



**National Voices**

People shaping health  
and social care

# National Voices

## **National Voices submission to the House of Commons Select Committee Inquiry into Management of Long Term Conditions**

**May 2013**

### Summary

- National Voices' members – health and social care charities in England – are impatient for a new deal for people with long term conditions.
- The models and approaches that can provide this are known and evidenced: the challenge is to 'move from rhetoric to reality'.
- Impetus for this has not been possible during the last two years of structural reform, but there are now significant opportunities to gather momentum behind the 'House of Care' concept for service delivery, the common definition of what service integration is about, the new statutory provisions for social care entitlements, and the duties for healthcare commissioners to promote patient involvement.
- However, healthcare commissioners will need support both from inside and outside NHS England, and social care entitlements must be funded.
- There needs to be clarity as to whether NICE will now publish common (integrated) Quality Standards across health and social care for the same conditions)

### About National Voices

1. National Voices is the national coalition of health and social care charities in England. We work together to strengthen the voice of patients, service users, carers, their families and the voluntary organisations that work for them. We have more than 150 members with 130 charity members and 20 professional and associate members. Our broad membership, rooted in people's experience, represents millions of individuals, and covers a diverse range of health conditions and communities.
2. National Voices grew out of the former Long Term Conditions Alliance. We have an active group of charity members, large and small, promoting our call for 'a new deal for people with long term conditions' and for the health and social care systems to 'move from rhetoric to reality' by delivering it.

### Submission

3. This submission is an overarching view from patient and service user charities which will give our view, based on previous consultations with members, of the adequacy of current provision for people with long term conditions, and of the potential for service redesign to create better services.

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4. National Voices members told the NHS Future Forum in 2011, during the 'pause' in the Health and Social Care Bill, that we wanted a 'new deal for people with long term conditions' based on getting the right care in the right place at the right time.<sup>1</sup>
5. We stated that patients and service users should be supported to:
  - understand our conditions and medications
  - learn how to use health information
  - take achievable steps to improve our health
  - prevent emergencies developing
  - navigate the available services and support
  - manage our own care and treatment, and
  - take part in deciding our care plans and our treatment options
6. We said that for this to happen, services must be both more personalised and more integrated – 'integration, integration, integration' was top of our list of demands.
7. These demands were securely based on the lived experience of the people with and for whom our charity members are working. With regard to health services, people managing long term conditions are using multiple services which are not joined up, which do not transfer information effectively so that it travels with the patients, which do not coordinate care around the patient, and where genuine care planning is still, despite the policy intentions of successive governments, only available to a minority.
8. NHS services are, by and large, dominated by GP and hospital-based services which primarily work on a medical model ('diagnose and treat') rather than a bio-psycho-social model that considers the whole person and their needs and capabilities, and works to support them to achieve health goals in the context of their broader life and circumstances.
9. With regard to social care services, the culture of care and support is very different, and more informed by the ethic of supporting people to identify and achieve their own goals for an independent life. However, funded social care services are increasingly limited to a small minority of people with substantial needs, leaving people with moderate needs to fund their own provision or remain without support. As is well documented, social care and health services often do not join up around the person.
10. In its White Paper of 2010, 'Liberating the NHS', the government rightly identified many of the challenges posed by the growing incidence of long term conditions, and also touched on some of the things people need, especially in relation to greater involvement in decisions about their health and healthcare.

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<sup>1</sup> '9 big shouts', National Voices, 2011:

[http://www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/9%20Big%20Shouts%20-%20National%20Voices%20response%20to%20the%20Listening%20Exercise\\_0.pdf](http://www.nationalvoices.org.uk/sites/www.nationalvoices.org.uk/files/9%20Big%20Shouts%20-%20National%20Voices%20response%20to%20the%20Listening%20Exercise_0.pdf)



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11. However, the last two years have been occupied with the structural reorganisations triggered by that White Paper, with the new organisations being barely established at 1 April 2013. Thus there has yet to be any impact at service level on the way people with long term conditions are identified, managed and supported.
12. In the view of National Voices members, many of the approaches that would both improve the quality of life of people with long term conditions, and lead to more rational and appropriate use of scarce system resources, are already known, and there is a substantial evidence base for them. For example, the NHS model for management of chronic conditions was published in 2004. National Voices manages a website which provides commissioners and providers with the results of 280 systematic and high level reviews of research evidence relating to the greater involvement of patients in healthcare<sup>2</sup>.
13. The problem, in the view of our members, is not with the 'what', it is with the delivery. The NHS has shown very little capacity to understand the changes both to culture and to service design which are required to deliver a new deal. Hence we do not wish to be involved in any further developments at the level of mere policy, but to assist the system to 'move from rhetoric to reality'.
14. National Voices members do believe that there are now opportunities within the reformed system to begin delivering better services, and we reference some of these in the remainder of this submission.
15. The key, in our view, is to understand clearly that the approaches that will better involve and support people to manage their conditions successfully – such as building health literacy, educating people for self management, giving people access to their records, training professionals in health coaching and motivational interviewing, involving people in treatment decisions, and enabling genuine care planning – are not one-off, stand-alone interventions. Rather, they require a delivery system that changes the design of services and pathways, and the broader culture of services and consultations, repositioning the patient as equal and active partner, rather than passive recipient.
16. As noted below, we believe this should be based on the 'Year of Care' or 'House of Care' approach piloted for the Diabetes Year of Care and recommended by the RCGP as a generic approach to long term conditions management.

### *Social care reform*

17. The Care Bill will introduce a clear single statutory framework for social care based on common entitlements that include holistic needs assessment and care and support planning both for adults with needs and their carers. National Voices has worked with the Bill team, the joint scrutiny committee on the draft Bill, and the Care and Support Alliance, to help strengthen and clarify draft provisions in relation to care

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<sup>2</sup> [www.investinengagement.info](http://www.investinengagement.info)



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planning and direct payments specifically; key areas which can drive a more coordinated approach to the delivery of care.

18. It is essential that the health system, nationally and locally, takes note of these new provisions, and works to ensure that, where a person has needs that span social care and health, there are common systems for these entitlements, shared by cross-boundary and multidisciplinary teams, rather than placing the person with needs in jeopardy of double assessments and competing care plans.
19. In order to aid this, National Voices is currently working with members and partners on a set of Principles for Care Planning. In due course, we hope that these will be adopted by health and social care professionals and used by patients and service users who could benefit from these processes. .
20. However, joint working and common systems for health and social care will only have meaning if social care is adequately funded for larger numbers of people with continuing conditions and disabilities. As part of the Care and Support Alliance, National Voices is calling for the funding of social care entitlements for people with moderate needs.

### *'Integration' and the Narrative for person centred coordinated care*

21. As noted above, integrated services are much more likely to be able to provide people with a holistic approach to treating and managing their conditions. We welcome the fact that duties to promote and provide integrated care were inserted in the Health and Social Care Act 2012; and we particularly welcome the announcement by all key national system leaders of a common approach to supporting integration<sup>3</sup>.
22. This common approach is based around a new common definition of 'integration' as 'person centred coordinated care', contained in a 'narrative' that shows what such care would look like from the point of view of patients and service users. National Voices co-produced this for the national partners and it represents many of our original demands from 2011 in a form approved both by members and service users, and by system leaders<sup>4</sup>.
23. The aim is to provide commissioners with a statement of goals and aims that they can use to benchmark progress towards integration, in a way which keeps them focused on the benefits to service users rather than the needs of organisations.

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<sup>3</sup> 'National Partners Make Commitment to Join Up Health and Social Care', DH and others, 14 May 2013: <https://www.gov.uk/government/news/national-partners-make-commitment-to-join-up-health-and-social-care>

<sup>4</sup> A narrative for person centred coordinated care, National Voices, May 2013: <http://www.england.nhs.uk/wp-content/uploads/2013/05/nv-narrative-cc.pdf>



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### *The domain 2 vision and ambition framework*

24. NHS national responsibility for achieving better outcomes for people with long term conditions lies with NHS England and in particular its 'domain 2' team. We are impressed by the commitment of this team and welcome the fact that they are seeking to place the 'House of Care' delivery concept, and the Narrative, securely at the heart of their approach.
25. However, this team will need full support from the NHSE Board, from national clinical directors, from the patient experience domain, and from the commissioning development directorate, to turn these ambitions into delivery through the commissioning system.
26. National Voices will play its part in developing and supporting these ambitions as a 'strategic partner' to NHSE. However, we believe there is a need to establish a strong external coalition of third sector organisations, think tanks and experts to gather momentum around the House of Care approach and to challenge commissioners to develop and implement it.

### *The patient involvement duties for commissioners*

27. As a result of a campaign by National Voices, the Health Foundation and others, the Health and Social Care Act 2012 was amended not once, but twice, to create the clearest possible common duties for NHSE and CCGs to 'promote the involvement of each patient' in decisions relating to prevention, diagnosis, care and treatment.
28. This gives a statutory push to efforts to introduce patient involvement interventions. National Voices has been and will continue to be involved in helping NHSE to publish statutory guidance on how the CCG duty should be fulfilled (currently in draft for consultation).

### *Support for commissioners*

29. Guidance, tools and incentives to help commissioners achieve better outcomes with and for people with long term conditions must now be produced by NHS England. In our view these should be securely based on the House of Care delivery concept; the Narrative for person centred coordinated care; and the best evidence for interventions to support greater patient involvement.
30. They should also draw on knowledge of the benefits of 'co-production', whereby service users are involved as equals in redesigning services, as evidenced recently by Nesta<sup>5</sup>. They should include models for commissioning the financially

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<sup>5</sup> The People Powered Health Programme, Nesta:

[http://www.nesta.org.uk/areas\\_of\\_work/public\\_services\\_lab/health\\_and\\_ageing/people\\_powered\\_health/assets/features/people\\_powered\\_health](http://www.nesta.org.uk/areas_of_work/public_services_lab/health_and_ageing/people_powered_health/assets/features/people_powered_health)



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small but crucial contributions to holistic care and support – such as patient information and literacy, education for self management, peer support, and motivational activities -- from voluntary and community organisations. VCS organisations have various concerns about their future role: they may be excluded from service delivery if there is too much focus on 'procurement' models of commissioning based on competitive tender, or conversely if there is a return to 'closed shop' models favouring NHS providers.

31. Recent research by the Nuffield Trust demonstrated what many of our members have described anecdotally – namely that much commissioning for long term conditions has struggled to move beyond 'bite size commissioning at the level of small, manageable service change, to tackle larger scale and generic service redesign<sup>6</sup>.
32. It is essential that commissioners are supported and trained to rise to this challenge. NHS England's new improvement body, NHS Improving Quality, has a programme of training and support called 'Transformational capability building within Clinical Commissioning Groups' that addresses this need. In National Voices' view, all CCGs would benefit from this programme, and NHS England should put priority resources into enabling them to do so. The draft authorisation framework should be further revised to ensure CCGs know they will be assessed on their capacity to initiate large scale redesign and to work collaboratively with local partners to achieve it.

### *Other issues*

33. In the government's reforms it was envisaged that Quality Standards issued by NICE would have a key role in promoting common standards and approaches across the health system. Subsequently NICE has taken over responsibility for setting standards for social care also. National Voices would support the production of common (integrated) standards across health and social care for the same condition or conditions. Clarity is required from the government and NICE as to whether this will be the goal.
34. The deal for people with long term conditions will be further enhanced by broader efforts to invest in and improve the quality of primary and community health services, which continue to be squeezed of funds in comparison with the acute hospital sector.
35. Finally, there is often a tendency in policy circles to underestimate the diversity of people with long term conditions. The needs of frail, older people are a big part of the picture but not the only part. It is also necessary to address the needs of children and young people, people with physical and learning disabilities, people with less common conditions (especially those not part of the national specialised

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<sup>6</sup> 'Commissioning High Quality Care for People with Long Term Conditions', Nuffield Trust, 2013:  
<http://www.nuffieldtrust.org.uk/publications/commissioning-high-quality-care-people-long-term-conditions>



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commissioning arrangements), people with complex and fluctuating conditions,  
people from marginalised or excluded communities and family carers .

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