Document collected by Ruth Marsden and Presented to the first meeting of the NAPF 2007

National Association of Forums

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Conservatives' 'Healthwatch', Parliament, 26th Oct '06

JB –John Baron, Shadow Health Minister
AL –Andrew Lansley, Shadow Health Secretary
NS –Nick Stace, Dir. Of Campaigns for 'Which'
LBL –Lord Bruce Lockhart, Chair of Local Gov. Assn
MS –Michael Summers, Chair of Patients' Assn
JH –Jeremy Hughes, C.E of Breakthrough, Breast Cancer
SB –Sally Brearly, Chair of Health Link

120 people here. They are:
-patient-reps
-FSOs
-national charities
-HCC
-reps from NHS, Trusts
-reps from local gov
-PPI F members

JB
-NHS has had 9 upheavals in 9 years. Needs to be stable for at least a decade!
-Local authorities are too integral to be a 'partner' with patients.
-Effective patients' group needs to be able to visit, receive information, get evidence
-OSCs have potential power
-ppi is a separate thing
-LINks can't refer to independent regulator and *make* the Trust board review things
-50 reps from OSCs were here last week consulting in parallel
-too much 'finding fault when things go wrong' and not enough 'directing things to be right'
-OSCs have a civic responsibility for all their area's services. A 'monitoring group' needs to be independent of the services it scrutinises.
-Healthwatch would be independent, have its own funds, be statutory, decide own agenda
-local authorities have 'public' interests
-Healthwatch would have 'patient interests'
-information drives quality.
-H/w needs powers to assist patients in pursuing complaints and should take collective responsibility for complaints, replace ICAS.
-H/w needs a strong brand-image

AL
-guarantee independence
-OSC powers can be 'beefed up'. H/w can trigger block to service-changes.
-could be coterminous with PCTs

-needs proper staffing, so resource implications
-should include patients for all healthcare, not just NHS
-needs marketing, presenting to the public
-needs powers to get behind 'commercial confidentiality' blocks
-how to involve national patient-organisations?
-trade-off between independence and influence

NS
-current catastrophe of 'dismantling'
-new system needs powerful individuals
-not just 'consulting for PR'
6 Key Things:
--must reach whole population
--every patient must give feedback, so must family, friends, without fear
--patients need help when things go wrong
--investment must be made in structures, tools, resources, staff.
--culture of NHS must change. All of it should put customer first
--NHS must be open to 'change and challenge'
Big barrier is unclear rights and entitlements

AL interposes:
Statutory responsibilities mean that you have to specify all details at the outset, start with a known model, so has to be 'top-down'. May be some elected, some appointed people. Don't know yet.

Anna Coote of Healthcare Commission interposes:
What about the burden of regulation on the service? Don't want to overdo it. Is 'Healthwatch' to connect to LINks or be instead of them? What about Foundation Trusts? Would local taxes go up with 'Healthwatch'? What about the responsibility of health and social care organisations to themselves to be accountable? If HCC moves more to assessments based on risk, then 'Healthwatch' or whatever would be important to this?

JB interposes:
Today is part of a wider consultation. Everyone can input their views onto the web-site.

LBL
-issues not easy
-l.a.s been 'restructured' every two and a half years since 1946!
-everyone wants 'a good hospital near me'
-l.a.leaders are interface between health and social care
-quality of health-outcomes very complex
-only a l.a. has democratic legitimacy here eg Local Area Agreements
-OSC could expand to be like a 'Select Committee' and have patient as Chair
-get info by a call-centre manned 24/7 to log issues to take to OSC

MS
-need platform for patients to influence care
-free confidential help-line?

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-web-sites?
-fact-sheets?
-CHC was a loss. Kept them in Wales
-CPPIH "too active" ????????
-LINks could be "run by local authorities"
-everyone knows the failures and disappointments
-selecting patients to treat based on finances not clinical need should be condemned
[This was rather a weak presentation]

Question from floor: what about re-imbursement for volunteers who missed work and were out of pocket? - No real answers to this one.

JH
-'Your Health, Your Care, Your Say' was a welcome dialogue.
-there is 'reform fatigue'
-charities offer real involvement, or people would stop donating and the charity would fold.
-those most in need are not white, middle aged, middle class
-internet can reach people
-more advocacy needed
-no personal agendas wanted
-'public health' is the Cinderella

SB
-1. 'Volunteer' does not mean 'amateur'
-2. No 'involvement' without 'influence'. "A Stronger Local Voice" was all about finding out about things: this (H/w) must actually go somewhere.
-HCC inspections are 'after the event'. Pro-active, day to day work will prevent concerns
-3. Don't despise the 'usual suspects'. PPI F members, like others, are the 'usual suspects'. We don't claim to speak for all, but we are the core-group who do speak. If the gov. wants to be all-inclusive, and says we're not 'typical', it won't have anyone. It can 'abolish us' but it won't make us go away!

Lots of questions from the floor were about mental health, about the ambulance service, about diabetes, about hospitals. It was noticeable that every speakers' examples were from the hospital sector.

[This was very much an ideas session. H/w was an outline and needed fleshing out. This was part of the process.
Everyone who spoke from the floor was unanimous in wanting independence, and powers.]

NB. SQUARE BRACKETS ARE MY OPINIONS

Ruth, 26th Oct '06 Ruth Marsden, Chair, PPI F for HEYHT
ruth@myford.karoo.co.uk

APPG, Commons, 30th October, '06

I took about 60 of the Briefing Papers ('Merits of Fs/flaws of LINks') and 40 of the 'Case for Retention of Specialist Forums', and put these on the side-table with the CPPIH bumf. Other colleagues also had brought batches and scattered them liberally around. Most of those attending therefore had a 'basic script', not that it seemed Forum-colleagues needed one!

Start was 1.0pm. Intro by Patrick Hall, Chair of APPG, as follows:

"Many more who couldn't be here. Need more opportunities for others to have their say. Yet again, change. I was in CHC. Now awaiting LINks legislation, possibly Queen's Speech, November. Need more opportunities to look at the proposals, be informed. Forum-members will wish to have contributed. This is the beginning of the process of communication.
APPG:
-made up of all parties
-gathers info
-informs Parliamentarians of both Houses
-assists MPs and Lords by meeting with those who deal with the 'real issues' (eg PPI F members)
-'neutral', but not 'silent'
-makes submissions to Ministers and gov

In its submission to Strategic Review of Jan 06, APPG said:
-reformed PPI Fs should be allowed a period of stability
-should be capable of following the whole patient-journey
-should comment on the wider, public-health agenda
-did not need to be connected to institutions but to 'localities' eg towns
-should have strong local voice
-have national voice too
-retain opportunities for specialist Fs
-debate health and social care at all levels
-Fs should be independent
-Fs should be properly resourced".

Then we were told that at 1.50, Harry Cayton would speak, so there was about half an hour of milling around, waiting.

But Sharon Grant actually spoke then, as follows:

"Opportunity to put our views. For every F-member here, there were thirty who had wished to be here but not enough room.
It is 'change again'. Whole network of Fs in England set up in Jan, 03. Uncertainty early on, yet real success with many Fs functioning extremely well. Takes time to bed in. Now real impact on locality. Pay tribute to the unpaid thousands who achieved over and beyond what was expected.

So much change now that involvement of the public is even more important. Time to strengthen ppi. Worries, fears and attractions of the new proposals. Legislation possibly to the Commons in the autumn. Should build, not overturn. Want to be part of a new system. Must consider the concerns over rights and powers, the real strength of information and inspection rights. Concern about the consultations. What is the role and scope of LINks? How to ensure national standards of involvement are adhered to when there is no national Commission. Don't want a 'post-code lottery' of ppi but a national ppi. Coverage? Workload? Large areas?
Rural and urban mix?
Responsibilities will be considerable with liaison over all commissioning, all providers. This will need to be 'a serious organisation'.
Loss of focus on specialist services. Concerns re relationship with local gov. Politicisation would mean loss of independence. LINks accountable to whom? What resources? Costs of really empowering the under-represented are very considerable.
Independence of Forums is their chief attraction re membership. Clear determination to retain independence."

Then Harry Cayton spoke, as follows:

"Significant that there are so many here. Level of interest and apprehension in new proposals. Over 500 responses to document (SLV). Clear themes emerged and principles arrived at. How to achieve these. Agree totally with strengthened not weakened system (Rosie W. 'Hear, hear')
-Members to come from local community and interest groups, extend franchise, reach other groups
-move from examination of buildings and facilities to 'patient-journeys'. Range of providers, not just NHS but also IS and voluntary.
-extend involvement to social care to complete the journey
-his strong personal view is that the sharing of knowledge and information means power and real engagement
-commissioning is fundamentally important. Currently, very weak incentives for these to focus on patients and communities.
So, he recommended:
-extend Fs to community work but keep expertise. Individual Forum could be one of the bodies which sets up a LINk.
-to build ppi capacity locally takes money
-strengthen voice in commissioning
-strengthen voice in social care
-locally funded and organised LINks. Up to local community to decide how to organise the LINk.
-must be empowering and enabling, not restrictive
-national voice? Work ongoing with local and national patient organisations to balance, and act on behalf of, the local voice/LINks"

Then Rosie Winterton spoke, as follows:

"Enormous lobbying for PPI Fs. Will address concerns. Fs done a fantastic job. Want to build on this.

PCTs look at health needs of pop, devolved budgets (80%) and decide how to meet needs.
-examine this and challenge this, in the new LINks That's why they will be PCT based. PPI Fs will have group- meetings to have a sense of what's going on in other areas of work.
-bigger PCTs now, working more closely with l.a.s to provide services so we need
1/ a good set of people
2/to look at the issues
3/ evaluate them
and an organisation to bring all this together and hold to account over local healthcare spending.
-PPI F members could automatically become members of LINks
-more money needed at the front line. I cannot tell you how much there will be but am clear that central resources will be devolved. We want to create this mechanism.
-work with the l.a.s but not be 'in hock to them', not be absorbed by them. (Many boos here!)
-we want you to look more widely, have extra powers, hold to account.
-specialist services Forums? I was at a meeting with the F in Doncaster. If a LINk wanted a certain number of people to focus on hospital/acute services they could continue to do that. Absolute right. They would have a specific relationship with that Trust.
-health outside hospitals, more moving to the community, eg blood tests, so look at services which used to be in-house in the hospital
-patients can now go anywhere in the country to a different hospital
-judge whether it's better or less good, look across the spectrum
-within a LINk, can be 'specialists' to look at a particular area and at what's happening to the patient. Eg stroke services start with GP, go to A and E, go to hospital, go back home again, use social services. Enhances our powers.
-Inspection? The HCC does this. We want a very clear ability to go into certain institutions and talk to patients and to staff. When the HCC do their inspections, they can involve the local LINks. It will avoid duplication and be complementary
-right of entry? Accreditation? If a LINk involves, say, Age Concern, joins all its members into the LINk, they can be surveyed about what they feel. General entry into hospital? CRB checks needed. Impossible when so broad in numbers, for all to have CRB check, all 500-600 people.
-what about entry to social services facilities, to nursing homes, to people's own homes if care is delivered there? Not impossible to have a system where named visitors have i/d and CRB. Can nominate a number of people for this. Be realistic.
-other LINks could decide to be without 'specialist-people' nominated.
-DECIDE AT LOCAL LEVEL HOW YOU WANT IT (my capitals) Talk about it in a practical way.
-it's not about removing rights but making them effective in a new structure
-why change? Use expertise in a new situation. Healthcare is changing in so many ways. More emphasis on commissioning, holding to account and changes in healthcare won't be accountable without people like you."

- This is exactly what the Minister said. If this does not sound very coherent or lucid, it wasn't.

Then there were questions. Forms had been sent to attendees for a question to RW to be written on. These forms were to be given to PH who would select the questions and give them to the attendee to read out/ask. In the event, the room was very long and thin and very crowded, standing room only really. There were about 16 chairs, but everyone else had to stand, holding their coats and clobber from the journey. There were soft drinks available, but only little canapes to eat and many people were very hungry, having left home pre-dawn. The microphones would not work, tho' the stand-mike at the front was eventually persuaded to. So the only place to be heard was at the mike at the front. It was so crowded it was hard to get to the mike and PH did not know/could not identify the people whose names were on the questions he had chosen, so this plan was abandoned. Also, a helicopter was circling low overhead most of the time so it was all but impossible to hear.

However, the questions/statements from the floor were all incisive, articulate, professional, impassioned and well-evidenced. Eg:

Q. What advantage is there in a LINk ?
Q Need right of entry so have real evidence, not anecdotal
Q. Why change, all you're describing we're already doing.
Q. Have dual-role functions already
Q. Mental health trusts have specific issues, nothing to do with ENT and dentistry!
Q You are missing the point. We already have the local input and liaison.
Q. Minister, you have just told us here, "You can decide at local level how you want it", and yet you're insisting it has to be your way!

And more of the same. There was not one acquiescent voice in the room. All of us thought what was on offer was unnecessary, confused, impractical and a retrograde step.

-Even the Minister seemed to realise that she was out of her depth. At one point, Meredith Vivian's guide-dog gave a subdued yowl, and the Minister tried to quip that at least the dog liked what she was saying! She was obviously 'on the back foot. Looking at the faces of those beside her on the platform, it seemed they thought she was digging herself into a hole. The Minister left without saying anything to indicate whether she had taken on board what she had heard from us.
Before she went, I gave her the Briefing Paper which you have all seen, and the Dossier containing the 80 letters of support from influential bods/organisations. She promptly handed them to her p.a. (Looking at his i/d, I saw it was Tom Strickland still, and I have his e-mail, so will contact him to follow up).

I went off, assisted by a colleague from SFYH, to find a wheelchair accessible loo and found one behind a staircase. We bumped into Rosie who was about to go upstairs, and my colleague had another go and told her she'd totally missed the point, we wanted Forums, not LINks. She a little petulantly said, "If you don't want to do it, you don't have to be in it", and went.

Steve Lowden and Laura Bruni were there in the meeting room, but they did not 'speak'. SL kept very low profile.
I was able to use the 'milling around time' to meet up with Baroness Cumberlege. Afterwards, I and colleagues from SFYH went off to talk with MPs in the dining room. Coffee, buns and biscuits were a life saver!

When I finally got home, there was an e-mail from Patrick Hall saying he hoped we 'got the chance today, let him know, and that he would be writing soon to all who attended'.

That's it.

Ruth, 31st Oct 06 ruth@myford.karoo.co.uk

Chair, PPI F for HEYHT

APPG, Westminster, 30th Jan '07

1. RT Bill has no details re funds, functions and form of LINks. Conditions are attached to access. Consultation over "significant" change –what is "significant"?

Standing Committee is chance for amendments. Report stage possible chance for amendments. Lords is another chance for amendments. It was the Lords who secured PPI Fs.
Select Committee proceeding in parallel. Not how it should be. Sel. Comm. supposed to scrutinise potential bills.

2. KB. Come to listen to you. Had discussion with PPI Fs in S Yorks. Sel. Comm. should publish evidence this week.

Bill not that descriptive. Two judicial reviews of healthcare in last 12 months: we don't want NHS shaped by the courts and lawyers.
We have not closed minds on any of this that Richard spoke of. Standing Committee here to find a way forward, clear up what's been "a bit of a mess".

3. Mike –we are all volunteers, done bloody good job. How can LINks involve so many to any effect? Time to stand up and make count all the good work that Fs have done.

4. Bob –Don't want talking shops. Currently have meaningful Trust/Forum relationships, thanks to active individuals. Trusts, OSCs and HCC want Fs to go on.

5. Pat –We've worked and trained. Fear loss of autonomy. L.a.s already overloaded. This Bill has been rushed through with scant regard for us.

6. Great Yarmouth –If KB says this is a "bit of a mess", why make it worse. Public won't get involved in a 'mess'. Fs are local, not subservient to anyone, serve the patients. MPs should remember they are there due to a cross on the ballot paper. Witness Dr R Taylor!

RT responds. We are on your side, the three of us. Tribute to you. Fs really work.

SG Need some co-ordination re LINks. National voice? A few 'bad' Fs have been used to rubbish the lot? I have sympathy with this view. You might not think much of CPPIH but we defend to the death your rights etc.

7. Michael English –Time allowed for Bill is too brief. Where is the evidence? All voluntary organisations have a financial interest. These will inevitably conflict.

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8. Southwark –Where is the accountability? A Forum monitors an organisation so that organisation is accountable to it. LINks are too arms-length. Inspection is vital, not just for itself, but because if information is poor or opaque, we can go and inspect and find out what's going on.

9. Malcolm, London Ambulance –What's the object of all this? Looks as if the Bill is meant to make an ineffective system. Why are you so keen to go ahead and not compromise? LINks look like a weak body, doing nothing. If a LINk was meant to have real power, it would be made powerful, not just part of a Bill that says "allow access". Ambulance Trust covers huge area, how can LINks get to grips?

10. Ian, N Yks –Should be a clear timetable for the Bill. Any change shouldn't be before April 08 and any system sorted with the assistance of the Forums.

MV. responds. I won't waste your time telling you our ideas are right. The referral power for LINks is explicit for social care. Regulations already exist for referral etc for health sector. Word 'inspection' not used as we do not think of LINks as' inspectors', but 'informed people' rather than an inspectorate. This is not a diminution of current powers of Fs.
The word "significant" is used re changes, as to date, there is no threshold for a 'change', it could be buying a different broom. (!!!!) "Significant" change could be a negative impact on only one person.
There is nothing in this Bill which is 'less' than PPI Fs have, and there is some that is 'more'. Eg l.a. has to say how it will respond.

11 –St Helens/Runcorn –Volunteers have given time and talent because they want to make a difference. This is vital. Money suggested for a LINk (£150k) is not enough. Why abolish Fs?

12-Mary, Swindon –We trained etc and it cost a lot of money. We are non-political organisations .

13 -Jim, Herefordshire – CPPIH is just at the stage when it could do something useful at last and it is chopped. OSCs, PCTs are worried, as well as Fs.

14 - Cambridgeshire –OSCs, what about their training, they serve a term and then are off. Where's the continuity?

15 –Martin, Manchester –We are an early-adopter site. We see the difficulties. F members should be appointed to LINks through this legislation. Without real independence, all this is pointless. Local authorities have political views. A LINk and the council may well disagree. L.a can remove host's contract if host is not representing the community properly, so could remove its contract for other reasons too! Host's staff are vulnerable to this dissent. Their jobs depend on keeping the contract with the l.a. Money for LINks should be stated and published within each l.a. The disabled and disadvantaged need high

budget to support. One deaf person, needing adequate support, could need £400 per day. We are volunteers, so does the DDA apply?

MV responds. Why abolish Fs? It's complicated. Health and social care are coming together, CPPIH is going, blah, blah.

16 -Trevor, NE Ambulance –Very large area, millions of people, little detail in Bill , concern over what is in it, as well as what isn't in it. All can be scrapped at the stroke of a pen, liquidated. Independence is vital.

17 -Ray, Mid Yorks –What's "significant"? Will a third party have to define and decide?

18 Wirral –All this about loads of members, it takes 2 to 3 months under current recruitment for anyone expressing an interest to hear anything. Applicants wait ages to hear from Regional Office. What about support? The current FSO situation is a shambles. We want no repeat of this. What about the "it takes up 2 hours a week" rubbish?

19 Audrey –Our area is very, very large. We have patients from Carlisle, Wales and the Isle of Man. We cope by focussing on the Trust.

20 -Ex-magistrate –This is a model guaranteed to build up conflict. It is not evidence based. What's wrong with having money ring-fenced? Call it 'virement'.

21 -Pat, Tyneside –LINks will smash the valuable relationships Fs have built up with Trusts. PALS are creatures of the system and ICAS has drowned and HCC complaints are stacking up. We need to evolve the current model, not scrap it.

22 Len, Surrey –We need the Parliamentarians to turn all this around. The little detail, the lack of detail can be used to advantage if the right things are added in. Fs must be the centre of any network. We already do this networking, but are short of resources. The Bill needs a strong centre for any LINks. We need rights as of law. We need better branding, 'LINks' says nothing to anyone. LINks won't be a statutory body and l.a.s are just going to say, "We don't deal with volunteers"

23 Eva, Oxford –Ours is a small Trust but a very specialised one and takes local, national and international patients. We are embedded with the Trust, on all key committees. Trust doesn't want our Forum abolished, it's asking us to stay on. Without Forums, the whole thing will be just a talking shop.

24 Gordon, Northamptonshire. -Look at us here, lots of us, eloquent, literate, hard working. We represent our patch. We have a social and community conscience. We are your most valuable resource, in that we cost you nothing but maintenance. Don't waste us.

If Rosie Winterton thinks that the HCC can do the inspections on its own, why is it that it misses so much that we find? If it's so good, why does it miss things?
Are there thousands wanting to be in LINks? If so, why didn't they join Forums? There's no evidence of all these thousands dying to get in on the act.

25 Borders –We are not coterminous, have two l.a.s wanting to be three. One votes with the government, the other always opposes, this is not effective management.
Patients come from across the border from Scotland as we are nearest. Does the D of H even know what goes on?

26 Dan, Essex, Mental health –A single LINk cannot possibly cope. Seriously worried. Mental health has been the Cinderella too long. Be wary of the organisation which hosts. People on the ground are frustrated that the work of Forums is being diminished. This feeling is very widespread.

26. Jean, E Yorks -'Consultation' as far as I have seen from PCTs is 'decide and issue'. They don't budge. Takes months and costs thousands.
PALS is only an advisory agency dealing with car-parking and late appointments etc. I am a lay conciliator and deal with post PALS and ICAS issues before they get to HCC. The government doesn't know whom it's got in us, should audit its Forum-members and see our qualifications, experience, skills, expertise, track record.

27 Andrea –As Patricia Hewitt admitted she'd plundered the training budget for medics to try and balance the books, we can have little confidence that l.a.s wouldn't plunder LINks monies.

28 Swindon –Some l.a.s are vast, I doubt you can recruit. If you do, how will you manage the numbers you speak of? To my mind, and from my experience, 'small is beautiful'. Small is what works.

29 Ruth, Hull –What about the specialist Trusts that are commissioned from wide area and would be subject to several LINks?
The Minister cites the "changing landscape of NHS provision" as reason to change PPI Fs but we already have dual-role members who link with providers and work across, and Fs already have, and have always had, the right to go to any provider where NHS patients are treated. There's a very long list of other groups and agencies whom we involve. Where in this Bill is the explicit right to 'enter' the private sector establishments that already try to hide behind 'commercial confidentiality'? 'Enter and view' makes us mere spectators.

SG responds. Refreshing to hear all this face to face. Strength and passion shows. Can't have a hiatus in transition. Must have something that works. Resources are a real issue. When Fs started, it was three months before we had any budget details. Ridiculous to aspire to a system of thousands without a budget. Involving in diversity, properly, does not come cheap. Current ppi is tiny part of the NHS budget. This is a test of the system of Parliament itself. We need evidence-based thinking.

MV responds. I shall write to you all, F members and the MPs here, with answers to all the issues you have raised. I will make clear what is, and what is not, in the Bill. We are not 'doing away with you' but making the best use of resources.

KB responds. There's very little 'evidence-based' decision making in the D of H. All this interaction between PALS, ICAS HCC, we shall be testing it out. It will be clearer in a couple of months.

RT responds. This is the most useful afternoon I have spent for a long time. The frustration comes across. The lack of detail in the Bill could be an opportunity. You need independence, ring-fenced money, arrangements for specialist trusts, and national voice: details are needed here.

PH = Patrick Hall
SG = Sharon Grant
RT= Richard Taylor
KB= Kevin Barron
MV= Meredith Vivian

Ruth, 30th Jan '07

Meeting to brief Alistair Burt, MP, re LINks/Bill etc

8th Feb '07, Parliament.

Remit: - to discuss the proposals for LINks
: - to refine a strategy for opposing the Local Gov. and P.I. in Health Bill

Present:

John Baron, MP, Shadow Health Minister.
Alistair Burt, MP, Shadow Local Gov. Minister.
Gareth Thomas, p.a to JB.
Forum members, about 23 of them. (Where I did not get a name or a Forum to identify the speaker, I put F. to indicate a Forum-member. Apologies to those individuals.)

List of Forum-members attending taken by AB. (ACTION, AB to distribute)

JB. Invitation extended to those who came to 'Healthwatch' seminar on 06. Not enough room here for them all. Not all could attend. AB is front-bench lead for Local Gov. so is charged with taking the Bill through the Committee stages. AB is Shadow Minister for Community and Local Government. Conservatives have two front-benchers involved, AB and Robert Syms, MP for Poole. The Bill has last week been through the 'witnesses' session; this is a new procedure to get information before getting to the 'meat' of the subject. The witnesses are chosen by the government and by the Clerk to the House. This procedure will no doubt be improved over time.
The LINks bit of the Bill (Part 11) will be reached by the Committee at the end of February. It is a systematic process and a big Bill and a lot to get though before the ppi bit. March 8th is the end of Committee stage. However, four full sessions of the Committee will be devoted to Part 11 of the Bill.
AB is dealing with this part for us. He has background from contacts in his constituency.
The Conservatives don't like Part 11 at all. However, the government will get its way, so the realistic thing is to achieve meaningful amendments. These have to be timely, as if rejected, the point/issue cannot be raised a second time.
We want your views.
There are fears in Parliament about the Bill. I see three particularly.

1. Loss of expertise.
2 Loss of independence
3. Loss of powers to "enter and inspect."

What are the core concerns to tackle?

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1. Ruth M. Draw attention to the Briefing Paper, detailing 10 key concerns, circulated to all 21 members of Standing Committee plus others, plus Lords. AB and JB have received this already.
RM also handed to AB the notes of the APPG meeting with F-members on 30th Jan '07. This details all the concerns raised by Forum-members then. JB has already been sent a copy.

2. Sheila White from Kettering Hospital F. Not sure about "inspection". Should we say "audit"? Our F. has done this and had many positive results from this work. What about the specialist services? Where are they in the PCT-empire? Ruth Kelly spoke of thousands of members for LINKs. Where are they all? Fs already have connections to many, many voluntary organisations. Lots of these are themselves struggling, due to shortage of funds, difficulty of getting active members.

3. F. The Healthcare Commission undertakes inspections. Rosie Winterton said that "Fs told us their inspections were considered secondary." Who says that's what they said? Where is the evidence? CRB checks will still be necessary so not everyone in LINks will be 'inspecting'.

4. SW. F-members will 'walk', they have been treated so badly, they are fed up.

5. James Padget, Great Yarmouth Hospital. There is no evidence-based work behind this proposal at all. What about the specialist services, the hospitals?

6. Martin Cox. Is anyone here from Dorset. (Someone was.) Dorset is in early-adopter project for LINks. There was a meeting in January. Only two F-members there, a few other people, and all outnumbered by loads of healthcare professionals.

7. F member for Poole Hospital. There are five Fs in our area who should have been included in the 'early-adopter' pilot and there was no-one.

JB I am sorry, but I have to leave you now and go to the House. But I do think that in all this there is too much emphasis on 'organisations' rather than 'individuals'.

8. Jean Turner, East Yorks. Inspections are vital. Care is being stripped from community hospitals, beds are going, the 'consultations' are a set-piece.

9. Isabel, Blackwell Forest and Berkshire East. Don't let us forget the FSOs who have been so badly treated. These proposals say grants "initially for three years". How can you get good staff to commit with this lack of permanence? It's no good.

Also, the OSCs will decide what representation they accept, who they have. Further, the host-organisation stands in danger of being a pressure group.

I am deeply concerned about the Mental Health Trusts: mental health has for too long been a Cinderella.

10 Roy, St. Mary's F. The HCC's inspections are so few. They do one a year to most Trusts, and another only if there is a serious issue or complaint. These proposals are in danger of losing focus. We should bench-mark to the best, not reduce to the worst.

11. Ealing PCT PPI F. We have three Fs in Ealing. There were some concerns in the locality that LINks would mean 20 people arriving to inspect a service. This is plainly not the case.

12. F. What about representation at national level, a National Association? Rosie Winterton said 'LINks can create their own.' What does this mean? Where will the support come from?

13. F. We do not need another Commission. CPPIH has been totally useless, a drag on the ration strength. All that is required is a skeleton staff at a lean HQ to handle FSO admin etc.

14. Poole Forum. This 'separation' we have at the moment, of individual Forums, is a good system. PCT PPI Fs are more 'loose'. The Specialist Trusts' Forums have a tighter and different focus.

15. West Sussex member.. Loss of locality is the big loss in these LINKs proposals. How can one support such an amorphous organisation as a LINk?

We have a dreadful FSO in West Sussex, who is positioning already to get the contract for the LINk, has taken 12 months' leave of absence to manoeuvre for it. This is scandalous.

16. F. If the government is going to allocate £150k for a LINk of thousands of people, it's not nearly enough money.

17. Roy, St. Mary's. A regional and national association should be a bottom-up development. We should get the local stuff right, it may take 12 – 18 months and then build up from there.

18. F. The terminology, I feel that 'monitor' does not convey professionalism, a real audit, but what is important is the right to go in and inspect.

There could be a secretariat, or a web-site to pull Forums together.
The public has no idea what LINks are supposed to be.

AB responds. Legislation has to be specific and words do matter. There is a distinction between 'enter' and 'inspect'. Those involved need to know what their remit is when they go in.
Too many 'consultations' are just going through the motions of hearing views and then going ahead with the decision anyway. "90% spoke against but 1% got it right" philosophy!

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19. F. Funding is a real issue. Look at funding for healthcare. Some areas get loads of money and the so-called affluent areas get less even when they have pockets of real deprivation. What formula is going to be used to decide which LINk gets what?

Many local authorities make no money available for OSCs. They are badly supported with a shared clerk at best. What hope does that give about the funds for LINks?

20. Mr. Kenworthy, Ambulance Forum. We cover Kent, Sussex and Surrey. This LINks thing will be a nightmare. How do we divide up between them all? They will have no direct access to the Trust as we in the Forum now have. Chairs of Forums meet but not the specialist Trusts' Forums. We shall be fragmented and subsumed.

21. Chris, Queen Victoria Hospital Forum., East Grinstead. Our hospital is opening satellites in Kent and Surrey. Who will have oversight of all this? We shall lose our independence.

22. Lymington Hospital Forum. About inspections, our hospital is becoming an Independent Sector pilot in July. All the services will go to a non-NHS provider. What about the ability to inspect that?

RM cited the Directive from the D of H dated Nov. '03 from the D of H to all PCT Chief Execs, requiring that any services they commission from private providers for NHS patients have built into the contracts that Forums must be admitted to inspect and that information requested by Forums must be provided.

RM had raised this issue with Meredith Vivian, Head of Accountability and Responsiveness at the D of H, on 30th Jan 07. RM pointed out to MV that the Bill listed the establishments which LINks could 'enter' and the private sector/IS providers were not mentioned. MV said that the current Directive cited was ongoing, and covered the point. LINks would have rights of access and information there, just as Forums now do under the Statutory Instruments 2123 and 2124.

(ACTION RUTH, to copy Directive to AB and JB)

23. F. Will there be minimum standards in the contracts for the 'hosts'? There must be probity, especially about the money which is not to be ring-fenced. There will be many pressures within the local authority and this 'pot' will be a tempting target.

24. F. What about the independent sector treatment centres? Kent is going for an APMS (Alternative Provider of medical Services) contract. There was absolutely no consultation. There are 6,000 patient affected, and 400 turned out to a meeting that had only one week's notice, only to hear that 400 was an "insignificant number". There was a refusal to correspond about it all. Patients were blanked. PPI Fs were blanked.

25. F. I think that the government wants to abolish PPI Fs because they have found their feet and the gov. is reeling. At the APPG meeting last week,

Kevin Barron, MP, said it was all “a bit of a mess”. We want things better, not messier.

What about training for all these new people who are supposed to be joining up? What about benchmarking this?

26. F. Ian, Kettering Hospital Forum. We feel very strongly about inspections and their value and what’s more, the Trust and the staff feel the value of them too. Feedback is vital and the Trust sees this. We support the good work done and drive the issues.

27. Mental Health Trust Forum. Our Trust had been in breach of care for three years and it was the Forum which tackled this. The HCC had not noticed. The in-patient beds were being reduced.

28. F. If this Bill gets passed and we all think it’s awful, we hate it, we walk away, it’ll be a disaster. LINks will be dead in the water.

AB responds. I was a Minister for Dept. of Social Security in John Major’s government. There is a general government fear of constructive criticism. Governments want to remove it. They remove Ministers, too! They are attuned to trying to squeeze out any ‘independent’ comment. They tend to perform through ‘systems’ not people.. It is managed for the convenience of ‘the system’. This Bill is about how the government reacts to ‘risk-taking’, letting people have a real say. There ought to be a handing-down of power. So many ‘best decisions’ have not been taken, and so much trust has been destroyed.

29. F. We need more younger members. It’s a hell of a job getting them. Very hard to recruit anyone younger. It’s a legitimate concern. LINks are supposed to be involving more people, being more inclusive and not discriminating against groups, encompassing everyone. There’ll be none of my age-group. If I’m still involved in PPI in ten years time, I’ll be almost the only one left! Nothing has been done to encourage the younger element: will this happen in LINKs?

30. F. So much legislation appears to be written by those who know nothing about the subject, what it is to be old, to be ill, to be a carer, to be part of the real world. Civil servants, Ministers, in ivory towers.

31. Ruth M. Two new angles. A)At the APPG last week, Kevin Barron said there had been two cases of judicial review of healthcare in 06, and he did not want to see healthcare decided by courts and lawyers. I have investigated judicial review and in particular the Derbyshire case. I have spoken with the lawyer concerned. One of the grounds for judicial review is “unfairness” the definition of which has recently been extended to include failure to fulfil “legitimate expectations”. It has been the ‘legitimate expectation’ of every Forum member that their role should continue. The legislation of 2003 was clear. Ministers have since repeatedly re-assured us that we are the “cornerstone” etc, etc. On the basis of this, we have

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committed years of our lives to the work. Now, suddenly, it is being ripped from under us. This is "unfairness"!

B) There will soon be a change of PM. It is likely to be Gordon Brown. His agenda is economics. There are very sound financial reasons to leave PPI Fs alone, and not waste more millions in a cash-strapped system by abolishing Forums. Perhaps we should major on this point?

32. Jean Turner. Forum-members have been expected to try and recruit. This is not our job. CPPIH should have been doing this.

Actions agreed:

1. Notes of AB, RM and GT to be shared, pooled and themes identified. (ACTION RM, AB, and GT)
2. Summary paper to be prepared re finance for LINks, need for ring-fencing etc (ACTION RUTH, distribution to AB, GT, JB)
3. Select Committee's Report of written evidence for 'Enquiry into PPI' to be trawled for issues, angles. These to be summarised. (ACTION RUTH, distribution to AB,GT,JB)
4. Individual Forum-members can write to the Standing Committee. (write to Charlotte Littleboy, Clerk to the Committee, Committee Office, Scrutiny Unit, House of Commons, London, SW1A 0AA with written submissions. With Briefing Papers, write to the individual members of the Standing Committee, eg Robert Syms, MP, House of Commons, London, SW1A 0AA)

Ruth Marsden, Chair, PPI F for Hull and East Yorks Hospitals' Trust. etc

8th Feb. '07.

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Briefing paper for Alistair Burt M.P. 11th Feb. '07

The Local Government and Public Involvement in Health Bill

A) The Select Committee for Health's Report of Written Evidence for its Enquiry, "Patient and Public Involvement in the NHS."

1. This Enquiry attracted a conspicuously large number of submissions, 140. (Eg the Report into 'Deficits' attracted 56, the Report into 'Workforce Planning' 75)

2. Of the 140 submissions, over <u>half</u> were from PPI Forums and PPI Forum members.

3. The obvious 'big-players' sent submissions: eg-

D of H
Centre for Public Scrutiny
Which
Health Foundation
Health Link
HCC
Keep our NHS Public
NICE
Picker Institute.
CPPIH
Etc

4. Submissions from Royal Colleges x 4

5. Submissions from OSCs x 3
SHA x 1

6. **No submissions** from NHS Trusts or IS care-providers. This clearly indicates that reliance on 'culture' or 'consent' are not enough. PPI is still nowhere near being part of the mainstream thinking of healthcare commissioners and providers!

B) The Independent Sector and inspection/entry rights

-important, as GPs and dentists, who are in the main contracted to PCTs, guard their independence furiously.
-some have 'patient groups' but these are more like supporters' groups than constructive critics.
-current PPI Forum entitlement to enter and inspect private providers of care ["persons providing services under Part 2 of the 1977 Act etc"] and to receive from them information requested is detailed in Statutory Instrument 2003, 2124, Section 3, clause 3 , (e), and is further supported by Directive from the D of H to all Chief Executives of PCTs. (See Directive, Nov, 2003, copy sent 9th Feb 07 to A. Burt, J. Baron, Gareth Thomas)
However, a single, overt and explicit statement within the legislation itself would have achieved greater clarity for all. It is recommended that the new Bill aims for that clarity, is explicit, and does not merely rely on the separate and less visible Directive. Experience has shown that this Directive is not universally known, recognised nor complied with.
There are to date about 28,000 separate healthcare contracts with private providers; clear and explicit legislation, enforcing within all such contracts access for LINKs and their rights to receive information requested, is essential.

C) Finance/ring fencing issue. (where numbers appear after points, they refer to page numbers in the Report of the Written Evidence to the Select Committee Enquiry "PPI in the NHS".

1. -LINks monies will be a "targeted specific grant" (Hansard, RW 15th Jan 07.) "Targeted" is un-ring-fenced!
-'Getting Ready for LINks' –Paddington Hilton, London, Dec 13th 06, Rosie Winterton in attendance. Delegates from local authorities were there and said it was simply not true that money in local authorities could not ring-fenced. Eg money for mental health is ring-fenced, so is money for schools. Though the amount of ring-fenced monies is being reduced, (13% of councils' budgets in 03-04, 11% in 04-05) it is still a recognised revenue-type.
-the resources/funding formula for LINks is unavailable, therefore the legislation is premature as what it details may not be achieveable. The Comprehensive Spending Review will not report until July 07. All the D of H will say is that "more of the £28m currently available will reach the front line."
-knowledgeable sources have suggested that a realistic figure to fund LINks should be £424,000 p.a per LINk.
-the cost of not getting the funding right will be more chaos and dis-illusionment.

2. -Patricia Hewitt admitted before the Select Committee for Health that there has been plundering of the clinical-training budget to try to get the NHS to

balance. If D of H/SHAs plunder non-ring-fenced monies , it creates an awful precedent.
-there have been significant concerns throughout 2006 about the impact that the need for healthcare Trusts to make financial savings has had on PPI in general 284
-recognise the current context; local authorities are expected to make "ambitious efficiency gains" that they "must achieve as part of the Comprehensive Spending Review of 2007".
-this concern bodes ill as there are the same pressures on local government as on healthcare trusts, and the proposed LINks' budgets will be a tempting target 284
-there are many examples of the plundering of non-ring fenced monies: eg the removal in 04-05 of ring-fencing for the Carers' Grant caused great hardship because the monies were 'flexed' elsewhere.
-Local authorities top-slice budgets. With local authorities under such financial strain, this is the worst time to introduce such a 'vulnerable' system 301
-funds must be secure. Local authorities will try to divert money, and this will inhibit the LINk

3. -just to advertise for, vet, and contract with a 'host' will cost the local authority in time and money. It is suggested the government will allocate £5k-15K for this process. The authority may take the line of least resistance, the handiest applicant, and sign them up. This is likely to become very incestuous from the start.
-local authorities and health authorities are groaning under huge administrative changes now. It is the worst time to burden them with more responsibilities. 301

4. -Forum Support Organisations currently have very different allocations to support the Forums. Their contracts were awarded on the basis of competitive tendering, rather than quality, so there was skimping, often resulting in limited support to ppi. 306

5. -LINks should see their budgets and accounts. CPPIH always refused Forums this, even though the Audit Office said it was right that Forums should see these. 272
-millions of pounds of public money has been absorbed at the centre by CPPIH. In 05-06, the CPPIH executive of six people took nearly £500,000 in salaries, yet all the thousands of Forum-members have used only £822,000 between them. The money never came down to the front line, the Forums. 271
-redundancy arrangements for CPPIH staff have been itemised as £800k for the last financial year alone. The 'sunk-cost' of all this re-organisation is enormous.
-funding should come directly to LINks from the D of H 8
-getting monies through local authorities affects the perception of political neutrality and blights the credibility of LINks. 54

6. -Rosie Winteron says she is "considering the ways in which LINks will be held to account for their use of public funds" (Hansard, 13 Sept. '06) yet won't even state the amount of the fund.

7. -D of H spent £1m on one initiative, "Your Health, Your Care, Your Say" and still did not reach many of the 'marginalised' whom it claims LINks will reach. 230

8. -budgets need an agreed inflationary uplift 4307
-budget could be simply population-based, but £30m p.a. only works out at £3.50p per head! 231
-LINks' budgets should be secured for five years and scoped for staff and an office and also a discretionary budget for research and projects. 265
-involving minorities? Monies needed for ethnicity. Translation/asylum-seekers/ immigration areas? (A big, acute hospital Trust will spend about £100k p.a. on translation/interpreters) 308
-LINks' members need computers, re-imbursement for phone calls, need travelling expenses. Travel expenses can be a few pounds, under £5 per month, to £200-£300 per month, dependent on individual, workload, area to cover. 338
-size of the patch with LINks will necessitate more travelling, and increase costs.
-many Forum-members have to fund their own phone charges, stationery, computer lines, pay for their own meals when away from home for long hours. 343
-a disabled person needing a carer is very costly, about ten pounds an hour.
-a deaf person, needing a signer, would typically need £400 per day.
-LINks will need specialist policy support. This will have to be paid for. 48

9.- it is critical that LINks have enough cash to be proactive, in at the beginning, not just nominally consulted at the end of things. 29

10 -PPI Forums have never been allowed to know/see/handle/scope their budgets. How can you plan work without knowing what's in the kitty? 322

11.-there has been some talk of payments to members. When it was mooted that Forum Chairs should be paid an allowance, this was rejected by all the F Chairs. They wished absolute independence.
-It has been suggested that members receive something like the local authority attendance-allowance. This is not a good idea. Once individuals receive payments, they are compromised, and they lose credibility and are regarded with suspicion, become someone's 'creature'.
-a financial-loss allowance may be necessary if you expect to get input from those who are in employment. 338

12 -voluntary organisations often use the full-cost recovery model. This will make their participation in LINks very expensive on the system. 8

-size of LINks and the vast range of their responsibilities mean that they are subject to domination by well-resourced organisations, bigger voluntary set-ups, that will run-away-with-the-issues.43

13.-Assumption that CPPIH's budget would be divided and distributed for LINks was refuted by Rosie Winterton. She said that she "did not recognise this assumption."

D) Themes from the Written Evidence to the Select Committee for Health's Enquiry, "PPI in the NHS".

1. Forums and Forum-members were the main contributors and there was strong agreement in their submissions, as follows:

-abolition of PPI Forums was inexplicable.
-the many requests for *evidence* as to why they should be abolished have been blanked. So-called 'evidence' in "Stronger Local Voice" has never been made public.
-the current model, PPI Forums, is into its stride, notwithstanding the shortcomings of CPPIH
-Forums already operate as 'links'. There are the elements in place to deliver. It makes more sense to evolve the current model, give them the funds and support.
-Forum members are already CRB checked. Why waste money?
-existing partners –Trusts, OSCs etc -are worried about loss of Forums.

2. OSCs and SHA.

–the SHA said that the strength of the Forums was that they mirrored the NHS structures, had productive relationships, and were 'critical friend'.
-the OSCs said that the LINKs would struggle, the areas were too big, there was little justification for reform of the current system, that PPI Fs had performed well despite poor planning that went into designing them. There was significant concern about the need for financial savings in PPI, and doubt of the authenticity of commitment of the government.
-healthcare and local authorities are different constituencies.

3. Charities and Voluntary Groups.

–these tended towards description of their organisations, and narrative of case studies rather than relating to the specific issue and the questions posed.

4. The 'big players' as listed above under **A)** said:

-independence, proper funding and stability was vital. Continual interference by government in PPI damaged its effectiveness and wasted scarce resources.
-So-called consultations were too short.
-Difficulties past and present were attributed to cultural limitations in the NHS and amongst healthcare professionals.
-The complexity of the healthcare system was stressed.
-There were fears of the politicisation of LINks through funding via the local authorities, and risk associated with the 'host', with the voluntary sector and conflicts of interest.
-Training and experience was regarded as vital.
-The most 'active' people were those with busy lives. Those 'on the margin' would take much effort, cost and time to reach.
-The social-care element could be problematic (small care-homes, clients' own homes) yet these users' voices must be heard.
-There was a concern that a LINk would become 'an organisation' rather then individuals acting for individuals. The CPPIH showed the impediment to PPI of too much bureaucracy.
-There was emphasis over and over again on how vulnerable people are when they are ill. Forums were responsive, and could and did act quickly. Relations with local Trusts were the key. Specialist services covered wide areas and needed particular focus. Issues here had powerful effect on the patient experience and the clinical outcome.

E) The Specialist Trusts, (ambulance, learning difficulty, hospitals, mental health)

The Specialist Trusts' Forums have provided a very real engine for improvement. They have assisted their Trusts by providing evidence-based information, have identified shortcomings, improved care and bettered the patient-experience. Forums provide a necessary resource for their Trusts who use them to accredit their services. This independent and informed input from Forums is vastly more meaningful than the isolated snap-shot in time of a rare Healthcare Commission inspection. The specialist Trusts need their dedicated PPI Forums as their advocate, champion and ambassador as much as they need them as their critic, scrutineer and clinical-conscience.

<u>Sources</u>

-Hansard, Second Reading of Local Gov. Bill Debate, 22nd Jan. 07
-Oral Evidence, Standing Committee, Feb, 07
-Report of Written Evidence to Select Committee "PPI in the NHS", Jan. 07
-APPG Meeting with PPI Forums, 30th Jan 07

-Conservatives' Seminar with PPI Forums, 8th Feb 07
-Transcript of Oral Evidence to Health Committee, 1st Feb. 07
-A Guide to Local Government Finance Settlements, (Office of Deputy Prime Minister), Jan, 06
-Written Answers, Rosie Winterton, Hansard.
-Three Year Development and Capital Settlements, Community and Local - Government.
-CPPIH Annual Report, 05-06.

Ruth Marsden, Chair of PPI F for Hull and East Yks. Hospitals Trust
Chair, SFYH
Lead, Associated Forums.
11th Feb. '07

Select Committee Report - "PPI in the NHS".

Issued 1.0pm, Friday 20th April, 2007

Summary

Given the lack of accountability in the NHS, often referred to as ' the democratic deficit', there remains a role for independent patient and public involvement structure.

No precise date has been set for the abolition of PPI Fs or CPPIH.

We are not convinced that PPI Fs should be abolished. We do not see why PPI Fs should not be allowed to evolve. The abolition of PPI Fs seems to have been driven by the need to abolish CPPIH rather than a real need to start again.

Once again, the Dept has embarked on structural reform with inadequate consideration of the disruption it causes.

Worryingly, the projects known as 'early adopters' which seek to explore how LINKs would operate, were established in '06 after the Bill was introduced, implying that the establishment of LINks was not an evidence-based decision.

We do not believe that it was necessary to abolish PPI Fs and establish LINks and we have concerns about the Dept's proposals.

There is much disquiet. People feel they are consulted after decisions have been made. There has been criticism of the NHS organisations' refusal to consult about major changes. We fear that the Bill will weaken Section 11 and lead to more court cases. We are not convinced that this change is needed. We conclude that there is no need to change the law.

This is threatening to undermine public confidence.

Our Report is intended to inform the House's consideration of the report stage of the Bill, but it goes wider than that. We investigate the system established in 2003/4 (PPI Fs)

2. Patient and Public Involvement: aims and organisations

Harry Cayton of the D of H was frank in his admission to us that the Dept's patient and public involvement strategy could be clearer. An obvious question

is whether introducing a further involvement mechanism such as LINks is really necessary or desirable.
OSCs do not all have sufficient resources to provide the depth and breadth of coverage of NHS issues in all areas.

For the time being at least, dedicated structures for ppi are necessary. A separate, independent patient and public involvement mechanism provides an important back up and should attend to the differing needs and views of both NHS patients and the wider public.

CHC had a larger overall budget than will be available to LINks. Each CHC had a budget roughly equivalent to that planned for LINks, approx £150k, but LINKs are expected to cover a wider area. Eg an area such as Herefordshire, there would be one LINk, with a budget of £150k, compared to 4 CHCs with a combined budget of £600k. Even taking into account the fact that CHC undertook functions now done by PALS and ICAS, this seems a substantial reduction.

There were originally 572 PPI Fs and are now about 400.

Doubts have been expressed over the effectiveness of OSCs—the weaknesses of scrutiny arrangements. OSCs have no mandatory powers to change anything. They can only be reactive rather than proactive. There is no lay or public representation.

PALS has become increasingly marginalised.

ICAS is being provided in an inconsistent way.

“Foundation Trusts appear to be failing in terms of ppi”.

HCC- PPI is included as a core standard –C17 and a developmental standard –D11

There is a widespread feeling that PPI Fs had done the best job possible given the circumstances they faced. Chair of PPI F for Leeds Teaching Hospital summed up the feeling of many, “Any actual failure has been within the Commission itself, its inadequate leadership and the excessive cost. Their current inefficiencies have to be seen to be believed.”

Witnesses argued that PPI Fs should remain. They may have a small membership but this could be improved and in any case there is not a large number of people willing to do work of this type. Moreover, they could develop to take account of changing circumstances. The balance of evidence suggests these witnesses could be right.

Local Involvement Networks.

There is little detail. The Dept did provide the Committee with draft document relating to Local Authorities’ contracts with hosts. However, these documents indicate that the Government will consult about powers, so the details will not be finalised until after the Bill received Royal Assent.

Early adopters, there are 9 of these. We questioned Meredith Vivian (Head of Accountability and Responsiveness at the D of H). He said," These are not pilots ; pathfinders might be a better word." We welcome these early adopters but are concerned that they are taking place after the Bill has been published which means that LINks cannot be evidence-based. We are also concerned that the D of H is drawing up guidance before projects have been evaluated. These seem to have been less an objective trial than a discussion with stakeholders. This is symptomatic of the Dept's failure to focus on what LINks will realistically be able to accomplish with the resources available to them.

"The worry about LINks is that they focus on the process and not on the outcome."

"Good PPI Fs are already forming their own links"

There are many aspects of LINks on which the Dept has yet to provide information --- but it seems that the Dept is moving away from the network model. The more time a LINk spends reaching out to the public the less time it has to scrutinise the NHS. In some areas there are likely to be few organisations to participate in a LINk and those that exist may be short of money or have few volunteers. We received a considerable body of evidence pointing out how difficult it would be to run a network on the scale of a LINk. Yet the Dept has made it clear that as well as running an extensive network, LINks would continue to undertake the work PPI Fs currently do.

There were warnings that LINks should not waste time collecting data since a great deal on a wide range of issues was already available. Where data was not available, LINks were not the right organisation to collect it; the responsibility should lie with the NHS.

"LINks are supposed to have broader focus but they are going to have very tiny resources, have very little in the way of support. LINks are not going to be the answer to all this."

"We are in favour of development rather than scrap."

The lack of clarity about LINks --- is likely to create confusion and inactivity. This would be particularly unfortunate at a time when significant change is occurring in the NHS.

Many witnesses said PPI Fs were under-resourced. If LINks are to be a network along the lines that the Dept proposed they will cost considerably more than PPI Fs
Whatever form a LINk takes, it could have nearly 200 NHS organisations in its area. Keeping in touch with these, let alone contributing feedback to them all, will be a massive undertaking.

The Minister told us the abolition of CPPIH would see £9m redirected to the front line and this would give LINks a third more money than PPI Fs received. She repeated the £9m figure several times during the evidence-session.
In contrast, CPPIH calculated that the actual saving would be £1.5m since a number of CPPIH functions such as contacting with and performance-managing hosts, running web-sites, training volunteers, undertaking CRB checks etc would still have to be in place. If LINks chose (as seems likely) to set up a national body, the saving would be even less. Harry Cayton seemed to agree that the functions would have to be performed and paid for.

The Minister told us there would be economies of scale. --- Many FSOs support several (often 10 – 15) PPI Fs, thus creating economies of scale. There are likely to be more hosts than FSOs; since each local authority will have to contract separately for a host, there may well be a different host for each LINk.

Further CPPIH told us that to support three deaf people to attend a meeting cost £1,200.

Harry Cayton told us, "What any decent organisation does is to look at the money it has got available and does the best that it can with those funds."

CPPIH, on the other hand, costed the proposed LINks at £64m, or more than double the current budget of Forums. In view of this, the organisation feels that LINks are being set up to fail.

We note that much of the money will be used to replace functions currently carried out on behalf of Forums by CPPIH. She (the Minister) argued that there would be significant economies of scale. But we are not convinced that this is so.
It is a matter of serious concern that the Dept has not taken the budget LINks will have into account when deciding their remit and function.

Volunteers find it easier to focus on service provision because you can see what is going on.

The Minister agreed that the lack of prescription would inevitably mean that different LINks would do different types of work. A clear direction is required in relation to what LINks should do. This the Dept has failed to give.
If volunteers are given a free choice, they are unlikely to make commissioning a priority as they prefer to concentrate on the quality of services which the NHS provides.

Harry Cayton said, " If being a member of a LINk is a miserable activity – a bit like, I fear, being a member of a forum today when it has been through such a difficult time –why would somebody bother?"

Evidence suggested that it may not be easy to find people prepared to play an active role in LINks.

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Voluntary organisations and their active members are concerned with their 'cause'.
Overall, numbers of volunteers are falling.
We are concerned that while there may be large numbers of people who will become involved in some campaigns relating to the health service, such as hospital closures, few are prepared to make a major commitment to patient and public involvement. Many of these people are members of PPI Fs.

It is vital that LINks have the same right of entry to places where NHS care is carried out as PPI Fs have at present. There must be no diminution of the powers of PPI Fs. Ideally, LINks should have the same rights in relation to social care premises with due regards to the needs and wishes of the residents.

We are concerned about social care providers acting as hosts. It will be difficult --- to avoid a conflict of interest. We were not satisfied with the Minister's response to our questions on this issue.

Witnesses had little positive to say about CPPIH. However, we received a considerable amount of evidence which argued there needed to be some national body for LINks. "It is not a reform if you take something apart and only put something back to replace half of it."

The Dept said LINks would be free to set up a national body if they wish. The Dept added that the National Centre for Involvement might perform some of the functions of a national body. Meredith Vivian said that the National Centre, "has an additional £2m on top of the existing £28m." The Dept later clarified that the £2m is not money to support LINks: it is the Centre's total annual budget.

The National Centre must not direct LINks, but supply advice and assistance on request.

Conclusions and Recommendations.

We do not see why PPI Fs could not have been allowed to evolve. The abolition of PPI Fs seems to have been driven by the need to abolish CPPIH rather than the real need to start again.

There are serious concerns over both models for LINks.

There must be no diminution of the powers of PPI Fs.

It will be crucial that at least a core of people in each Link is trained to ensure they have the skills to carry out their task.

Once again the Dept has embarked on structural reform with inadequate consideration of the disruption it causes.

3.

Too often NHS bodies have sought to avoid consultation under Section 11 about major issues. Unfortunately, the D of H has supported those organisations in trying to limit the scope of Section 11

It is crucial that national consultations cannot be open to the accusation of being 'cosmetic'.

(NOTE: Quote marks indicate evidence from witnesses cited in the Report. Everything else is the text of the Report itself.

The titles in these notes correspond to the chapters of the Report in which the text appears.

I make no apology for having been selective. The Report is 100 pages long. It is important members have access to the Report and its findings as soon as possible. I believe my notes are a faithful representation of the Report).

Ruth Marsden.

Chair, PPI F for HEYHT.
Chair of Specialist Forums of Yks and Humberside.
Lead of Associated Forums.
Member of Nat, Assn. of Fs.

21st April, 2007

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Updates

To:

Chairs and Presidents of the Royal Colleges of Medicine, esp.
-Radiol
-ASGBI
-A and E
-Paeds
-Obs and Gynae
-Pathology
-Psychiatry
-BMA
AMRC (Academy of the Medical Royal Colleges)
King's Fund
Healthcare Commission
Key members of the Lords
Key members of the House of Bishops
Political advisor to the Archbishops
Centre for International Public Health Policy
Healthlink
Health Foundation

and others

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Update No 1 - Patient and Public Involvement Forums, 4th Nov. 06

The Conservatives held a 'summit' at Westminster on 26th October to refine their Healthwatch model of patient and public involvement. The event was chaired by John Baron MP and Andrew Lansley MP was a speaker. I and many PPI Forum members attended and contributed to the debate.

On 30th October, the All Party Parliamentary Group for Health hosted a meeting for Forum-members with Rosie Winterton, the Minister of State with the portfolio for PPI. About 20 MPs and some members of the Lords were in attendance.

This was not a very satisfactory meeting. The Minister was presenting on LINks, proposed as replacements for PPI Fs, but gave no convincing detail of how LINks would work, and what influence they could bring to bear. Much of what she said they were to be introduced to do was in fact already being done by PPI Fs. I and colleagues were dismayed at her lack of understanding of the current workings of PPI Fs.

The question and answer session revealed bigger gaps in Ministerial proposals. What she was advocating was impractical, general, and without any meaningful end-product.

Delegates were unanimous in arguing the retrospective step that LINks would be, and robustly and vividly evidenced the merits and growing successes of PPI Fs, insisting that the powers of inspection etc were non-negotiable. Before the end, the Minister appeared to be giving ground.

I took the opportunity to give her a dossier of all the letters of support for PPI Fs and expressions of concern at their abolition that I have received. I also gave her a Briefing Paper on 'The Merits of PPI Fs and the Flaws of LINks', and a summary 'The Case for Retention of Specialist Forums'.
(The meeting was reported in "Health Service Journal" 2nd Nov 06)

On 3rd Nov. Forum-members heard that the decision to abolish PPI Fs had been postponed, probably until the end of 2007 (ostensibly to "avoid too long a gap between the abolition of PPI Fs and the establishment of LINks")

On Nov 4th, the Select Committee announced it was undertaking, in early 2007, an Enquiry into 'Patient and Public Involvement in the NHS'. This will consider:
-the purpose of public and patient involvement
-the proposed establishment of LINks, their powers and make-up
-public consultations over changes to services in both primary and acute sectors. (Section 11 of the Health and Social Care Act 2001)

I have no doubt that the meeting of the 30th November was instrumental in bringing about these developments.

Ruth Marsden, 6 Nov. '06

Chair, SFYH

Update No. 2 -Patient and Public Involvement Forums, 20th Nov. '06

The Queen's Speech failed to reveal any of the detail of the health programme for this Parliament. Andrew Lansley, MP asked, "Where is the legislation we thought would be included in the Queen's Speech? The Secretary of State talks about looking for an early legislative opportunity to reform patient and public engagement—but there is little understanding or support for the LINks that the government propose". (Hansard 16th Nov.)

The Minister of State for Health, Rosie Winterton, acknowledged "the experience gained over the last three years by Forum-members ---- and the collaborative work they have conducted with local partners" (Hansard, 8th Nov.) and further admitted to the House on 20th October that "there has been no formal evaluation of the effectiveness of Patient and Public Involvement Forums". (Hansard, Column 1475W)

Yet with no real details of LINks available, it appears the government is pushing ahead with its proposals for LINks.

On 9th November, 06, Rosie Winterton wrote to "all Local Authority CEs with social services responsibilities" inviting them to an event, 'Getting Ready for LINks' to be held at the Paddington Hilton, London, on Dec. 13th. Her letter says that "the proposed legislation will be introduced as soon as Parliamentary time allows", and that she envisages local authorities hosting the LINks, writing of the " tender specifications we are currently developing." This meeting is open to local authorities, and to PPI Forum members and I have indicated my intention to attend.
There are apparently to be further such events next year.

Is it reasonable that while inmates in Britain's prisons merit the protection of the Independent Monitoring Boards, patients in secondary care/specialist Trusts may lose the protection of Patient and Public Involvement Forums?

Ruth Marsden. 20th Nov. '06

Chair, SFYH.

Update No. 3 –Patient and Public Involvement Forums, 10th Dec. '06

The Parliamentary Select Committee for Health has published its Terms of Reference for its Enquiry into patient and public involvement. The closing date for submissions is January 10th, '07.

The Local Government Bill which I have been tracking, and last visited on 24th November '06, has suddenly become The Local Government and Public Involvement in Health Bill. This is no doubt to satisfy the government assertion that patient and public involvement in health would be part of primary legislation, and to side-step MPs who have been asking since the Queen's Speech, "Where is this legislation?"

It is disturbing on two counts. First, a bill has been thus denominated ready to start its progress through Parliament just when the Terms of Reference of an important enquiry of pivotal relevance have only just been announced, and the Select Committee undertaking this enquiry will not be able to report for some time. It has first to consider the written evidence received, and take oral evidence and then make recommendations. Second, patient and public involvement is being embedded in local government considerations, strengthening fears that Minister's descriptions of the proposed LINks have aroused –that patient and public involvement will be reliant on local government for finances, for shape, organisation and structure, for focus, for administration and for selection of members. This is not the independent patient-voice.

It is all too reminiscent of the situation described by the Select Committee for Health in their report of 15th Dec '05 re the 'consultations' about Section 11 of the Health and Social Care Act. The Committee said," Most concerning of all is that these announcements ----anticipate the outcome of the Government's flagship consultation 'Your health, Your care, Your Say,' which is supposed to shape the Government's forthcoming White paper on out-of-hospital care. For a Government to announce its intended direction of travel a full five months before its consultation on this subject comes to an end makes a mockery of the consultative process."

If the Government has any genuine commitment to patient and public involvement, it is difficult to see why this Bill has morphed now, rather than waiting for the results of the Select Committee's enquiry and other consultations.

D of H released yesterday "Government Response to 'A Stronger Local Voice'"

Ruth Marsden, 10th Dec. '06

Update No. 4 –Patient and Public Involvement Forums, 12th Jan '07

The Local Government and Public Involvement in Health Bill is to have its second reading before the House on the 22nd January.

1. Ppi has been shoe-horned into a huge bill about local government.
2. The ppi section is Part 11, at the end of a very long and complex bill that has 14 Parts and 176 clauses. Part 11 may well receive no scrutiny as process will be out of time. Any amendments tabled will be dwarfed by local Government issues and are unlikely to get heard.
3. The Bill is being steered through by the local government minister, whose interest is administration not health.
4. The Bill is in general a good bill, so the majority of MPs will not want to hold it up. However, the section on ppi is a disaster.
5. For example, a key clause of Part 11 states that the Secretary of State can alter any or all of it. So it's worthless.
6. Meanwhile, the Select Committee for Health's current Enquiry into PPI will not report for several weeks by which time the Bill will have had its second reading and be on its way through Standing Committee.

Integrity must be obligatory, not optional, in government.

The Select Committee is asking for the programme to be revised so that this section of the Bill can be delayed. Ideally, it wants this section to be removed from the Bill and dealt with separately to have the attention it merits.

ACTION; MPs should support the Select Committee's requests.

ACTION; The Select Committee is asking Forum-members and all other interested parties to write to their MP immediately, making the points detailed above and asking their MP to support the Select Committee's demand for the postponement and reconsideration of Part 11 of this Bill.

Ruth Marsden, 13th January, '07

Update No. 5 –Patient and Public Involvement Forums, 9th Feb '07

Patient and public involvement proposals are contained within Part 11 of the Local Government and Public Involvement in Health Bill currently going through Parliament. Part 11 was subject to vigorous and critical debate by MPs of all parties on 22nd Jan. (See Hansard) The Bill is soon to go to Standing Committee where Section 11 will have four sessions allocated for scrutiny and amendment. This will conclude on March 8th. This being a Local Government Bill, there will by no 'health' lead from either side of the House. No postponement of Part 11 has been granted.

The APPG (All Party Parliamentary Group) held a meeting on 30th Jan to get input from Forum members. The Conservatives held a similar meeting yesterday, 8th Feb. Close co-working by PPI Forums with both groups continues.

A Briefing Paper from PPI Forums, summarising key concerns and highlighting areas for amendment, has gone to all 21 MPs on the Standing Committee. Representations to the Committee can be made through the clerk, Charlotte Littleboy, Clerk to the Committee, Committee Office, Scrutiny Unit, House of Commons, London, SW10 0AA.

The Select Committee for Health's on-going enquiry into "Patient and Public Involvement in the NHS" has just published the written evidence received. There were 140 submissions (twice as many as submitted to the previous Enquiry into 'Deficits in the NHS') over half of them from PPI Forums and members, these presenting a compelling weight of evidence and unanimity of view. A few of the Royal Colleges submitted evidence. There was not one single submission from an NHS Trust! This is a damning omission.
The Select Committee is still hearing oral evidence. Its final Report and recommendations are awaited.

MPs and Forum members agree that Part 11 of this Bill is a test of the Parliamentary process, the integrity of consultation and the authenticity of the D of H's supposed commitment to the "patient-led NHS."

Part 11 lacks detail and assurances. Legislation has to be specific and words matter.

Concerned parties are urged to make representations, via the Clerk of the Committee, above.

Ruth Marsden, 9th February, '07

Update No. 6 –Patient and Public Involvement Forums, 16th April '07

It has just been announced that Ministers wish to wait until Parliament has fully considered the PPI provisions (the proposed LINks) of the Local Government and Public Involvement in Health Bill before definitive moves are put in place to bring about any closure of PPI Forums.

The necessary Royal Assent to this legislation, should it be given, is not expected before November 07, so funding is confirmed for the current system of PPI Forums and their Forum Support Organisations until at least March '08.

The Select Committee for Health has yet to report on its enquiry into "PPI in the NHS". The sheer volume of evidence it received has made the proper consideration of all the concerns a heavy task. However, the Committee is expected to produce its Report any day.

Forum members have been continuing to represent to the Dept of Health the Forums' misgivings over the proposed legislation, and to co-work with MPs of all parties. More recently, Forums' contacts with members of the House of Lords have been extended and developed as realistically, it now rests with the Lords to bring to Part 11 of this Bill the scrutiny it deserves and the amendments it requires.

The willingness of local authorities to take on their part, that of selecting and installing appropriate 'host' organisations for LINks in the proposed new system, is in question. Many have not even nominated a 'designated individual' despite being instructed in November '06 by the Minister of State for Health to do so.
The imminence of the local elections will pre-occupy all local authorities for some time.

In the meantime, Patient and Public Involvement Forums all over England continue their statutory responsibilities to monitor and assess services, and represent the interests of the patients and the public.

Ruth Marsden, 16th April, '07.

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Update No 7 –Patient and Public Involvement Forums, April 30th '07

On Friday 20th April '07, the Select Committee for Health released its Report, "PPI in the NHS". The findings were clear:
-there remains a real need for independent and effective patient and public involvement to counter the entrenched 'democratic deficit' in the NHS.
-the proposals to abolish PPI Forums and create LINks are unnecessary and ill-evidenced.
-the proposals are vague and woolly.
-the Minister's evidence to the committee was unconvincing.
-the balance of evidence shows that PPI Forums should remain.

Many parts of the country have big local authorities with very large populations. Typically, any LINk could have 200 NHS establishments on its patch. The burden of communicating with these would be massive and expensive, even before anything further was undertaken. This was unworkable.

Any failures of PPI Forums were in fact failures of the Commission. The proposal to abolish PPI Forums was driven by the need to abolish the Commission rather than by anything else.

While particular campaigns, such as hospital closures, sometimes attracted a lot of attention, those prepared to be involved in on-going PPI were few, and most of these were PPI F members.

Change to PPI was wholly undesirable in this period of unprecedented change in the provision of health services. By the time any new organisation had had time to bed in, two years or more would have passed without effective PPI oversight. This should not happen.

A National Association of Forums has at last been elected. This has the authority to spearhead further representations to the government for the retention of Patient and Public Involvement Forums.

Ruth Marsden, 30th April, '07.

Chair, SFYH

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Ruth Marsden

From: "Ruth Marsden"
To: "ruth" <ruth@myford.karoo.co.uk>
Sent: 13 May 2007 14:23
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Early Day Motion

EDM 1407 Printable EDM.. Signatures

PATIENT AND PUBLIC INVOLVEMENT IN THE NHS 02.05.2007

Vis, Rudi

That this House welcomes the Third Report of the House of Commons Health Select Committee, on Patient and Public Involvement in the NHS, and supports its recommendation that local involvement networks should have the same rights of entry to places where NHS care is provided as patient and public involvement forums have at present; believes that local involvement networks should not have to write to the regulator and wait for a reply before being able to visit premises and that the regulator should not have the ability to request a local involvement network to postpone its intended visit; and calls on the Government to remove proposed restrictions on service providers' duties to allow entry by local involvement networks from the Local Government and Public Involvement in Health Bill.

Signatures(22)
Standard Order ▾
Status
Open signatures ▾

- **Vis, Rudi**
- *Bottomley, Peter*
- *Etherington, Bill*
- *Cryer, Ann*
- *Gibson, Ian*
- *Conway, Derek*
- Jenkins, Brian
- Jones, Lynne
- McDonnell, John
- Meale, Alan
- Dismore, Andrew
- Hancock, Mike
- Hopkins, Kelvin
- Hoyle, Lindsay
- McCafferty, Chris
- Dobbin, Jim
- Drew, David
- Taylor, David
- Truswell, Paul
- Cable, Vincent
- Clapham, Michael

4.

Ruth Marsden

From: "Ruth Marsden"
To: "ruth marsden" <ruth@myford.karoo.co.uk>
Sent: 13 May 2007 14:24
Subject: EDMDetails

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Early Day Motion

EDM 1169

Printable EDM.. Signatures

PATIENT FORUMS 20.03.2007

Meale, Alan

That this House is aware that contained within the Government's proposed Local Government and Public Involvement Bill introduced on 12th December 2006 is its wish as identified in its clauses 153 to 164 to abolish Patient Forums and replace them with new bodies called LINks; recalls Patient Forums as being established just over three years ago in local primary care trusts in replacement of community health councils; believes such a move to be too hasty, ill-thought-out and if enacted likely to weaken considerably statutory independent local scrutiny and inspection of NHS provision; and calls upon the Government to desist from such moves and to give forums time to deliver their worthwhile remit.

Signatures(36)
Standard Order
Status
Open signatures

Meale, Alan
Vis, Rudi
Etherington, Bill
Penning, Mike
Leech, John
Taylor, David
Hopkins, Kelvin
Conway, Derek
Cryer, Ann
Wilshire, David
Williams, Stephen
Drew, David
Wyatt, Derek
Illsley, Eric
Winterton, Nicholas
Davies, Dai
Flynn, Paul
Stunell, Andrew
Davies, Philip
Hoyle, Lindsay
Jenkins, Brian
Cable, Vincent
George, Andrew

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McDonnell, John
Francis, Hywel
Simpson, Alan

44

Ruth Marsden

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Early Day Motion

EDM 313 Printable EDM.. Signatures

FUTURE OF PATIENT AND PUBLIC INVOLVEMENT IN HEALTH 27.11.2006

Lansley, Andrew

That this House believes that the design and delivery of NHS services benefit when patients and the public are fully involved both in decision making and in monitoring acute and primary healthcare; notes the Government's intention to abolish patient forums, which it set up after abolishing community health councils in 2003, and replace them with local involvement networks (LINks); is concerned that LINks will not have powers to inspect and monitor the NHS on behalf of patients, will not have the credibility with the public that accompanies true independence, and will not have the networking capability to represent patients on a regional or national level; believes that the Government should reconsider urgently its proposal for the future of patient and public involvement in health; and calls for the creation of a new body with both a national and a local presence which would be truly independent of health and social care services and would have the power to refer matters of concern to the health service regulator, so that patients and the public are given a much stronger voice in decisions about the NHS.

Signatures(44)
Standard Order ▾
Status
Open signatures ▾

Lansley, Andrew
Baron, John
Loughton, Tim
Murrison, Andrew
O'Brien, Stephen
Rosindell, Andrew
Spink, Bob
Lewis, Julian
Watkinson, Angela
Winterton, Ann
Winterton, Nicholas
Davies, Philip
Jackson, Stewart
Penning, Mike
Scott, Lee
Soames,

Moss, Malcolm
Featherstone, Lynne
Milton, Anne
Hemming, John
Willis, Phil
Robinson, Iris
Donaldson, Jeffrey
Cable, Vincent
Vaizey, Edward
Gray, James
Horwood, Martin
Garnier, Edward
Bercow, John
Pelling, Andrew

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List of MPs

Alison Seabeck
Alistair Burt
Andrew Gwynne
Andrew Lansley
Andrew Stunnell
Angela E Smith
Ann Cryer
Celia Barlow
David Davis
Eddie O'hara
Erci Illesly
Jeremy Wright
John Baron
John Pugh
John Reid
Jon Trickett
Jonathan Shaw
Kerry McCarthy
Kevin Barron
Lawrence Robertson
Lynn Brown
Lynda Waltho
Lynne Jones
Ann McCartney
Michael Fabricant
Neil Turner
Paul Truswell
Peter Bottomley
Peter Soulsby
Phil Woolas
Philip Davies
Philip Dunne
Richard Taylor
Robert Goodwill
Robert Neil
Robert Syms
Roberta Blackman-woods
Ronnie Campbell
Tom Brake
Tom Levitt
Eileen Wright

Crossbenchers with interests in health and related issues.

Baroness Finlay of Llandaff
Lord Habgood
Lord Walton of Detchant
Baroness Warnock MEDICINE

Lord Adebowale ALCOHOL, LEARNING
DIFFICULTIES

Lord Baldwin of Bewdley
Lord Burt
Viscount Brookeborough
Baroness Emerton
Baroness Finlay of LLandaff
Lord Kilpatrick of Kincraig
Countess of Mar
Baroness Masham of Ilton
Baroness McFarlane of Llandaff
Baroness Meacher
Baroness Murphy
Lord Quirk
#Baroness Richardson of Calow
Lord Stevenson of Coddenham
Lord Walton of Detchant. HEALTH

*Baroness Finlay of Llandaff
Lord Laming
#Countess of Mar
#Baroness Murphy
Lord Turner of Eccinswell HEALTH SERVICE

Lord Adebowale
Baroness Howarth of Breckland
Lord Molyneaux of Killead
Baroness Murphy
Lord Ouseley
Lord Patel
Lord Patel of Bradford
Lord Rix
Lord Stevenson of Coddenham
Lord Williamson of Horton MENTAL HEALTH

#Baroness Emerton
Baroness Howe of Idlicote
Baroness McFarlane of Llandaff NURSING

#Lord Patel WOMEN'S HEALTH

Lord Best
Viscount Brookeborough
Baroness Chapman
Baroness Darcy de Knayth
Baroness Howarth of Breckland
Lord Low of Dalston
Baroness Masham of Ilton
Lord Palmer
Baroness Richardson of Calow
Lord Rix
Lord Walpole

DISABILITY

= more than one area of interest

Members of the House of Lords.

Patient and Public Involvement in Health.

Lord Ramsbotham
Baroness Cumberlege
Baroness Masham
Earl Howe
Lord Harris of Haringey
Lord Carlile
Lord Alderdice
Lord Layard
Lord Ashley of Stoke
Lord Lofthouse
Lord Wallace of Saltaire
Lord Patel of Bradford
Rowan of Canterbury
Sentamu of York
Bishop of Ripon
Bishop of Peterborough
Bishop of Winchester
Bishop of Worcester
Bishop of Liverpool
Bishop of Leicester
Bishop of Chelmsford
Baroness Morgan
Lord Turnberg
Lord Bradley
Lord Dubs
Baroness Neuberger
Baroness Golding
Lord Haworth
Lord King of West Bromwich
Baroness Massey
Baroness Wall
Lord Rooker
??Baroness Jay
Lord Rea.

Statutory Instrument 2003 No. 2123

The Patients' Forums (Membership and Procedure) Regulations 2003

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STATUTORY INSTRUMENTS

2003 No. 2123

NATIONAL HEALTH SERVICE, ENGLAND

The Patients' Forums (Membership and Procedure) Regulations 200

Made	*13th August 2003*
Laid before Parliament	*14th August 2003*
Coming into force	*1st September 2003*

The Secretary of State for Health, in exercise of the powers conferred on him by sections 19(1) to (4) and 38(5) to (7) of the National Health Service Refor and Health Care Professions Act 2002[1] and of all other powers enabling hi in that behalf, hereby makes the following Regulations:

Citation, commencement, application and interpretation

1. - (1) These Regulations may be cited as the Patients' Forums (Membership and Procedure) Regulations 2003 and shall come into force on 1st September 2003.

(2) These Regulations apply to England only.

(3) In these Regulations -

"the Act" means the National Health Service Reform and Health Care Professions Act 2002;

"the 1977 Act" means the National Health Service Act 1977[2];

"chairman" means, unless the context otherwise requires, the chairman a Patients' Forum;

"Commission" means the Commission for Patient and Public Involvement in Health[3];

"the health service" shall be construed in accordance with section 128(1 of the 1977 Act;

"health service body" means -

(a) a Strategic Health Authority, Special Health Authority, Primary Car Trust or NHS trust;

(b) a Health Board or Special Health Board constituted under section 2 of the National Health Service (Scotland) Act 1978[4]; or the Scottish Dental Practice Board, the Common Services Agency for the Scottish Health Service or an NHS trust respectively constituted under sections 4 10 and 12A of that Act;

(c) the Dental Practice Board constituted under section 37(1) of the 197 Act;

"member" in relation to a Patients' Forum includes the chairman except where the context otherwise requires;

"PCT Patients' Forum" has the meaning given in section 16 of the Act

[5];

"primary care list" means -

(a) a list of persons undertaking to provide general medical services, general dental services, general ophthalmic services or, as the case may be, pharmaceutical services prepared pursuant to regulations made under sections 29, 36, 39, 42 or 43 of the 1977 Act[6];

(b) a list of persons approved for the purpose of assisting in the provision of any such services prepared pursuant to regulations made under section 43D of that Act[7];

(c) a services list referred to in section 28DA of that Act[8] or section 8ZA of the National Health Service (Primary Care) Act 1997[9]; or

(d) a list corresponding to a services list prepared by virtue of regulations made under section 41 of the Health and Social Care Act 2001[10].

Membership of Patients' Forums

2. - (1) A Patients' Forum established for an NHS trust shall have at least 7 members and a PCT Patients' Forum shall have at least 7 members plus members appointed under paragraph (4).

(2) Subject to regulation 6 (termination of tenure of office) a member's term of office shall be for a period between one year and four years as is agreed between the prospective member and the Commission at the time of the appointment.

(3) In appointing members to a Patients' Forum, the Commission shall ensure that -

(a) the majority of members are persons for whom services are being or have been provided by the NHS trust or Primary Care Trust for which the Patients' Forum is established and, in the case of a PCT Patients' Forum, are living in the area of the Primary Care Trust; and

(b) subject to regulation 4(1)(i), the members include persons who are members or representatives of a voluntary organisation whose purpose, or one of whose purposes, is to represent the interests of -

(i) persons for whom services are being provided under the 1977 Act, or

(ii) persons who provide care for such persons, but who are not employed to do so by any body in the exercise of its functions under any enactment.

(4) In the case of a PCT Patients' Forum, in addition to the 7

members referred to in paragraph (1), the Commission shall appoint members to include -

(a) at least one member of the Patients' Forum established for each NHS trust all or most of whose hospitals, establishments and facilities are situated in the area of the Primary Care Trust; and

(b) subject to regulation 4(1)(i), if it appears to the Commission that there is a body which represents members of the public in the Primary Care Trust's area in matters relating to their health, at least one person who is a member or representative of that body (or, if there is more than one such body, of any of those bodies).

Appointment of chairman and deputy chairman

3. - (1) The members may appoint

(a) one of their number to be chairman; and

(b) one or two of their number, other than the chairman, to be deputy chairman,

for such period as they may determine on making the appointment.

(2) A chairman may at any time resign from that office by giving notice to the members and to the Commission.

(3) A deputy chairman may at any time resign from that office by giving notice to the members.

Disqualification for appointment

4. - (1) Subject to regulation 5 (cessation of disqualification) a person shall be disqualified for appointment as a member if -

(a) he has within the preceding five years been dismissed, otherwise than by reason of redundancy, from any paid employment with a health service body;

(b) he is a person whose tenure of office as the chairman or as a member or director of a health service body has been terminated on the grounds that -

(i) it was not in the interests of, or conducive to the good management of, that body that he should continue to hold office,

(ii) it was not in the interests of the health service that he should continue to hold office,

(iii) he failed, without reasonable cause, to attend any meeting of that body for a period of 3 months or more, or

(iv) he failed to declare a pecuniary interest or withdraw from consideration of any matter in respect of which he had a pecuniary interest;

(c) he -

(i) is subject to a national disqualification imposed by the Family Health Services Appeal Authority constituted under section 49S[11] of the 1977 Act,

(ii) is subject to a national disqualification under a decision of the National Health Service Tribunal, which is treated as a national disqualification by virtue of regulation 6(4)(b) of the Abolition of the National Health Service Tribunal (Consequential Provisions) Regulations 2001[12],

(iii) has been refused nomination or approval to fill a vacancy for a medical practitioner pursuant to regulations made under section 29B(2A) of the 1977 Act[13] or refused admission to a primary care list, on grounds corresponding to the conditions referred to in section 49F(2),(3) or (4) of the 1977 Act[14] (efficiency cases, fraud cases and unsuitability cases) and has not subsequently been approved or, as the case may be, included in a primary care list,

(iv) is conditionally included in a primary care list,

(v) has been removed from a primary care list on any of the grounds set out in section 49F of the 1977 Act, or by a direction of the National Health Service Tribunal and has not subsequently been included in such a list,

(vi) is contingently[15] removed from a primary care list, or

(vii) is suspended from a primary care list or is treated as so suspended by virtue of regulation 6(2) of the Abolition of the National Health Service Tribunal (Consequential Provisions) Regulations 2001,

and in this sub-paragraph any reference to a provision in the 1977 Act includes a reference to the provision corresponding to that provision in Scotland and Northern Ireland;

(d) he is an employee, officer or member of the NHS trust or Primary Care Trust for which the Patients' Forum is established;

(e) in the case of a PCT Patients' Forum, he is an individual who, or an employee, officer or member of an organisation which, provides services under arrangements made by the Primary Care Trust;

(f) he is an employee, officer or member of the Strategic Health Authority which is responsible for performance managing the NHS trust or Primary Care Trust for which the Patients' Forum is established;

(g) he is a member of an executive of a local authority (within the meaning of Part II of the Local Government Act 2000 (arrangements with respect to executives etc.)[16]);

(h) he is an employee, officer or member of the Commission;

(i) he is a person who provides staff support to the Patients' Forum under a contract between the Commission and an organisation of which he is an employee, officer member or representative;

(j) he has previously served as a member of the Patients' Forum for 8 consecutive years and less than four years have passed since he ceased to be such a member;

(k) he is a member of another Patients' Forum, unless he is a member appointed to a PCT Patients' Forum under paragraph (4)(a) of regulation 2;

(l) he is a person whose role relates to the provision of independent advocacy services[17] as an employee, officer or member of an organisation (other than a PCT Patients' Forum) which provides such services;

(m) he is a member of the relevant overview and scrutiny committee (within the meaning of section 15 of the Act).

(2) For the purposes of paragraph (1)(a), a person shall not be treated as having been in paid employment by reason only of his having been the chairman or a member of, and in the case of an NHS trust, a member of the board of directors of, the health service body in question.

Cessation of disqualification

5. - (1) Subject to paragraph (2), where a person is disqualified under regulation 4(1)(a) he may, after the second anniversary of the day on which he was dismissed, apply in writing to the Secretary of State to remove the disqualification.

(2) Where the Secretary of State refuses an application to remove a disqualification, no further application may be made by that person until the second anniversary of the day of the refusal and this paragraph shall apply to any subsequent application.

(3) Where a person is disqualified under regulation 4(1)(b) the

disqualification shall cease on the second anniversary of the termination of his tenure of office, or such longer period as may be specified on the termination, but the Secretary of State may, on application being made to him by that person, reduce the period of disqualification.

Termination of tenure of office

6. - (1) A member may resign his office at any time during its term by giving notice to the Commission.

(2) Where the Commission is of the opinion that it is not in the interests of the Patients' Forum or the health service that a member should continue to hold office, it may terminate his tenure of office by giving him notice in writing to that effect.

(3) Where a person has been appointed to be a member, and -

(a) it comes to the notice of the Commission that at the time of his appointment he was disqualified under regulation 4, the Commission shall declare that the person in question was not duly appointed and notify him in writing to that effect; or

(b) he becomes disqualified for appointment under regulation 4 and notifies (as he should) the Commission; or

(c) he becomes disqualified for appointment under regulation 4 and this comes to the attention of the Commission otherwise than by the member's notification, the Commission shall notify him in writing of such disqualification,

and upon receipt of notification from the member or the Commission, as the case may be, his tenure of office, if any, shall be terminated and he shall cease to act as a member.

(4) If it appears to the Commission that a member has failed to comply with regulation 11 (disability of members in proceedings on account of pecuniary interest) it may terminate that person's tenure of office by giving him notice in writing to that effect.

Appointment of committees and joint committees

7. - (1) A Patients' Forum may appoint a committee to discharge, or assist it in discharging, any or all of its functions subject to such conditions as the Patients' Forum may consider appropriate.

(2) Two or more Patients Forums' may appoint a joint committee and arrange for such functions, in relation to any (or all) of those Patients' Forums, as those Forums agree, to be exercisable by the joint committee subject to such conditions as those Patients' Forums may consider appropriate.

(3) A committee or joint committee appointed under paragraph

(1) or (2) may consist wholly or partly of members of the appointing Patients' Forum or Forums provided that -

(a) a committee appointed under paragraph (1) shall have a minimum of two members of the appointing Patients' Forum; and

(b) a joint committee appointed under paragraph (2) shall have a minimum of one member of each of the appointing Patients' Forums.

(4) Sub-paragraphs (a), (b) and (c) of regulation 4(1) and regulation 5 shall apply to the appointment of members of committees and joint committees appointed under this regulation as they apply to the appointment of members of a Patients' Forum.

Funding, premises, other facilities and staff

8. - (1) The Commission shall provide such funding and secure the provision of such support, including staff and office accommodation, for each Patients' Forum as the Commission considers necessary to enable the Patients' Forum to perform its functions.

(2) Any staff provided under paragraph (1) shall be under the direction of the members.

Allowances

9. The Commission may pay to any member of a Patients' Forum, or of a committee or joint committee set up pursuant to regulation 7, such travelling or other allowances (including attendance allowances or compensation for loss of remunerative time) as it may determine.

Meetings and proceedings

10. - (1) Subject to the following paragraphs of this regulation and to regulation 11 (disability of members in proceedings on account of pecuniary interest), a Patients' Forum may conduct its meetings and proceedings in such a manner as it may determine.

(2) The proceedings of a Patients' Forum shall not be invalidated by any vacancy in its membership or by any defect in a member's appointment.

(3) Any member who wishes to have the assistance of a carer, advocate, interpreter or other helper may be accompanied by such person at any meeting of the Patients' Forum.

(4) No decisions shall be made in any proceedings or at any meetings of a Patients' Forum in relation to -

(a) agreeing annual and other reports;

(b) reviews to be carried out under section 15(3)(a) of the Act;

(c) agreeing the annual accounts;

(d) agreeing how expenditure of its annual budget is to be allocated; or

(e) making a referral to another body or person,

unless a majority of the members agree.

(5) Proceedings or meetings at which any of the matters referred to in paragraph (4) are to be discussed, shall be open to the public and, at least seven clear days before any such proceedings or meetings, a notice specifying the business to be transacted shall be published, and issued to individual members, in whichever way the Forum considers most appropriate.

(6) This regulation applies to a committee or joint committee set up under regulation 7 as it applies to the Patients' Forum and applies to a member of any such committee or joint committee (whether or not he is also a member of the Patients' Forum) as it applies to a member of the Patients' Forum.

Disability of members in proceedings on account of pecuniary interest

11. - (1) Subject to the following provisions of this regulation, if a member has any pecuniary interest, direct or indirect, in any matter and is present at any meeting of the Patients' Forum at which the matter is the subject of consideration, he shall at that meeting, and as soon as practicable after its commencement, disclose his interest and shall not take part in the consideration or discussion of the matter or vote on any question with respect to it.

(2) The Commission may, subject to such conditions as it may think fit to impose, remove any disability imposed by this regulation in any case in which it appears to the Commission to be in the interests of the health service that the disability should be removed.

(3) The Patients' Forum may exclude a member from a meeting of the Patients' Forum while any matter in which he has a pecuniary interest, direct or indirect, is under consideration.

(4) Any allowances paid or payable to a member by virtue of regulation 9 shall not be treated as a pecuniary interest for the purpose of this regulation.

(5) Subject to paragraphs (2) and (6), circumstances in which a member shall be treated for the purpose of this regulation as having an indirect pecuniary interest in a matter include -

(a) one where he, or a nominee of his, is a director of a company or other body, not being a public body, which has a direct pecuniary interest in the matter under consideration;

or

(b) one where he is a partner of, or is in the employment of, a person who has a direct pecuniary interest in the matter under consideration,

and in the case of persons living together as a couple (whether married or not) the interest of one shall, if known to the other, be deemed for the purpose of this regulation to be also an interest of that other.

(6) A member shall not be treated as having a pecuniary interest in any matter by reason only -

(a) of his membership of a company or other body if he has no beneficial interest in any securities of that company or other body; or

(b) of an interest in any company, body or person with which he is connected as mentioned in paragraph (5) which is so remote or insignificant that it cannot reasonably be regarded as likely to influence him in the consideration or discussion of, or in voting on, any question with respect to that matter.

(7) Where a member -

(a) has an indirect pecuniary interest in a matter by reason only of a beneficial interest in securities of a company or other body;

(b) the total nominal value of those securities does not exceed £5,000 or one-hundredth of the total nominal value of the issued share capital of the company or body, whichever is the lesser;

(c) if the share capital is of more than one class, the total nominal value of shares of any one class in which he has a beneficial interest does not exceed one-hundredth of the total issued share capital of that class; and

(d) he has declared his interest,

this regulation shall not prohibit him from taking part in the consideration or discussion of the matter, or from voting on any question with respect to it.

(8) This regulation applies to a committee or joint committee appointed under regulation 7 as it applies to the Patients' Forum and applies to a member of any such committee or joint committee (whether or not he is also a member of the Patients' Forum) as it applies to a member of the Patients' Forum.

(9) In this regulation -

6

"public body" includes any body established for the purpose of carrying on, under national ownership, any industry or part of any industry or undertaking, the governing body of any university, university college or college, school or hall of a university and the National Trust for Places of Historic Interest or Natural Beauty incorporated by the National Trust Act 1907[18];

"securities" means -

(a) shares or debentures, whether or not constituting a charge on the assets of a company or other body, or rights or interests in any share or such debentures; or

(b) rights (whether actual or contingent) in respect of money lent to, or deposited with, any industrial or provident society or building society;

"shares" means shares in the share capital of a company or other body or the stock of a company or other body.

Signed by authority of the Secretary of State for Health

Rosie Winterton
Minister of State, Department of Health

13th August 2003

EXPLANATORY NOTE

(This note is not part of the Regulations)

These Regulations make provision concerning the membership and procedure of Patients' Forums established by section 15 of the National Health Service Reform and Health Care Professions Act 2002. In particular, they make provision for the numbers, appointment, qualification for membership and tenure (regulation 2), the appointment of a chairman and deputy-chairman (regulation 3), disqualification for appointment (regulations 4 and 5), termination of tenure of office (regulation 6), the appointment of committees and joint committees (regulation 7), funding, premises, other facilities and staff (regulation 8), allowances (regulation 9), meetings and proceedings (regulation 10) and disability of members in proceedings on account of pecuniary interest (regulation 11).

Notes:

[1] 2002 c. 17.back

[2] 1977 c. 49.back

[3] Established under section 20 of the Act.back

[4] 1978 c.29. Section 2 was amended by the Health and Social Services and Social Security Adjudication Act 1983 (c. 41), Schedule 7, paragraph 1 and by the National Health Service and Community Care Act 1990 (c. 19) ("the 1990 Act"), section 25; section 4 was amended by the Health and Medicines Act 1988 (c. 49), section 12(3) and Schedule 3; section 10 was amended by the Health Services Act 1980 (c. 53), Schedule 6, paragraph 2 and the 1990 Act, Schedule 10; section 12A was inserted by the 1990 Act, section 31 and amended by section 46(1) of the Health Act 1999 ("the 1999 Act").back

[5] *See* also section 15(1)(b) of the Act under which such Patients' Forums are established.back

[6] Section 29 was extended by the Health and Medicines Act 1988 (c. 49) ("the 1988 Act"), section 17 and amended by the following: the Health Services Act 1980 (c. 53) ("the 1980 Act"), sections 1 and 7 and Schedule 1, paragraph 42(b), the Health and Social Services and Social Security Adjudications Act 1983 (c. 41), Schedule 6, paragraph 2, the Medical Act 1983 (c. 54), section 56(1) and Schedule 5, paragraph 16(a), S.I. 1985/39, article 7(3), The Health Authorities Act 1995 (c. 17) ("the 1995 Act"), Schedule 1, paragraph 18, the National Health Service (Primary Care) Act 1997 (c. 46), Schedule 2, paragraph 8, the 2001 Act, section 17 and the Act, Schedule 2, paragraph 3: section 36(1) was so numbered by the Health and Social Security Act 1984 (c. 48) ("the 1984 Act"), Schedule 3, paragraph 5(1) and amended by S.I. 1981/432, article 3(3)(a), S.I. 1985/39, article 7(10), the 1988 Act, Schedule 2, paragraph 4, the 1990 Act, section 24 and the 1995 Act, Schedule 1, paragraph 25(a); section 36(4) to (8) was inserted by the 2001 Act, section 20(1)(4)(c); section 39 was extended by the 1988 Act, section 17 and amended by the 1980 Act, sections 1 and 2 and Schedule 1, paragraph 52, the 1984 Act, section 1(4), Schedule 1, paragraph 1 and Schedule 8, S.I. 1985/39, article 7 (12), the 1995 Act, Schedule 1, paragraph 28, the 1999 Act, section 9(4), the 2001 Act, section 20(5) and 23(4) and the Act, Schedule 2 paragraph 12; section 42 was substituted by the National Health Service (Amendment) Act 1986 (c. 66), section 3 (1), extended by the 1988 Act, section 17 and amended by S.I. 1987/2202, article 4, the 1990 Act, section 12(3), the 1995 Act, Schedule 1, paragraph 30, by the 2001 Act, section 43(2), (3) and (4) and by the Act, Schedule 2, paragraph 16; section 43 was amended by the 1995 Act, Schedule 1, paragraph 31 and by the Act, Schedule 2, paragraph 17.back

[7] Section 43D was inserted by the 2001 Act, section 24 and

amended by the Act, Schedule 2, paragraph 20.back

[8] Section 28DA was inserted by the 2001 Act, section 26(1).back

[9] 1997 c. 46; section 8ZA was inserted by the 2001 Act, section 26(2).back

[10] 2001 c. 15.back

[11] Section 49S was inserted by the 2001Act, section 27.back

[12] S.I. 2001/3744. The National Health Service Tribunal was abolished by the 2001 Act, section 16 with effect from 14th December 2001, subject to article 2(5) and (6) of S.I. 2001/3738 which provided for a later commencement date for section 16 in respect of certain types of case before the National Health Service Tribunal.back

[13] Section 29B was inserted by the 1997 Act, section 32(1) and section 29B(2A) was inserted by the 2001 Act, section 20(1) and (3)(a) and amended by the Act, Schedule 2, Part I, paragraph 5 (1) and (2).back

[14] Section 49F was inserted by the 2001 Act, section 25.back

[15] *See* section 49G of the 1977 Act and the powers to make corresponding provision in sections 28DA(7) and 43D(6) of that Act.back

[16] 2000 c. 22.back

[17] *See* section 19A of the 1977 Act.back

[18] 1907 c. 36.back

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Prepared 29 August 2003

Statutory Instrument 2003 No. 2124

The Patients' Forums (Functions) Regulations 2003

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STATUTORY INSTRUMENTS

2003 No. 2124

NATIONAL HEALTH SERVICE, ENGLAND

The Patients' Forums (Functions) Regulations 2003

Made	*13th August 2003*
Laid before Parliament	*14th August 2003*
Coming into force	*1st September 2003*

The Secretary of State for Health, in exercise of the powers conferred on him by sections 15 (7), 17(1) to (3), 19(1) and (2)(j) to (p) and 38(5) to (7) of, and paragraph 12(1) and (2) of Schedule 6 to, the National Health Service Reform and Health Care Professions Act 2002[1] and of all other powers enabling hir in that behalf, hereby makes the following Regulations:

Citation, commencement, application and interpretation

1. - (1) These Regulations may be cited as the Patients' Forums (Functions Regulations 2003 and shall come into force on 1st September 2003.

(2) These Regulations apply to England only.

(3) In these Regulations -

"the Act" means the National Health Service Reform and Health Care Professions Act 2002;

"the 1977 Act" means the National Health Service Act 1977[2];

"the 2001 Act" means the Health and Social Care Act 2001[3];

"the Commission" means the Commission for Patient and Public Involvement in Health established under section 20 of the Act;

"working day" means any day other than a Saturday, a Sunday, Christmas Day, Good Friday or a day which is a bank holiday under the Banking and Financial Dealings Act 1971 in any part of the United Kingdom.

Joint exercise of functions and co-operation

2. - (1) Where a PCT Patients' Forum exercises functions in relation to services provided by an NHS trust under arrangements made by the Primary Care Trust for which the Forum is established, the PCT Patients' Forum and th Patients' Forum of that NHS trust shall co-operate with each other in the exercise of those functions.

(2) Where an NHS trust provides services under arrangements made by mo than one Primary Care Trust, the Patients' Forums established for the NHS tru and the Primary Care Trusts shall co-operate with each other in the exercise o their functions in relation to those services.

(3) Patients' Forums which have agreed that co-operation or joint exercise o functions would assist them in the exercise of their functions and would be in the interests of the health service, shall co-operate with each other or exercise functions jointly as agreed.

(4) PCT Patients' Forums shall co-operate with each other in determining

how best to provide or arrange for the provision of independent advocacy services. Where they agree that it is appropriate, two or more of them shall act jointly in providing or arranging for the provision of those services.

(5) In acting in accordance with paragraphs (1) to (4), Patients' Forums shall have regard to any advice given to them by the Commission.

Entry and inspection of premises

3. - (1) Subject to the following paragraphs of this regulation, persons authorised in writing by a Patients' Forum may at any reasonable time enter and inspect premises owned or controlled by -

(a) in the case of a PCT Patients' Forum, those mentioned in paragraph (3);

(b) in the case of a Patients' Forum established for an NHS trust, that NHS trust,

and, except where, in the opinion of those persons or bodies, this would compromise the effective provision of health services or patients' safety, privacy or dignity, and without prejudice to paragraph (2), those persons and bodies shall comply with any request for entry.

(2) Each person authorised by a Patients' Forum under paragraph (1) shall be furnished with written evidence of his authority and, on making a request for entry to any premises referred to in paragraph (1) for the purposes specified in that paragraph, if so requested by the owner or occupier of those premises or a person acting on either of their behalf, shall produce that evidence.

(3) Those referred to in paragraph (1)(a) are -

(a) Primary Care Trusts;

(b) Local Health Boards;

(c) local authorities;

(d) NHS trusts;

(e) persons providing services under Part 2 of the 1977 Act or under arrangements under section 28C of that Act;

(f) persons providing piloted services under pilot schemes established under section 28 of the 2001 Act, or providing services under an LPS scheme established under Schedule 8A to the 1977 Act; or

(g) persons who own or control premises where services as mentioned in (e) or (f) are provided.

(4) A person authorised by a Patients' Forum under paragraph (1) may not enter any premises or part of premises used as residential accommodation -

(a) by persons employed by any of the bodies referred to in paragraphs (3)(a) to (d);or

(b) by persons referred to in paragraphs (3) (e) to (g),

without first having obtained the consent of those persons.

(5) In exercising rights of entry and inspection under this regulation, a Patients' Forum shall have regard to the need to safeguard patients' safety, privacy and dignity, the need not to compromise the effective provision of health services, and to any advice given to it by the Commission.

Annual accounts

4. - (1) A Patients' Forum shall prepare and keep annual accounts in respect of each financial year which shall give a true and fair view of any income and expenditure and cash flows of the Patients' Forum for that financial year.

(2) The accounts shall be -

(a) prepared in a form agreed with the Commission;

(b) included in the Patients' Forum's annual report.

(3) A Patients' Forum shall send a copy of its annual accounts for each financial year to the Commission no later than 31st May after the end of that financial year and the Commission shall include a summary of all Patients' Forums' annual accounts in its annual accounts.

Obtaining information

5. - (1) Subject to regulation 6 (restrictions on disclosure of information to a Patients' Forum), a Patients' Forum may require those mentioned in paragraph (3) to produce any information which appears to the Patients' Forum to be necessary for the effective carrying out of its functions and those mentioned in paragraph (3) shall comply promptly and in any event no later than the twentieth working day following the date the requirement was made.

(2) A requirement made under paragraph (1) shall be in writing.

(3) Those referred to in paragraph (1) are -

(a) a Strategic Health Authority;

(b) an NHS trust;

(c) a Primary Care Trust;

(d) the Commission;

(e) a person providing independent advocacy services (within the meaning given by section 19A of the 1977 Act); and

(f) another Patients' Forum.

Restrictions on disclosure of information to a Patients' Forum

6. - (1) A person shall not be required to produce information under regulation 5 (obtaining information) which -

(a) is confidential and relates to a living individual, unless at least one of the conditions specified in paragraph (2) applies; or

(b) is prohibited from disclosure by or under any enactment or is protected by the common law, unless paragraph (3) applies.

(2) The conditions referred to in paragraph (1)(a) are -

(a) the information can be disclosed in a form from which the identity of the individual cannot be ascertained; or

(b) the individual consents to the information being disclosed.

(3) This paragraph applies where -

(a) the prohibition of the disclosure of information arises because the information is capable of identifying an individual; and

(b) the information can be disclosed in a form from which the identity of the individual cannot be ascertained.

(4) In a case where the information falls within paragraph (1)(a) or (3)(b), a Patients' Forum may require the person holding the information to disclose the information in a form from which the identity of the individual concerned cannot be ascertained.

Referrals to Overview and Scrutiny Committees

7. - (1) Where a Patients' Forum considers that the NHS trust or Primary Care Trust for which it is established is not carrying out its duty under section 11 of the 2001 Act, or is not doing so in a satisfactory manner, it may refer the matter to a relevant overview and scrutiny committee (within the meaning given by section 15(9) of the Act).

(2) A Patients' Forum shall not refer any matter under paragraph

(1) until it has made all reasonable efforts to resolve the matter with the NHS trust or Primary Care Trust concerned and it considers that those efforts have failed.

Annual and other reports

8. - (1) At the conclusion of each review carried out under section 15(3)(a) of the Act, a Patients' Forum shall prepare and produce a report to the Primary Care Trust or NHS trust for which the Forum is established.

(2) A report referred to in paragraph (1) shall include -

(a) an explanation of the methods used by the Patients' Forum to obtain the views of patients and their carers on the services reviewed; and

(b) a list of the Patients' Forum's members and, where appropriate and subject to their consent, of other participants involved in the review.

(3) A copy of the report referred to in paragraph (1) shall be provided to -

(a) any body or person, other than the NHS trust or Primary Care Trust for which the Forum is established, that provided the services reviewed;

(b) the provider of any independent advocacy services mentioned in the report;

(c) the Strategic Health Authority responsible for the performance management of the NHS trust or Primary Care Trust to which the report relates;

(d) any other Patients' Forum which had a role in carrying out the review;

(e) the Commission; and

(f) any other person or body requesting a copy of the report.

(4) Where a Patients' Forum requests a response from the NHS trust or Primary Care Trust for which it is established and to whom it has made a report or recommendation, that trust shall respond in writing to the Patients' Forum promptly and in any event no later than the twentieth working day following the date the request was made giving an explanation of -

(a) any actions it intends to take; or

(b) why it does not intend to take any action.

(5) If the trust from whom a response has been requested under paragraph (4) fails to respond in accordance with that paragraph,

or the Patients' Forum is not satisfied that appropriate action has been or will be taken by that trust following such a response, it may refer the matter to -

(a) the Strategic Health Authority responsible for the performance management of that trust; and

(b) a relevant overview and scrutiny committee (within the meaning given in section 15(9) of the Act).

(6) A Patients' Forum shall not refer any matter under paragraph (5) until it has made all reasonable efforts to resolve the matter with the NHS trust or Primary Care Trust concerned and it considers that those efforts have failed.

(7) A copy of any response made by a trust under paragraph (4) may be published by the Patients' Forum in whichever way the Forum considers most appropriate.

(8) A copy of a Patients' Forum's annual report shall be provided to any member of the public on request.

Signed by authority of the Secretary of State for Health

Rosie Winterton
Minister of State, Department of Health

13th August 2003

EXPLANATORY NOTE

(This note is not part of the Regulations)

These Regulations make provision in relation to the functions of Patients' Forums established under section 15 of the National Health Service Reform and Health Care Professions Act 2002.

The Regulations make provision in relation to the exercise of Patients' Forums' functions in England. In particular, they make provision for joint exercise of functions and co-operation (regulation 2), rights of entry and inspection of premises (regulation 3), annual accounts (regulation 4), the provision of information to Patients' Forums (regulations 5 and 6), referrals to overview and scrutiny committees (regulation 7), and annual and other reports (regulation 8).

Notes:

[1] 2002 c. 17.back

[2] 1977 c. 49.back

[3] 2001 c. 15.back

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PART 11 – PATIENT AND PUBLIC INVOLVEMENT IN HEALTH AND SOCIAL CARE

Introduction

363. Section 237 of the National Health Service Act 2006 (‘‘the 2006 Act’’) requires the Secretary of State to establish Patients' Forums for NHS trusts, Primary Care Trusts and NHS foundation trusts. The principal role of Patients’ Forums is to monitor and review the provision of health services on behalf of patients.

364. Section 243 of the 2006 Act provides for the Commission for Patient and Public Involvement in Health ("CPPIH"). The principal role of CPPIH is to advise the Secretary of State on arrangements for public involvement in, and consultation on, matters relating to the health service. CPPIH also represents, and manages the performance of Patients’ Forums.

365. Part 11 of the Bill makes provision for the abolition of CPPIH and Patients’ Forums. In their place, it imposes a duty on local authorities to make contractual arrangements for the involvement of people in the commissioning, provision and scrutiny of health services and social services. The means put in place under the contracts for involving people in this way are referred to as “local involvement networks”.

366. Section 242 of the 2006 Act provides for public involvement and consultation on the planning of the provision of health services, proposals for change in the way that those services are provided and decisions to be made affecting the operation of those services. Part 11 of the Bill amends section 242 as it applies to certain English health-service bodies. Section 242 also applies to NHS trusts all or most of whose hospitals, establishments and facilities are in Wales: the Bill does not alter the way in which section 242 applies to those trusts.

367. Part 11 also imposes a new duty on each Primary Care Trust to report on consultation arrangements and the influence that the results of consultation have on commissioning decisions.

368. Although the 2006 Act does not come into force until 1st March 2007, as it is a consolidation of the existing law, its provisions have the same effect as the provisions which it replaces.

Clause 153 - Health services and social services: local involvement networks

369. Clause 153 requires a local authority (as defined in clause 159) to make contractual arrangements for the purpose of ensuring that there are means by which the activities specified in subsection (2) can be carried out.

370. Those activities are:

- promoting and supporting the involvement of people in the commissioning, provision and scrutiny of local care services as defined in subsection (5);
- obtaining the views of people about their needs for, and experiences of, local care services and making these views known to people responsible for commissioning, providing, managing or scrutinising those services;

- making reports and recommendations about how local care services could be improved, to people responsible for commissioning, providing, managing or scrutinising those services;

371. Subsection (3) provides that the Secretary of State may by regulations add to, omit or vary the activities specified in subsection (2).

Clause 154 - Arrangements under section 153(1)

372. Clause 154(3) requires arrangements made under clause 153(1) to be made with a person who is not a local authority.

373. Clause 154(4) provides that a local involvement network must not be one of the bodies there specified. One result of this is that a person who contracts with a local authority under clause 153(1) will not be a local involvement network but will be responsible for ensuring that one or more local involvement networks are put in place. Clause 154(2) refers to the fact that a local involvement network could be a body (whether a body that takes on being a local involvement network in addition to its existing activities or a body set up specially to act as a local involvement network) or could be some other means of carrying on activities specified in clause 153(2).

374. Clause 154(5) enables arrangements to include the making of payments by the local authority.

375. Clause 154(6) provides that arrangements must include the required provision about annual reports (see clause 158).

Clause 155 - Duties of services-providers to respond to local involvement networks

376. Clause 155 provides that the Secretary of State may, by regulations, impose a duty on a services-provider to:

- respond to requests for information made by local involvement networks;
- deal with reports or recommendations made by local involvement networks.

377. Subsection (4) provides that the Secretary of State must consult such persons as he considers appropriate before making regulations under this section.

378. In clauses 155 and 156 "services-provider" includes: certain NHS bodies; and local authorities as defined in clause 159.

Clause 156 - Services-providers' duties to allow entry by local involvement networks

379. Clause 156 provides that the Secretary of State may, by regulations, impose a duty on services-providers to allow authorised representatives of local involvement networks to enter and view, and observe the carrying on of activities on, premises

controlled by services-providers. Such visits will enable local involvement networks to carry on, in particular, their activities in connection with the scrutiny of local care services and in connection with the making of recommendations about improving local care services.

380. Subsections (2) and (3) provide that the regulations may include conditions, restrictions and limitations.

381. Subsection (4) provides that the Secretary of State must consult such persons as he considers appropriate before making regulations under this section.

382. In clauses 155 and 156 "services-provider" includes: certain NHS bodies; and local authorities as defined in clause 159.

Clause 157 - Local involvement networks: referrals of social care matters

383. Clause 157 provides that where a local involvement network refers a matter relating to social care services to an overview and scrutiny committee, that committee must acknowledge receipt of the referral and keep the referrer informed of the committee's actions in relation to the matter.

384. Subsections (3) and (4) require the committee to decide whether its powers are exercisable in relation to the matter and, if they are, whether or not they are to be exercised.

385. Subsection (5) provides that in exercising its powers in relation to the matter, the committee must take into account relevant information provided to it by a local involvement network.

386. Subsection (6) provides that the Secretary of State may by regulations make provision as to the time by which an overview and scrutiny committee must acknowledge receipt of a referral made by a local involvement network.

387. "Overview and scrutiny committee" is defined in subsection (8) since not all local authorities have overview and scrutiny committees appointed under section 21 of the Local Government Act 2000. In the case of the Council of the Isles of Scilly, it is required to appoint a committee under that section by virtue of the Isles of Scilly (Functions) (Review and Scrutiny of Health Services) Order 2004 (Statutory Instrument 2004 No. 1412) made under section 265 of the Local Government Act 1972.

Clause 158 - Local involvement networks: annual reports

388. Clause 158 sets out the required provision about annual reports referred to in clause 154(6).

389. Subsection (2) requires that the arrangements entered into by a local authority must make provision, for each local involvement network, for an annual report in relation to the activities of the network.

390. Subsection (3) provides that the report must address, in particular, such matters as the Secretary of State may direct and must include details of amounts spent in relation to the network's activities.

391. Subsection (5) provides that a copy of the report must be sent to:

- the local authority;
- each Primary Care Trust and Strategic Health Authority in the area concerned;
- any relevant overview and scrutiny committee of the local authority;
- the Secretary of State; and
- any other person the Secretary of State directs.

Abolition of Patients' Forums etc

Clause 160 - Abolition of functions of Patients' Forums

392. Clause 160 abolishes specified functions of Patients' Forums and makes provision for final reports and accounts.

Clause 161 - Abolition of Patients' Forums

393. Clause 161 abolishes Patients' Forums and makes provision for the transfer of property, rights and liabilities of each forum to the Secretary of State for Health.

Clause 162 - Abolition of Commission for Patient and Public Involvement in Health

394. Clause 162 abolishes the Commission for Patient and Public Involvement in Health and makes provision for the transfer of property, rights and liabilities of the Commission to the Secretary of State for Health. Subsection (5) states that the Secretary of State may fix the Commission's final reporting period.

Consultation about health services

Clause 163 - Duty to consult users of health services

395. This clause amends section 242 of the National Health Service Act 2006 ("the 2006 Act").

396. Section 242 applies to Strategic Health Authorities, Primary Care Trusts, NHS trusts and NHS Foundation Trusts. However, the amendments do not change how section 242 applies to NHS trusts all or most of whose hospitals, establishments

and facilities are located in Wales. The amendments do alter how section 242 applies to the rest of the bodies to which the section applies, and the bodies to which the amendments do apply are referred to as "relevant English bodies". The amendments replace the existing duty imposed by section 242 on relevant English bodies with a new duty to make arrangements to consult with the users of health services.

397. The new section 242(1B) provides that relevant English bodies must consult on the planning of the provision of services, the development and consideration of significant proposals for change in the way services are provided and significant decisions affecting the operation of services.

398. New section 242(1C) to (1E) establish when proposals or decisions are "significant" for the purposes of new section 242(1B)(b) and (c).

399. New section 242(1G) provides that a relevant English body must have regard to any guidance issued by the Secretary of State as to the discharge of its new duty under section 242(1B).

Clause 164 - Primary Care Trusts: reports on consultation

400. This clause provides that each Primary Care Trust must, at such times as the Secretary of State may direct, prepare a report on the consultation it has (or proposes) to carry out and on the influence the results of consultation have on its commissioning decisions. Subsection (3) provides that the Secretary of State may give directions in this respect.

242 Public involvement and consultation

(1) This section applies to-

(a) Strategic Health Authorities,

(b) Primary Care Trusts,

(c) NHS trusts, and

(d) NHS foundation trusts.

(2) Each body to which this section applies must make arrangements with a view to securing, as respects health services for which it is responsible, that persons to whom those services are being or may be provided are, directly or through representatives, involved in and consulted on-

(a) the planning of the provision of those services,

(b) the development and consideration of proposals for changes in the way those services are provided, and

(c) decisions to be made by that body affecting the operation of those services.

(3) For the purposes of this section a body is responsible for health services-

(a) if the body provides or will provide those services to individuals, or

(b) if another person provides, or will provide, those services to individuals-

(i) at that body's direction,

(ii) on its behalf, or

(iii) in accordance with an agreement or arrangements made by that body with that other person,

and references in this section to the provision of services include references to the provision of services jointly with another person.

(4) Subsection (5) applies to health services for which a Strategic Health Authority is not responsible by virtue of subsection (3), but which are or will be provided to individuals in the area of the Strategic Health Authority, and for which-

(a) a Primary Care Trust any part of whose area falls within the Strategic Health Authority's area, or

(b) an NHS trust which provides services at or from a hospital or other establishment or facility which falls within the Strategic Health Authority's area,

is responsible by virtue of subsection (3).

(5) A Strategic Health Authority may give directions to Primary Care Trusts falling within paragraph (a) of subsection (4), and NHS trusts falling within paragraph (b) of that subsection, as to the arrangements which they are to make under subsection (2) in relation to health services to which this subsection applies.

DRAFT – DO NOT COPY

Service specification and tender requirements for the provision of a Local Involvement Network (LINk)

This document in is two parts. Firstly, the specification sets out some basic requirements of what the Department of Health expects from both a LINk and its host organisation. The specification is a starting point for the contract with a host organisation and the subsequent development of a LINk and is not a final document. Local authorities will need to ensure that it is applied to their style of commissioning and integrate it with any existing standard documentation.

The Department of Health will produce more detailed guidance for LINks and host organisations once the Local Government and Public Involvement in Health Bill receives Royal Assent. This guidance will set out, for example possible LINk governance structures and arrangements for carrying out engagement activities.

Secondly, the draft tender requirements set out some of the requirements that local authorities can use to advertise for a host organisation. They are a starting point for the tendering of a host and again do not constitute a final document. Commissioners may wish to integrate the content of a draft document with any existing, local standard documentation.

Introduction

The nature of health and social care delivery has changed radically in recent years. The changes to the configuration of Primary Care Trusts (PCTs), their changing role to focus on the commissioning of services, the move towards greater choice of service delivery and increased joint commissioning across health and social care are just some examples of how significantly the system has changed.

These changes and the launch of the Your Health, Your Care, Your Say consultation prompted the Department of Health in August 2005 to undertake a strategic review of patient, user and public involvement. .

The White Paper, *Our health, our care, our say: a new direction for community services* published in January 2006, set out the key elements for delivering a 'stronger voice' for users of health and social care services and the public in the development of those services.

A stronger local voice published in July 2006 set out Government policy on the future development of the patient, user and public involvement system. This included proposals to establish Local Involvement Networks (LINks). These networks will be able to provide flexible ways for communities to engage with health and social care organisations in ways that best suit the communities and the people in them. They will build on the best work of Patient and Public Involvement Forums and many other user involvement activities creating a strengthened system of user involvement and will promote public accountability in health and social care through open and transparent

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communication with commissioners and providers. Further details were set out in the Government response published in December 2006.

Each local authority with social services responsibilities (county council, unitary authority and London Borough Council, plus the Isles of Scilly and the Common Council for the City of London) will have a statutory duty to make contractual arrangements with a host organisation, on receipt of money from the Secretary of State for Health. In accordance with its contract with the local authority, the host will be responsible for the establishment, maintenance and support of a LINk in the local authority area to carry out the following activities:

- promoting and supporting the involvement of people in the commissioning, provision and scrutiny of local health and social care services;
- obtaining the views of people about their needs for, and their experiences of local health and social care services; and
- making their views known to the people responsible for commissioning, providing, managing and scrutinising those services.

The proposed legislation to create this duty forms part of the Local Government and Public Involvement in Health Bill which was introduced to Parliament in December 2006. The specification and tender requirements are intended to assist local authorities in making their contractual arrangements.

Given the skill requirements of host organisations, it is likely that they will chiefly be drawn from local non-profit organisations with skills in community development, networking and links to a wide range of organisations and communities.

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Service specification for the provision of a LINk

1.0 Timing

1.1 The duty on the relevant local authorities to make contractual arrangements with a host organisation will be in place after commencement of the Local Government and Public Involvement in Health Act. LINks will then be able to be established and become fully operational once any necessary regulations have been laid and debated in Parliament.

1.2 We would expect contracts to be let to host organisations for a 3 year period, subject to satisfactory performance.

2.0 Purpose

2.1 LINk

2.1.1 Local Involvement Networks (LINks) should be local community-based networks of organisations and individuals committed to strengthening and widening the voice of patients, users of social care services and the public in the process of planning and improving health and social care services. We envisage that LINks will have a wide membership and involvement which is inclusive, diverse and made up of both individuals and organisations and will need to utilise different formats and methods of involvement and communication.

2.1.2 LINKs' role will be to:

- promote and support the involvement of people in the commissioning, provision and scrutiny of health and social care services;
- obtaining the views of people about their needs for, and experiences of, health and social care services and making these views known to people responsible for commissioning, providing, managing or scrutinising those services; and
- making reports and recommendations about how health and social care services could be improved, to people responsible for commissioning, providing, managing or scrutinising those services.

2.1.3 We are not seeking to prescribe how their role will be carried out, LINks will be able to determine what work they do, when and how.

2.1.4 LINks will be a key part of enabling effective citizen engagement in health and social care decision-making at a local strategic level, getting involved, for example, in PCT and local authority commissioning decisions and engaging with PCTs in the development of the PCT prospectus that will demonstrate how the public have influenced decisions. LINks will be independent and should be accountable to their membership and the local community as well as to the Secretary of State for Health. This will enable them to establish a local agenda driven by the priorities and interests of local communities. A LINk can only be successful in this if it is strong, credible and inclusive across its community.

2.1.5 LINks should reach out into communities that experience exclusion from traditional decision-making processes in health and social care to ensure that their views and opinions are both audible and influential. LINks and their hosts need to acknowledge that communities are not homogenous but are made up of individuals with diverse needs and preferences, rights and entitlements, and that some groups are particularly disadvantaged or vulnerable to breaches of their human rights. LINks should have a role in providing capacity building support to those people who are not accustomed to having their views heard or indeed conveying their views, through training or mentoring.

2.1.6 The LINk will operate independently of the local authority, within its own governance structure and decision making processes. The host organisation will enable and support the LINk members.

2.1.7 LINks will have specific powers to enable them to influence the improvement of local services. These powers mean they will be able to:

- enter specified types of premises and view the services provided;
- request information and receive a response within a specified timescale;
- make reports and recommendations and receive a response within a specified timescale; and,
- refer matters to an Overview and Scrutiny Committee (OSC) and receive a response.

2.2 LINk governance arrangements

2.2.1 Arrangements should be put in place to provide leadership for the LINk. The form of this governance structure will be for the membership to decide, supported by the host organisation and Department of Health guidance setting out examples of best practice. This might be achieved, for example, by the membership electing a Board or the members might choose to take a co-operative approach. The chosen governance structure will need to:

- Agree the overall priorities and work plan of the LINk in consultation with the wider LINk membership.
- Have an overview of the wider LINk membership including being the arbiter of membership decisions within the governance framework
- Create, review and make recommendations on the governance framework.
- Decide where, when, how and by whom its powers should be used.
- Sign off external reports.
- Ensure the LINk operates within the agreed governance framework and for the purpose it was intended.
- Promote the LINk and report on its activities including production of its annual report.
- Contribute to the Performance Management of the Host by the local authority.
- Ensure that equality and human rights principles are integral to the LINks work

2.2.2 The governance structure should always seek to involve and communicate with the wider LINk membership in all its activities. It should not itself act as a consultative body or speak on behalf of the LINk without its involvement and consent. The governance structure will carry out its function with the support of the Host.

2.3 Host

2.3.1 It will be for the LINk to decide what work it does, when and how and how to spend its funds. The purpose of a host organisation is to enable, support and guide the LINk in their activities. The hosts' role will be to:

- Work with the LINk membership to facilitate the establishment of the LINk's governance arrangements for managing and deciding its activities. The governance arrangements would include terms of reference for the LINks governance structure, LINk membership and participation, decision-making arrangements, dispute resolution.

- The Host is required to operate within the agreed performance frameworks laid down in its contract with the local authority. LINk governance arrangements are a matter for the LINk membership and do not come under the control of either host or local authority. The LINk will have to bear in mind the resources of the host when determining its governance arrangements.

- Hold the finance of the LINk
    - be the responsible accounting organisation for the LINk expenditure decisions – the LINk is responsible for how the money is spent but the host will hold the finances and report where necessary on how the money is spent.
    - meet audit and accounting requirements
    - Report on expenditure against activity – both to the LINk and externally as agreed by the LINk governance structure.

- In partnership with existing LINk members, recruit members to the LINk:
    - Advertise and promote the LINk
    - Hold introductory workshops/meetings
    - Make contacts with existing voluntary and community sector and user led groups to encourage joining up
    - Seek out membership and involvement from hard to reach/under represented groups
    - Arrange any training and development as appropriate.
    - Develop local networks to support ongoing sustainable recruitment activity

- Support the LINk in the development and promotion of its priorities and work plan and activities. This might include:

  - Questionnaires and surveys
  - Community / Citizen Panels
  - Consultation and Involvement Workshops
  - Focus Groups
  - Events and campaigns
  - Staff to operate on an outreach basis to meet, listen to and record the views and experiences of local people
  - LINk governance Meetings
  - Provide appropriate venues and support for the LINks activities utilising wherever possible existing community and public facilities and venues of stakeholder organisations.

- Facilitate the correspondence and communication activities of the LINk, including, for example, regular LINK members newsletters and the maintenance of a web site to ensure LINk information is publicly available to interested parties and that the public can put forward their views and experiences easily

- Data management and record keeping

- Provide advice and support for the LINk
  - Explain or signpost any national guidance to LINk members
  - Liaise with the NHS National Centre for Involvement (NCI) and the Social Care Institute for Excellence (SCIE) and others for best practice guidance on supporting of a LINk, methods of consultation etc.
  - Resolve disputes and have in place their own complaints policy (according to the established guidance)
  - Facilitate the establishment of a member code of conduct/constitution and enable the LINk to manage complaints of conduct within the agreed governance framework (based on Department of Health guidance and models of good practice)
  - Reimburse LINk members reasonable out-of-pocket expenses
  - Allow convenient access for LINk members to relevant information from DH, NHS, voluntary sector organisations etc…

- Assist to develop effective working relationships with local partners, e.g. liaison with
  - the local authority, OSC(s) and PCT(s)
  - Health and social care providers
  - Health and social care regulators
  - LSP partners, achieving agreed and mutual targets/outcomes
  - other hosts/LINks

- Report back to the local authority on LINk/host activity in accordance with the terms of their contract and ensure LINk annual report on expenditure, activity and achievements is sent to the Department of Health

3.0 Principles

3.1 A LINk should seek to represent the views of all sections of its population, either through membership, open to organisations and individuals, or by reaching out to the community, especially those under-represented parts of it to gather their views. It is not necessary for individuals or organisations to become formal 'members' to be involved.

3.2 A LINk should base any reports, recommendations or referrals on solid evidence which encompasses views from an appropriate cross-section of the local population.

3.3 LINks should be transparent and open in their governance arrangements, in accordance with the Nolan principles.

3.4 LINks should develop a strategic focus, looking at for example, service commissioning.

3.5 A LINk (and the service a host provides) must be appropriate to people's needs and not discriminate on the grounds of their disability, race, culture, religion, sexuality, age and gender, both in terms of membership and obtaining and presenting those peoples' views or experiences. A LINk should actively encourage the involvement of traditionally excluded groups.

3.6 The host organisation must provide high quality support and guidance to enable a LINk to carry out its activities.

3.7 LINks and their hosts must have a strong commitment to forming strategic partnerships with other organisations.

4.0 Accessibility

4.1 The host organisation's premises and any proposed venues for meetings arranged for the LINk must be accessible and compliant with the Disability Discrimination Act 1995 and Equality Act 2006 and must maintain a safe and clean working environment in compliance with Health and Safety at Work Legislation.

4.2 Any communication methods used must respond to user needs – translating and interpreting facilities should be available to provide information in the major community languages or in specialist formats such as braille or audio.

4.3 The host organisation's office hours should be fully communicated to LINk members as well as staff contact details, any changes in staff or absences. The host should agree with the LINk governance structure how they would like relevant information to be cascaded to the LINk membership and the wider community.

4.4 The host organisation should encourage compliance with both the Data Protection Act 1998 and the Freedom of Information Act 2000 and ensure that LINk members are aware of their responsibility under both of these acts.

5.0 Contract Monitoring and Management

5.1 Host to local authority

5.1.1 The Host Organisation should be contractually required to report on its activities and finances to the local authority at least on a 6 monthly basis during the term of the agreement and more frequently if this is required as part of a formal performance management review process.

5.1.2 The host organisation will be expected to report on the activities of the LINk in relation to:

- The LINks work plan;
- Reports and publications including those set out in the Department of Health guidance;
- Key Indicators as agreed locally based on suggested criteria to be set out in Department of Health guidance;
- Host's activities and financial report against the contract with the local authority.

5.1.3 The six monthly reviews will also take into account feedback and recommendations from the LINk governance structure including proposals on how the host might support the LINk better.

5.1.4 Regular meetings will be organised by the local authority to review this information and to amend and improve this specification and the host organisation and representatives of the LINk Board will be expected to be full partners in this process. It is essential for the LINk to be able to input into the local authorities performance management of the host.

5.1.5 The Host organisation will need to be able to demonstrate its performance of the contract to local authorities by the fulfilment of key performance indicators to be agreed locally. The Department of Health will set out a minimum set of requirements that a host of a LINk should reach in order to satisfy the requirements of the contract, in guidance to follow this year.

5.1.6 The host organisation will be accountable to the local authority as the contract holder. The host is expected to undertake regular reviews or audits of its service and to link these to its development plans. The host organisation should have a written complaints procedure, which should include a role for a person who is independent of the organisation, as either an investigator or decision maker at an appeal stage.

5.1.7 A regular performance review meeting will be organised by the local authority to ensure the host is performing and as a result meeting the LINk's need and ensuring its success locally. It is essential that the LINk inputs into the local authorities performance management of the host.

5.1.8 Where the host's own management reporting, stakeholder feedback, the review process or other contract management activities reveal the need for remedial action, the host must agree a timetable for submission of an action plan which:

- Identifies in detail the issues and associated risks;
- Identifies appropriate solutions;
- Identifies responsible owners for all remedial actions required;
- Indicates timescales for all remedial actions; and
- Identifies monitoring arrangements to ensure remedial actions completed.

5.1.9 The host organisation should have its own internal quality assurance system, which should include standard setting, monitoring, management and review processes, to ensure the required service quality is maintained.

6.0 Accountability

6.1 LINk to local people and centre

6.1.1 A LINK should be accountable for its activities to the local community. It must provide evidence that it is delivering a credible work programme, based on local priorities, that meets local needs. This evidence needs to demonstrate active outreach and engagement with communities and the outcome of that outreach. This could be achieved in a number of ways, for example, by publishing their work programme with a transparent description of how they decided their priorities based on what they have heard is important to local people.

6.1.2 The LINk governance structure, on behalf of the wider LINk will report to the Secretary of State for Health on an annual basis on the activities of the LINk. The report will be independent of the local authority and be produced with the support of the host organisation. This report should also be made publicly available. The report should provide details of:

- How much money was spent on the LINk at a local level;
- How many people were 'involved' and how – what it has done in the course of the year including details of whom it has heard from, what subjects it dealt with, what were the outputs of its activities and what happened as a result; and
- General themes about the health and social care needs of local people and about the perceptions of health and social care services.

6.1.3 Examples of the contents of the report will be part of the supportive materials set out in the LINk guidance to enable individual reports to be summarised into a National LINKs report which will be laid in Parliament. The Department of

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Health will be asking a suitable organisation such as the NHS Centre for Involvement to assist them in the production of the National LINks report.

6.2 LINk to local authority

6.2.1 The LINk is not accountable to the local authority. Local authorities will have the role of procuring the host organisation that will support the LINk. It will not however, have any power in determining the LINk's actions or the way in which it spends its money – this will be for the LINk to decide itself.

6.3 Host to LINk

6.3.1 As set out in 2.3 the purpose of a host organisation is to enable, support and guide the LINk in their activities. It will be for the LINk to decide what work it does, when and how and how to spend its funds. The host will be accountable to the LINk for any actions it takes on its behalf or any money it spends.

7.0 Funding

7.1 Local authorities will receive an allocation of funding via a specific grant from the Department of Health based on XX funding formula. This will mean each local authority will receive a targeted amount of money depending on its size and population.

7.2 Host organisations will outline their costs to provide the support function to LINks, within the total proposed budget, and to give a breakdown of how this is arrived at. Headings will include: 1) Administration and overheads; 2) Management, training and supervision; 3) LINk member expenses; 4) communication costs – translation, accessibility (of written materials and events), newsletters etc…

8.0 **Possible indicators** (– work is in process to develop indicators – there are currently only a few included as examples.)

8.1 A LINk will be a success if it addresses the following lettered points, there are some examples of bulleted performance indicators attached to these to enable them to demonstrate success – these will need to be decided locally. It is important that the Key Performance Indicators (KPIs) focus on the qualitative aspects such as quality of interaction, the building of relationships, influence and achievements as well as the number of people reached, reports made etc…. Outcomes and KPIs will need to be negotiated locally to ensure they are appropriate to local circumstances and informed by the knowledge and experience of the local partners.

(a) People know of its existence, what its role is and perceive it as a credible local organisation
(b) People are able to gain access to it through the avenues and opportunities that suit them
(c) People know what it is doing and why, and are able to comment on it

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- Total number of (a) members and (b) people a LINk has heard from in the course of its activities and through what medium, eg. via a web site, through interviews, by receipt of letters or comment cards, in public meetings
- Relevant web presence
- Total number of hits to website
- Breakdown of what opportunities the LINk has put in place to enable peoples' views to be heard, and how often those opportunities have been put in place
- breakdown of membership recruitment and turnover
- records of any complaints or compliments the LINk or host receives

(d) It has reached out widely and deeply into the community and can show evidence of the effectiveness of this.

- demographic breakdown of (a) membership and (b) the people it has heard from, broken down by age, gender and ethnicity
- LINk policy/strategy on equality & diversity and community engagement in place
- Open and transparent mechanism setting out how the LINk governance structure reflects local demographics

(e) It knows what peoples' needs are for health and social care services – it should have an evidence base which encompass views from an appropriate section of the local population

(f) It has an evidence base of how people in its area perceive the health and social care services they have received

-

(g) It has identified areas in which health and social care services can be improved in the eyes of the public or users of services – and has made recommendations to those bodies responsible for those service.

- breakdown of how many requests for information it made to health and social care commissioners and providers and what the subjects of those requests were
- breakdown of how many reports, recommendations or referrals it made to:
  (i) health service commissioners
  (ii) health service providers
  (iii) social care commissioners
  (iv) social care providers
  (v) overview and scrutiny committees
  (vi) Strategic Health Authorities
  (vii) health and social care regulators
  and what the subjects of those reports were
- what actions resulted from its reports and recommendations

(h) It has established constructive and open relationships with health and social care commissioners and providers
(i) It has a focus on partnership, outreach, networking, relationship building and making common cause
(j) It has a constructive and open relationship with its support organisation
(k) It has a constructive and open relationship with relevant overview and scrutiny committees, with health and social care regulators, with Strategic Health Authorities and with local voluntary and community sector organisations
(l) It is rated by key local organisations as a credible partner, scrutineer and holder to account

-

(m)It is able to account (via the host) for the money that has been made available to it to fulfil its activities

- how much money it spent, and a breakdown of what it spent it on

8.2 The local authority may want to attach its standard clauses on equal opportunities, employment practices, misconduct, adult abuse policy and insurance policy.

Tender requirements for the provision of a LINk

1.0 General requirements

1.1 The host organisation should:

(i) Provide information on its size, organisational structure and experience; its constitution and its code of practice (if it has one);

(ii) Demonstrate experience of providing similar type of support service or explain how it will develop this skill;

(iii) Show experience of working in community development and networking and demonstrate capacity and ability of networking both locally and at a national level;

(iv) Demonstrate knowledge of LINk locality and networks and groups already working in the area;

(v) Demonstrate knowledge of health and social care and experience of working in this field;

(vi) Illustrate experience of providing a service which demonstrates an active commitment to equal opportunities;

vii) Illustrate experience of working with all sectors of the community, providing examples of translating equality and human rights principles into practice.

viii) Demonstrate experience of working with people from ethnic minorities; those who do not have English as their first language; those who need specialist communication tools and those who communicate through informal methods.

ix) Confirm that it employs staff in a manner that ensures the staff are fit for purpose;

x) Demonstrate it can deliver the contract without any conflict of interest. It will need to state what interests it has and demonstrate that it can deal with these.

xi) Provide an annual report together with financial accounts for the last financial year, as well as details of its public and employers' liability insurance (if it has any).

xii) Provide information on methods of working.

2.0 Method of working

2.1 The host organisation should provide:

i) A description of its existing experience (if applicable) with a) volunteers in local communities; b) community development, and c) networking;

ii) A description of similar types of support it has provided;

iii) Any related policy documents, together with any case studies.

2.2 The host organisation should also:

i) specify the number of staff they propose to dedicate to support the LINk (within the stated budget) and whether these are part time or full time;

ii) describe its proposed monitoring arrangements;

iii) identify what indicators and methods would be used to evidence that individual and service outcomes have been achieved.

3.0 Funding

3.1 Local authorities will receive an allocation of funding via a specific grant from the Department of Health based on XX. This will mean each local authority will receive a targeted amount of money depending on their size and population.

3.2 Host organisations will be asked to outline their costs to provide the support function to LINks, within the total proposed budget, and to give a breakdown of how this is arrived at. Headings will include: 1) Administration and overheads; 2) Management, training and supervision; 3) LINk member expenses; 4) communication costs – translation, accessibility (of written materials and events), newsletters etc…

3.3 Appropriate outcomes will be agreed with the host organisation to ensure value for money and good results for the LINk established.