrated and safe service, and to continuity of care-especially as these services are already about both health and social care, and the co-terminosity of providers is important. Increasing the presence of the service user's voice is much more important than choice, and the role of an independent HealthWatch could be key.

Baroness Wheeler: My Lords, in this marathon of debates, I want to focus my attention on two of the key issues that I will be leading for on behalf of the Front Bench. These arise from Part 5 of the Bill, and it is clear from the debate so far that they are matters which will absorb much of your Lordships' attention in the coming weeks. First, I refer to the issue of how patients' voice and involvement can be truly embedded into the Bill, and, secondly, how we might ensure that the Bill promotes integration across the NHS, public health and community and social care and gives impetus and encouragement to the progress that has been made over the past few years, despite the difficulties and obstacles that can be faced joining services up to the benefit of patients and carers.

In the 15 September debate in your Lordships' House on the implementation of the Future Forum recommendations, which noble Lords variously described as an overture or limbering up for today, my noble friend Lady Pitkeathley described reflecting patients' voice in health and social care as,

"enabling disadvantaged individuals-clients, carers and patients-to speak up for themselves and to contribute to policy formation".-[Official Report, 15/9/11; col. 873.]

This sums up in a nutshell what must arguably be the major priority if the laudable aim of "no decision about me, without me" is to become a reality for the majority of patients and clients. The Future Forum underlined the importance for the voice of patients and the public to be embedded in our health services, including the voices of children, vulnerable adults, carers and those who are often excluded. In evidence to the House of Commons Select Committee on the reconvened Bill, the chief executive of the mental health charity Rethink, Paul Jenkins, supported the need to,

"put patients and carers on the same footing as specialist clinicians in terms of the requirement to seek advice, so the advice of expert patients is as important in some aspects of long-term conditions as that of clinicians".

We support that aim, which, along with harnessing the collective patient view of such organisations as Rethink or the Stroke Association, will be essential if services that are high quality and sustainable in the future are to be designed. We will seek changes in the public involvement provision in the Bill to place greater emphasis on the proactive involvement of public and patients before decisions are made. I would also ask how lessons in future are to be learnt from the mid-Staffs experience, where we know that this collective patient voice was ignored.

It is clear from the contributions in the debate today that there needs to be much discussion and development to define what patient involvement and shared decision-making actually means at each level, and that the Bill as currently constructed does not deal with or address these issues and is in effect woefully inadequate in embedding the patients' voice into the new structures. From these Benches we will table and support amendments to the Bill which strengthen the emphasis on patient and public involvement in the structures of all local bodies, including foundation trusts, clinical commissioning groups and health and well-being boards. We will aim to get the current loopholes and get-out provisions, for example in the requirement for these bodies to hold public meetings, well and truly plugged. Health commissioners and providers must operate under the same standards of good governance to which local authorities and other public bodies comply.

We will also support the proposals from key patient groups to define what the duty under Clauses 20 and 23 to promote the involvement of each patient means, and the specific aspects of involvement that commissioners should promote. We will seek specific proposals in the Bill to recognise expert patients, carers and patient organisations as people from whom commissioners should obtain advice. As the Patient Voice has said:

"It is about commissioning care and treatment services in such a way that those services engage patients as fully as possible in managing and controlling their health and care".

How will the NHS Commissioning Board and CCGs be held to account for promoting patient involvement?

We also support the need for the establishment in the Bill of a duty of candour for any organisation providing NHS and social care, so patients and clients can be informed when things go wrong with their care and treatment, as soon as it is known, not after months of denial, legal obfuscation and cover-up. This is a new area of development, and I ask the Minister if the Government would support the provision of such a duty.

Finally HealthWatch England must have the teeth, strength and independence to be an effective patient champion. We strongly support the principle of a national body representing patients, with local outposts, but running alongside other measures which ensure patients and public are directly involved in decision-

making. We do not support HealthWatch England being a sub-committee of the Care Quality Commission, and will seek amendments to the Bill that delete this provision. We agree with members of the current Local Improvement Networks, LINks, that HealthWatch's role, work, independence and authority will be severely compromised if the proposed CQC relationship remains. Instead, HealthWatch's powers should be extended to enable it to make recommendations direct to the Secretary of State and to the various arm's-length bodies to which it relates. We will also be seeking to ensure that these bodies are required to respond publicly to HealthWatch. We will also seek to ensure that local HealthWatch organisations are properly resourced to undertake the important and key work that they will have.

Lord Harris of Haringey: My Lords, at this two-thirds point in this debate, I make no apology for focusing my remarks on Part 5 of the Bill, and the quality of the voice for patients that it offers. This Bill is likely to damage irreparably the National Health Service, creating a service that is less accountable and more fragmented; that is increasingly provided by for-profit organisations; and where the relationship of trust between doctors and their patients is undermined. Under such circumstances, an effective structure is essential to support patients in navigating their way through the new arrangements, to ensure that their needs and concerns-both individually and collectively-are not neglected in the brave new world of private suppliers feeding on the remnants of public provision. It is essential to guarantee that, with the democratic deficit that will now open up in health provision in this country, the impact of the changes is catalogued and drawn to the attention of those charged with regulating the new system, of Parliament and ultimately of the public who are paying for it.

I declare a former interest as someone who-for 12 years-was director of the Association of Community Health Councils, then the statutory body representing the interests of the public and the users of the NHS. The Government are now bringing forward another round of proposals to fill the void left by Community Health Councils when they were abolished in 2003. They were succeeded by patient and public involvement forums, which lasted four years before they were replaced by local involvement networks. Again, with a life of four years, LINks are to go, to be replaced by HealthWatch. The sequence of change in consumer organisations is a poor recommendation of the previous Government. I am shocked to see that the current Government are moving forward in a similar vein.

Of course, the Government's objectives are laudable: "No decision about me without me" is as resonant as previous rhetoric about putting the patient at the heart of the NHS or the mantras about patient empowerment 10 to 15 years ago. Some of your Lordships will even remember John Major's Patient's Charter-that daughter of the Citizen's Charter and that cousin of the Cones Hotline. How does the high-sounding rhetoric match up to the reality of this Bill? How far are patients going to be involved in decisions about managing their own care and treatment? It is simply not clear whether these are adequately safeguarded in the Bill. A duty to promote involvement or a duty to promote choice is not a sufficient guarantee. Who will hold clinical commissioning groups or the NHS Commissioning Board to account for the extent to which they have promoted that involvement or choice? Where will patients go for redress if they find that their family doctor will not refer them for treatment or investigation but insists on managing that treatment or conducting that investigation within the practice, thereby keeping the resource that would otherwise go with that patient? What will be the process for ensuring that key commissioning decisions are in line with the preferences of those affected by them and that those decisions reflect the expertise that patients have in their own conditions and the experience that patients collectively have of their local services?

Presumably we will be told that this is where HealthWatch will come in, but what will HealthWatch mean in practice? The first problem is that it is unclear how local healthwatch groups will be constituted. If individuals are simply going to be self-selected, their views, though valuable, will not necessarily be representative of all service users, and there is a risk that because of that they will not be treated by commissioning groups as having legitimacy. Members of local healthwatch groups need to have their own local accountability and must have the resources to engage with the wider community to be able to assess and represent their views.

Resources will also be necessary to enable local healthwatch groups to provide advice, support and advocacy. This will be an important and potentially substantial role in the brave new world of the NHS that this Bill creates: a world where patients will no longer be clear whether their GPs are acting in their interests or to bolster their practice's coffers; a world where decisions about what is to be commissioned will be taken with no clear system of public accountability; and a world where for-profit providers will increasingly squeeze out those that are not-for-profit and where profitable treatments will be cherry-picked.

A strong system of patient advocacy and support will be needed, but will it be provided? This will depend on the decisions of hundreds of local councils. The money provided by the Department of Health will not be ring-fenced, and there will be no mandating of local authorities about the nature and quality of HealthWatch services that should be supported. All this is in the name of localism, that same localism that has seen the budgets of LInks drop dramatically this year, in some instances by more than 50 per cent, despite, as the Minister told a number of us last night, the Department of Health saying that it has increased the resources available. The resources went up, but the resources available for local healthwatch went down. It is a localism that means that the Minister can offer us no assurances that those advocacy services that he promises us will be adequate. In future spending rounds who will argue with the Treasury for the moneys for HealthWatch? Will it be the Department of Health, which will have no say in whether the services expected are being delivered, or DCLG, which will have no interest in those services, or will the current commitment be allowed to wither on the vine as no department fights its corner?

Is it even appropriate that local healthwatch groups should be resourced via local authorities which themselves will have responsibilities for social care provision? Is there not a potential or perceived conflict of interest here? How comfortable will a local healthwatch group be in criticising its paymasters about the quality of that provision?

Finally, there is the relationship with national HealthWatch. A national structure is essential for the views and concerns of local healthwatch groups to be captured and articulated at national level, but that national structure must grow from and be a creature of the local groups, not sit above them as a mere sub-committee of a regulator, moreover a regulator to which requests for action and even criticism may need to be directed by that structure.

The new NHS will need a strong and independent user voice. The Government keep citing the proposals on HealthWatch as evidence not only that such a voice will exist but that the patient will indeed be central to the myriad new structures that they are proposing.

Yet the danger is that what we are being offered is no more than a fig-leaf whose own legitimacy will be flimsy, a fig-leaf whose resources will be plundered as local government itself faces a future with rapidly dwindling money, a fig-leaf whose independence is compromised by its relationship with a paymaster whose provision it is supposed to be monitoring, and, above all, a fig-leaf protecting the nakedness and insufficiency of the protestations that no decisions about the patient will be taken without him or her. My Lords, it is just not good enough.

Baroness Hughes: the Government stress their aim to put patients and public views at the centre of commissioning, yet there are very few mechanisms for children and young people to influence the commissioning and delivery of health services. Research by the National Children's Bureau published recently shows that existing structures for patient consultation, the local involvement networks, are struggling to register children's voices. Any new mechanisms to involve local people in determining health needs must include children and young people from the outset.

Above all, the Bill makes no specific reference to children and young people and, perhaps more importantly, nor has discourse from the government Benches. That commentary has not signalled the

need for the reforms to work better for children. I want many changes to be made to the Bill to ensure that the system works better for children and young people. I shall restrict my comments to the Minister to five issues. Although I relate those issues to children and young people, they arise from endemic flaws in the Bill and will therefore have an impact on other groups of patients.

How will the Minister ensure that the voices of children and young people are given strong recognition and clear ways to express themselves within the system? The Government talk much about giving patients and the public greater influence over decisions about healthcare, but there is no mention of children and young people. Local healthwatch organisations and HealthWatch England must be required to have specific and dedicated child-friendly ways in which the views of children and young people can be elicited and acted on. Will the Minister amend the Bill so that this is an explicit requirement on local and national healthwatch organisations?

Baroness Massey of Darwen: First, the voice of the child must be heard. Children must have a say in decisions about local services and care, as recommended by the NHS Future Forum. HealthWatch England and local HealthWatch must be instrumental in this. Local HealthWatch organisations must promote the involvement of children and young people. There must be clear accountability for promoting the health and well-being of looked-after children and care leavers within new structures

Lord Whitty My final point relates to consumer representation. HealthWatch is a good new concept. However, consumer representation has to be independent not only of the provider and the Government but of the regulator as well. The location of HealthWatch in the CCG is not independence. It is not clear that it will have its own resources or staffing, and it is regarded in the proposed legislation as a sub-committee of the regulator. That is not appropriate, independent consumer representation for the patients of the NHS.

Lord Crisp: There is not enough focus on patient power, for all the reasons that the noble Baroness, Lady Masham, raised.

House adjourned at 12.23 am.