Health Link's view on the Essentials of Patient & Public Involvement in Health & Social care

1. Background to this paper

During the committee stage of the Local Government and Public Involvement in Health Bill, the House of Commons Bill Committee invited evidence from Health Link on Part 11 of the Bill and requested this paper. The Bill abolishes Patients Forums and the Commission for Patient and Public Involvement in Health (CPPIH), set up by the NHS Reform and Healthcare Professions Act 2002 and replaces them with Local Involvement Networks at local level (LINks). Patients Forums and CPPIH were themselves a replacement for Community Health Councils (CHCs) and the Association of Community Health Councils for England and Wales (ACHCEW), set up in 1974 and 1977 respectively. A matrix comparing the functions, powers and provisions relating to the three variations in patient and public involvement (PPI) is attached at Appendix 1.

Health Link is a social enterprise working on PPI in health, set up in January 2004 as a company limited by guarantee. It is funded from contract work with the Department of Health and other agencies, with a small amount of grant funding. Like the voluntary sector generally, Health Link's independence is protected by the Compact with government. Its Director and Management Committee have variously been involved in PPI for over 10 years and include ex CHC members now on Patients Forums, a local councillor and an NHS PPI lead previously a CHC Chief Officer. More detail is given in Appendix 2.

In the short time available we have endeavoured to validate our views by circulating this paper to our 120 strong London PPI network and to those Patients Forums whom we are able to contact. We also requested its distribution by CPPIH to Forum members and invited views on it from the NHS Confederation. We will forward these responses to the Committee.

2. Our views on the essentials of effective patient and public involvement (PPI)

A brief description is given below of our essentials for effective PPI in health and social care. We consider the prime purpose of PPI to be to improve the users' experience of, and access to care services and to facilitate public accountability for those services locally, regionally and nationally. Users should always specifically but not exclusively include those at risk of social inclusion or health inequalities.

2.1 Functions:

a) **Influencing** health and social care policy-making, strategic planning, and the commissioning, design and delivery of care services. ***How:*** the host organisation must provide clear information to all LINk members about these matters in a timely manner and should skill up 'authorised representatives' with the leadership to procure 'a seat at the table' for their views and needs.

b) **Monitoring** the delivery of care services against commissioned standards and user needs and preferences, through visits conducted in accordance with a Quality Framework, acting as 'ambassadors' for the local community in care services. ***How:*** the right to enter and view care premises, including talking to users and staff sensitively, reporting and recommending and the right to a response.

c) **Gathering views**: Ascertaining the experiences of users of care services and seeking the views of actual or potential users, on how their needs and preferences can best be met by care services. ***How***: consultation and discussion within the LINk and beyond it on topics selected by the LINk or suggested by the OSC.

d) **Making those views matter:** Taking account of those views and experiences in its influencing and monitoring roles. ***How***: as a result of a LINk's duty to have regard to these, an 'audit trail' should be apparent showing what the LINk has done about a significant set of views, perhaps tracking it into the LINk's work programme or the PCT consultation report in Clause 164.

e) **Engaging and supporting local service users to get involved**: helping build capacity locally for the community to respond to the involvement and consultation work undertaken by service providers, commissioners, performance managers and Foundation Trust Governors, whether under section 242 or otherwise. ***How:*** This would be done by providing information and support within LINks and beyond, acting as 'honest broker' or guarantor of the soundness of information put forward by those consulting or involving.

f) **Equality of Opportunity to Involvement**: Promoting equality of opportunity to PPI for service users so that those with health inequalities or social exclusion have the same opportunity to influence services as those who are healthier or more articulate. ***How*** by proactively inviting participation in LINks from groups who support such service users and adopting flexible ways of giving them influence and input to the work of the LINks. Section 242 should be amended to include a similar equal opportunities duty on those charged with the duty of consultation and involvement.

g) **User focused**: Influencing the quality of the users' experience as a whole across health and social care, not the separate organisational activities that make it up. ***How***: organising LINKs round geographical areas and user pathways, not institutions and arranging subcommittees for members with special expertise such as mental health.

h) **Supporting Overview and Scrutiny**: Support local authority OSCs in health and social care with reports and recommendations on care services and unmet needs of service users, adding value through an informed user focused perspective. ***How:*** power to make and duty to react to such reports and recommendations.

i) **Working co-operatively if necessary**: Collaborating with other LINks to consider sub-regional, regional and national issues or to support joint Overview and Scrutiny committees (OSCs) in doing so, in appropriate geographical clusters or through a lead LINks arrangement. ***How***: putting in place sufficient resources and legal powers to collaborate with competent, knowledgeable support and clear governance.

j) **Participation in a national body:** Support the LINks national body (see below) with information about local care services, good practice and issues of particular concern that cannot be resolved locally, enhancing its credibility with national evidence.

k) **A national LINks body** which is publicly accountable for its expenditure and performance, has a clear remit and transparent governance processes and which is accountable to its constituent LINks members whom it supports in peer review and good practice. Abolishing a national body altogether is unthinkable.

2.2 Delivery of Functions

The following requirements would be necessary to enable LINks to perform their functions effectively:

2.2.1 Resources: The core of 'authorised representatives' acting corporately as the 'executive' or management committee of the LINks should have the following resources:

a) An office
b) Competent administrative support and committee secretariat
c) Control over their own budget
d) Authority over staff provided under the contract with the local authority
e) Mandatory governance procedures for decision-making when necessary
f) Flexible practices to engage diverse communities in LINks and its work

2.2.2 Ways of Working

a) **Internal relationships in LINks:** it is necessary to have a core of authorised representatives and sufficient due process to ensure effective and accountable decision-making. However, this must not create an excluding ethos to those not in this group. ***How:*** to be covered in the Code of Conduct.

b) **Community relationships**: To get the most from the existing community engagement activity by the local authority and its work on the power of well-being, LINks would need to work in partnership with Local Strategic Partnerships, whose role covers health, and Community Empowerment Networks, to exploit any potential cross-overs with the work of Local Area Agreement partners. This would appear more coherent to the local

community, have greater credibility and be more cost effective. ***How***: by offering opportunities for combined events and sharing knowledge and by encouraging community and voluntary groups to engage in both networks, rather than setting them up in compete against one another for the time and attention of groups which are already hard pressed.

c) **Provider relationships:** Authorised representatives should have the time, skills and capacity to build a constructive, stable relationship with care services organisations. This will lessen the chance of controversial plans being made and when they are made, enhance the opportunity for dialogue. They should be accountable for disinterestedly promoting the interests of service users and taking account of the input from the rest of the LINks in their dealings with such organisations. ***How:*** This could be achieved through a Code of Conduct, by elected officers, with limited terms to ensure rotation and through progression from less engaged groups within LINks to the elected officer positions – avoiding a separate privileged tier of the LINKs. Enforcement of S. 242 duties would ensure that LINks were not ignored. Proper transition would import existing relationships into the new system.

d) **Relationships with local OSCs:** LINks can be the 'eyes and ears' of the OSC because of their regular dialogue with the care providers, their visiting and their knowledge, from LINk members and others, of the needs and preferences of local people. They would need to be safeguarded from any political interference in their work by the local authority. ***How:*** There should be a lead councillor responsible for liaising with the LINk and a lead Link member able to sit as an observer on the OSC. LINks should have a Right of Referral of concerns with the local OSC or relevant Joint OSCs.

e) **Accountability:** The LINk should be accountable for operating in an open and transparent way and for performance against clear outcome based standards. ***How:*** Peer review could be used between LINks to improve their performance. They would have a duty to engage the broadest range of groups and individuals as possible, particularly those suffering social exclusion or at risk of health inequalities. LINks should have specific race equality duties similar to those affecting other public bodies.

f) **National Influence:** LINks should be able to influence national debate and raise national issues through a statutory national body of appropriate scale and proportionate powers and duties which can operate with immunity from government interference and. The creation of such a body by any government is a sign of openness and willingness to be accountable. It would in all likelihood inspire a degree of public confidence out of all proportion to the comparatively small amount of power that would be ceded to such a body. ***How***: A national body would be created funded by top slicing LINK's budgets, giving them a sufficient stake in making the organisation work well and holding it to account. Links should also have a right of referral to national agencies such as the Healthcare Commission or the National Patient Safety Agency.

g) **Guarantee of independence**: A 'bottom-up' national body with independent statutory status would restore public confidence about the intentions behind the serial reform of ppi and demonstrate the independence of the whole system. ***How***: Despite any concerns about the funding relationship between LINks and local government, an independent national body able to support its member LINks without interference would act as a guarantor of their independence and could rule on conflicts of interest for local voluntary sector service providers involved in LINks.

2.3 Responsibility for Functions: Committed, supported, informed membership could undertake these functions, acting as a channel for information and involvement to the wider community, operating in a transparent open and socially inclusive way.

a) **Committed organisations as members of LINks**: Organisations who find that their own core objectives are served through their membership of LINks will be incentivised to join and stay. If they are merely expected to contribute for no financial reward in a way of no relevance to their 'day job', it is hard to see why they would bother. ***How***: LINks' work needs to be aligned to the objectives of its constituent organisations. For example if an older people's group is seeking activities for its members, they will be interested in supporting them to volunteer to train to do visits. If a group supporting young unemployed people is able to give those it supports skills in team working through involvement in LINks, they are more likely to participate.

b) **Valued volunteers:** Individuals who derive sufficient benefit from their involvement will sustain it. A clear progression route would be needed for individual volunteers, from peripheral involvement to undertaking visits and other more skilled activities as an authorised representative. Experience as a volunteer can assist long term unemployed people start to build up a CV. New skills and social contact can attract people who are isolated. The networking of groups of people who are unaccustomed to meeting can break down barriers and help build social cohesion. There are many benefits that can be offered to and are offered by volunteers. ***How***: The Compact Code on Volunteering can be adapted to LINks membership. Reasonable expenses should be paid, including daily allowances as in the jury system.

c) **Recruitment and Transition:** some members need to be recruited with enough knowledge to maintain scrutiny of local services and new ones involved in flexible ways**.** ***How*:** after transition (described below), Patients Forum members can assist with the recruitment of members in partnership with the host organisation and working to a model specification.

d) **Competent Volunteers**: mandatory quality assured training should be provided for all individual members and group representatives. ***How***: this might include IT, committee work, social care payment systems, partnership working, health inequalities and visiting. Training would need to be

professionally designed and delivered, continuously evaluated against quality standards and accredited.

e) **Integration**: LINks should work closely with Foundation Trust members to avoid a fragmented and hierarchical PPI system. ***How***: Foundation Trust members could be invited to join LINks.

f) **Social inclusion:** Individuals and organisations should be able to engage in the LINk to the degree that they are able and willing to do, supported by appropriately trained staff. ***How***: as many organisations and individuals as possible should be invited to join LINks although the costs of advertising and recruiting need to be kept within bounds. If people are asked outright their opinion about health and social care, they are likely to give it. Being a member of something called a LINk is unlikely to make them more willing to do so. In our experience, outreach engagement is a more effective way of obtaining input form socially excluded people. – go where they are and ask them what you want to know, with the support of groups whom they trust.

g) **An organisational memory** at the start of LINks is essential. LINks must be able to give the community confidence that commitments given by service providers and commissioners are honoured. When CHCs were abolished our predecessor body, London Health Link compiled as Promises Register of the commitments given in each locality as recorded by the CHC. It is not known what happened to this. The disposal of Forums and setting up LINks should reduce accountability, especially at a time of widespread cuts and unpopular reconfigurations. ***How***: an effective transition where all Forum members are automatically transferred into LINks and can become authorised representatives after mandatory training, bringing with them their local knowledge, commitment and relationships with providers.

The above are our own views on how effective PPI could be set up, starting from the current situation which is not an ideal one. We hope these thoughts are of assistance to the Committee in considering the Bill.

Elizabeth Manero
Director
Health Link
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Statutory provision	Community Health Councils (CHCs)	Patients Forums (PFs)	Local Involvement Networks (LINks)
1. Functions: Reviewing Services	*'To **represent the interest in the health service of the public** in its district'*[1] In relation to the HA: ▪ **Review** local health service ▪ **Recommend** improvements ▪ **Advise** on any aspect of local health service at its discretion	**Joint working** between Forums *'in the interests of the health service'* (All PFs) In relation to the Trust or PCT to which PF relates: ▪ **'Monitor & review'** health services,[2] ▪ **Obtain and Report** patient/carer views ▪ **Advise, report & recommend** on health services (PCT PFs): ▪ **promote local public involvement i**n public service providers' policy affecting health ▪ **Bring public views** on health to OSCs ▪ **Advise** on & **monitor** involvement in health	'**Activities'** (defined below) pursuant to contractual **arrangements** by a Local Authority and a host organisation ('host') ▪ **Enter, view and observe** activities on care services ▪ **Obtain and Report views** about needs and experiences of care services ▪ **Make recommendations** to **commissioners, providers**, **managers** and **scrutineers** of care services ▪ **Promoting & supporting involvement** of people in **commissioning**, **provision** & **scrutiny** of **health and social care** ('care services') The S of S can extend, change or reduce the activities by regulation, subject to consultation
2. Functions: Information	Not applicable	▪ **Provide advice & information** to patients/carers on those services,[3]	Not Applicable
3. Rights	▪ **Refer to Secretary of State** (S of	▪ **Refer concerns** to Overview &	No explicit rights – rather the object

[1] S.20 & Schedule 7 NHS Act 1977
[2] Patients Forums (Functions) Regulations S.1. 2124 2003
[3] NHS Reform & Health Care Professionals Act 2002

	S) inadequate consultation or duration; ▪ Call for **information** from HA; ▪ **Appeal to S of S** if information not provided; ▪ Send **speaking observers** to NHS board meetings[4]	Scrutiny (OSC) ▪ **Refer to national bodies** at discretion ▪ Call for **information** from NHS (response within 20 days) ▪ **Refer inadequate response** to recommendations to Strategic HA or OSC. ▪ **Refer** poor PPI under S. 11[5] to OSC	of duties by others. *Duties on the face of the bill:* ▪ Duty on OSC to respond to a **referral by a LINk on a social care matter.** [6] ▪ OSC must take account of information from LINk *Duties to be covered by regulation*: (Permissive regulation) to create: ▪ Duty on NHS, Foundation Trusts local authorities or others specified in regulations to respond to **calls for information** and to **reports and recommendations**
4. Role in Consultation or Involvement	▪ Be consulted on **substantial developments** or **substantial variations** in services ▪ Be consulted on **Trust establishment, mergers** or **property transfers**[7] ▪ To be consulted on **health authority** area changes[8] Role transferred to OSCs in 2001[9]	No specific role	No specific role
5. Monitoring Visits	▪ Right to **enter & inspect** NHS premises	▪ Right to **enter & inspect** NHS premises (including primary care	Permissive regulation to create: ▪ Duty for NHS organisation,

4 Guidance on the Membership, Meetings & Proceedings of NHS Authorities 1991
5 S.11 Health and Social Care Act 2001, imposing consultation and involvement duty on NHS organisations
6 We understand that referrals on healthcare by LINks will be achieved by regulation under existing regulation-making powers
7 NHS Trust (Consultation on Establishment & Dissolution Regulations) S.1 1996 653
8 NHS Act 1977 S. 8
9 Health & Social Care Act 2001 S.7

	▪ Times & conditions to be agreed with the NHS ▪ Not staff accommodation without consent	contractors) on written authority; ▪ No duty to permit entry if NHS feels compromise to '*effective' service* provision, patients' safety/privacy/ dignity; ▪ No entry to staff accommodation without consent	Foundation Trust, local authority or others.[10] **to permit access to enter, view and observe** activities on NHS premises ▪ **Conditions, extent, restrictions, authorisation** in relation to duty
6. Complaints	Independent **complaints advice**, locally determined – non statutory. Anonymised details informed member activity	▪ Statutory Independent Complaints Advice Service (ICAS) ▪ To be provided by PCT PFs (not yet transferred from DH)	Unchanged. No relation to LINks
7. Public Accountability	▪ Annual Report **to which HA must respond,** detailing & publicising actions it has taken as a result ▪ Annual Joint meeting with HA. ▪ CHC meetings & papers to be public [11]	▪ **Annual Report** detailing methods of seeking patient/carer views to which **NHS must respond** on actions or non-actions ▪ Meetings covering reports, budget setting, accounts or referrals, to be held in public and decided by majority ▪ Otherwise PF discretion on proceedings	▪ An organisation will be **contracted** by the local authority to a DH model specification to ensure the LINks carries out its functions ▪ **Annual Report** by the LINk on its activities.
8. Membership	Appointed by : **Local Authority:** at least 1/2 **Voluntary sector:** at least 1/3(elected) **Secretary of State:** Remainder	At least 7 members: ▪ **Majority local patients**/past patients ▪ Include **Voluntary sector reps** representing patients /carers ▪ For PCT PFs , rep from Trust PFs ▪ Rep. from body representing community on health	None specified. ▪ '**Authorised representatives'** referred to in duty to allow entering and viewing

[10] We understand that Directions will require private providers to permit access under their contracts

[11] CHCs (Access to Information Act) 1988

9. Exclusions from Membership	The following from the local area: ▪ Health Authority (HA) members/employee ▪ NHS employees ▪ Primary care providers (e.g. GPs) ▪ Employees of private provider	The following from the local area: ▪ Strategic HA members/employee ▪ NHS employees ▪ Primary care providers (e.g. GPs) ▪ Employees of private provider ▪ Employee of Forum Support Organisation (FSO)[12] ▪ OSC member ▪ ICAS provider	LINks cannot be: ▪ Local authorities, ▪ NHS organisations ▪ Foundation Trusts
10. Term of Office	4 years (max. 8 then 4 year gap)	4 years (max. 8 then 4 year gap)	None specified (no regulation-making power)
11. Member Accountability	(Non statutory) Code of Conduct including: ▪ No party political bias ▪ No Personal interest ▪ Must contact disadvantaged groups ▪ Declare interests ▪ Respect confidentiality	Pecuniary interest prevents participation (e.g. partner of member employed in health service provider)	None specified (no regulation-making power)
12. Termination	a) **Non attendance** for 4 months b) If after consulting the CHC, the Secretary of State decides '***not in the interests of the health service'*** for member to continue	If CPPIH considers '***not in the interests of the PF or the health service'***	None specified (no regulation-making power)
13. Governance	▪ **Elected** Chair & 2 Vice Chairs; ▪ Subcommittees (two thirds CHC); ▪ Joint committees with other CHCs.	▪ ***May appoint*** Chair & deputy(ies) ▪ Subcommittees (2 PF members) ▪ Joint committees with other PFs	None specified (no regulation-making power)
14. Funding	Budget, premises, member	▪ Budget, premises, member	▪ Funding will be transmitted by

[12] Voluntary sector organisation contracted by CPPIH to provide support to one or more PFs, e.g. the Scout Association

	expenses, staffing, channelled to CHC from DH through host HA Staff to be '**acceptable to the CHC'** [13]	expenses, staffing, channelled to PFs from CPPIH[14] and determined by CPPIH. ▪ Staff to be under direction of members	local authorities through contracts to host. ▪ No specifics on face of the bill what this will be spent on,
15. Support	Chief Officer & staff employed **by an HA not in the CHC's area** to run office, serve meetings & support members.	FSOs appointed under contract by CPPIH to ▪ Enable PFs to develop networks ▪ Facilitate access to information ▪ Provide training for members ▪ Support member recruitment ▪ Meet PF administrative requirements ▪ Provide FSO premises[15]	None specified other than ensuring *'that there are means by which'* the '**activities'** happen under '**arrangements**.' [16]
16. Financial Accountability	**CHC**: holds budget. Annual Report **Chief Officer**: accountable officer **Host HA**: HR, 'pay & rations'	▪ Annual accounts[17] showing income and expenditure	▪ Annual Report must show money spent by host on LINk (but not other money spent by them e.g. on management) ▪ **Host holds budget** under the contract
17. Area of remit	By Health Authority (**area based**)	Organisation to which PF relates i.e. one per NHS Trust and PCT **(organisation based)**	Local Authority area
18. National Body	Statutory ('bottom up')	Statutory ('top down')	None
19. Function	To '***advise'*** & '***assist'*** councils on	▪ **Advise** S of S and others on PPI,	N/A

13 CHC Regulations S.1 1996 640
14 Commission for Patient and Public Involvement in Health
15 CPPIH tender documents for FSOs, Annex A March 2003.
16 We understand that the model specification will provide more detail
17 Note: in practice these have always been provided by the Forum Support Organisation

	'the performance of their functions'	ICAS and views of PFs ▪ **Promote PPI** in decisions and policies affecting health ▪ **Report** an issue arising from PF reports affecting patient safety or welfare to e.g. Healthcare Commission ▪ **Call for information** from NHS bodies	
20. Support to CHCs	Independent Legal Advice, spreading best practice, (non statutory requirement)	▪ **Provide staff** to PCT PFs, ▪ **Assist and coordinate** PFs ▪ **Performance manage** PFs	N/A
21. Governance	Standing Committee made up of representatives of regional associations of CHCs, of which all CHCs were members and whose Chair is elected by CHCs.	▪ **10 members** including 3 from NHS, ▪ **Appointed** by the S of S. ▪ 3 year term ▪ Pecuniary interest disqualification ▪ Meetings in public[18]	N/A

[18] CPPIH (Membership and Procedure) Regulations S.1 3038 2002

Appendix Two

2.1 Funding: Health Link has a number of contracts for patient and public involvement with statutory organisations including the Department of Health and the Greater London Authority as well as grant funding from the Halley Stewart Trust) to fund its health and homelessness work.

2.2 Accountability: Health Link works to the government's Compact with the voluntary sector, which includes the following undertakings:

- **Government undertakes**: '*To recognise and support the independence of the sector, including its right within the law, to campaign, to comment on Government policy, and to challenge that policy, irrespective of any funding relationship that might exist, and to determine and manage its own affairs*.'

- **The Voluntary Sector undertakes**: '*To ensure that service users, volunteers, members and supporters are informed and consulted, where appropriate, about activities and policy positions when presenting a case to Government or responding to Government consultations, and to communicate accurately the views put to them in the course of such representations*.'

Activities: Health' Link's work is project based, mainly under contract to DH, NHS Connecting for Health and NHS organisations, with some grant funding:

- Running a Choose and Book Patient Reference Group for NHS Connecting for Health, to advise on implementation in London.
- Setting up the NW London Patients' Parliament for NW London Strategic Health Authority (STHA), recruiting and training members from 8 boroughs, designing governance materials and Code of Conduct.
- Outreach consultation for London Patients Choice project, on the choice information needs of socially excluded groups. The resulting Taking Soundings recommended how to avoid Choice inequalities.
- Acting on Taking Soundings: with 4 STHAs, the DH and NHS Connecting for Health, we developed a Patients' Information Tool, to enable patients to compare hospitals, in response to Taking Soundings findings.
- Cross-government Partnership for Patients: Setting up 9 library pilots to test the role of libraries in patient choice, as suggested by Taking Soundings, through a Partnership led by ourselves and comprising the DH, DEFRA, the Museums, Libraries and Archives Council, the London Libraries Development Agency and London Health Libraries.
- Health and Homelessness: involving homeless volunteers in monitoring and improving A & E services from the homeless perspective, in partnership with Whittington and Homerton Patients Forums. This Project was independently evaluated and funded by the Kings Fund. With funding from the Halley Stewart Trust, we are now implementing the resulting recommendations.
- PPI in the determinants of health: working with the London Health Commission to help grass roots community groups to engage with pan-London decision-making bodies on the determinants of health and health.