

Health & Care Bill Committee – Written Evidence

(Submitted by Nora Everitt)

My Experience in Public Involvement

I am a retired involvement development worker with over twenty five years experience in developing and facilitating service user, carer and public involvement at strategic board level in health and care.

I am currently involved as a volunteer representative at strategic level for an independent mental health service user and carer forum sharing forum members' lived experience of service system failures affecting their recovery, and their suggestions how these could be prevented. The forum has developed a set of service user and carer quality standards which is included in the local mental health strategy. The forum maintains a continual dialogue with mental health service users and their carers across the borough, giving more real time information than the existing 'engagement' systems that tend to only explore views on proposals to change services.

In my local Integrated Care System there is no such direct patient or public involvement and no direct dialogue with service users or carers at system level, despite being in place since 2017. From 2019 transparency in planning and decision-making is absent, and clinical leadership significantly reduced. (I can give further detail on my statements in this submission if needed.)

Why I submit my evidence to the Committee

- I wish to comment on the Health and Care Bill around the sections on Public Involvement and Accountability as it gives an opportunity to provide greater clarity in the duties that exist in the current Health and Social Care Bill for "*public involvement and consultation*"
- The current Health and Social Care Act is not clearly worded in describing how the public involvement duty should be met and has failed to give the public a clear legal right to be individually involved in commissioning plans, proposals, decisions and in monitoring services in order to influence the range and delivery of services available to them
- The Health and Care Bill adds to this lack of legal clarity about public involvement and consultation affecting individual patients' power to legally challenge decisions to change service availability if they were not involved or consulted on changes that reduced their access to the services they rely on
- None of the words used in the sections in the Bill about public involvement are defined, as in other parts of the Bill, despite many words being open to different interpretations.

Also a number of guidance documents have been issued very recently describing the process for establishing the new Integrated Care Boards (ICBs) and Integrated Care Partnerships (ICPs) so they will be ready to take responsibility for health and care in April 2022.

["ICS implementation guidance on working with people and communities"](#) (02/09/21)

["Guidance on the development of place-based partnerships as part of statutory integrated care systems"](#) (02/09/21)

["Interim guidance on the functions and governance of the integrated care board"](#) (August 2021)

- In my area, however there is a significant discrepancy between the current preparations being made and the most recent guidance, and no public information about any plans for an ICB, ICP, ICB constitution or and ICS (Integrated Care System) forward plan

There needs to be greater consistency between the law, relevant guidance documents and practice – on the duty for public involvement in decisions about NHS services.

The parts of the Health and Care Bill that directly relate to public involvement

The relevant sections of the Health and Care Bill are as follows, (1) & 7) apply to NHS England; and 1), 2) 3) 4) & 5) apply to Integrated Care Boards) – and each says commissioners “must” :

- 1) Section 19. 14Z44 (P 18/19) – “make arrangements” to involve the “*individuals*” they provide services for in:
 - the planning of the commissioning arrangements – Section 14Z44 (2)(a)
 - development and consideration of plans and proposals to change how services are delivered to them or the range of services available to them – Section 14Z44 (2) (b)
 - decisions about commissioning services affecting the operation of commissioning arrangements once implemented – Section 14Z44 (2) (c)
- 2) Section 13 14Z26 (P9) “consult” on their proposed constitution for the first Integrated Care Board to be established in their area
- 3) Schedule 2 paragraphs 11 & 13 (P121/122) “specify” in the ICB constitution both the procedure for making decisions, how they will make sure the decisions are made transparently and how they will make arrangements for public involvement
- 4) Section 19. 14Z50 (2) (a) (P21) “specify” how they will make such arrangements for public involvement in their forward plans before each financial year
- 5) Section 19. 14Z52 (2) (P22) “consult” people they serve on their forward plans about services to be made available to them
- 6) Section 20. 116ZB (4) (b) (P29) “involve” the people who live or work in that area in preparing an integrated care strategy (under Section 20)
- 7) In Section 19. 14Z57 (3) (e) (P25) NHS England will assess each financial year how well the Integrated Care Boards have discharged their duty for public involvement (14Z44)

Proposed changes to the Bill and actions preparing for its implementation

The Bill’s public involvement duty needs to be enshrined in, and implemented, in all areas, including the creation of the Integrated Care Board constitutions and forward plans and any subsequent monitoring. (see Appendix 1)

The Bill’s sections – I would argue – show that the clinical commissioning groups should consult the public on the content of the proposed ICB constitutions and forward plans that they are currently developing – there appears to be no intention to do so (see Appendix 1 & Appendix 2)

The Bill should include but omits any requirement to involve the public directly in:

- the plans describing how the commissioners intend to involve them to meet 14Z44
- monitoring how well the Integrated Care Boards carry out those plans (see point 7))
- monitoring how effective are the actions taken to improve the NHS patient experience

The Bill needs to be strengthened in section 19. 14Z44:

- to be clear and specific how Integrated Care Boards’ public involvement duty must be met
- some words in Section 19. 14Z44 (2) need to be defined (see Appendix 2)
- words “provided with information” and “or in other ways” to be deleted (see Appendix 2)

The Bill is inconsistent in who Public Involvement refers to, and in to ‘consult’ or ‘involve’ them:

- Section 19.14Z44 (2) says to ‘**involve**’ “*individuals that use, or may use services*” which describes everyone – but adds representatives, (removes involvement from “*individuals*”)
- Section 19. 14Z52 (2) says to ‘**consult**’ all people registered with a GP , and all who are not registered but live in the area, which again describes everybody
- Section 20 116ZB (4) (b) says to ‘**involve**’ people living and working in the [ICS] area

- **Appendix 1**

The need to directly involve the public in the current preparations to establish Integrated Care Boards and in particular their constitutions and forward plans:

- Clinical commissioning groups currently have a duty to involve the people they serve in the planning of commissioning arrangements, and plans, proposals and decisions about changing how services are delivered and the range of services made available to them
- And yet the clinical commissioning groups are writing forward plans and constitutions for the Integrated Care Boards that will replace them in just over six months time and will also fundamentally change commissioning arrangements and the delivery and range of services
- The clinical commissioning groups are neither informing nor involving the public in the preparation of these documents, as section 26.14Z2 of the Health and Social Care Act 2012 currently requires

Appendix 2

To improve section 19 14Z44 some wording should be defined and some deleted, to specify the requirements more clearly:

a) Words that need deleting:

- ***“or provided with information”***:
 - How exactly does getting information involve an individual in decisions (14Z44 (2) (c))?
 - This implies that the public’s, patients’ and carers’ views are not wanted or respected
- ***“or in other ways”*** – this is meaningless, and:
 - Is open to wide interpretation which prohibits any member of the public from challenging a commissioning decision that affects them directly by not being consulted on it
 - allows tokenism, discrimination, and dismissal of the views of ‘individuals’– and
 - **is disrespectful to the people that the NHS is there to serve**

b) Words that need defining include:

- **“carers”** – usually refers to friends or family who give significant unpaid support
- **“representatives”** should represent the ‘wider public voice’, not act in the ‘public interest’
 - They should be selected by the public, and be fully and directly accountable to them
 - There should be mechanisms and resources to allow them to have regular dialogue with the wider public to demonstrate their accountability to the people they represent
 - Lay members and other self-selected, appointed people only ‘act’ in the public interest
 - * they do NOT ‘represent’ the public, the public voice or collective experience
 - * they can only speak from their own knowledge and experience
 - Representatives can also be advocates for individual service users in decisions about their individual care, including those with Lasting Power of Attorney
- **“involvement”** – usually means equal participation as implied in subsections (2) (a)(b)(c)
- **“consultation”** – usually means seeking opinions on existing plans, that may well be and often are, disregarded without any explanation, despite the [Gunning Principles](#) requiring that it must be demonstrated that consultation responses were fully considered