BOARD PAPER – NHS ENGLAND

Paper NHSE 131102

Title: Patient and Public Voice

Clearance: Tim Kelsey, National Director for Patients and Information

Purpose of Paper:

NHS England is committed to:

- promoting and upholding the values, rights and pledges enshrined within the NHS Constitution;
- putting patients and the public at the heart of everything it does;
- promoting and embedding a truly customer focused culture within the NHS; and
- ensuring that patient and public voice is not just heard, but actively used to inform commissioning decisions taken by the Board and clinical commissioning groups (CCGs).

This paper highlights key activities underway across NHS England which demonstrates that the vision of a patient-centred approach is being delivered, and showcases one patient and public voice activity in particular, supported by a case study. An update on progress relating to one of the workshop themes from the NHS England Annual General Meeting in September 2013 is also included.

Key Issues:

This paper:

- Highlights two key public voice 'headlines' from across NHS England;
- Outlines the launch of *'Transforming participation in health and care;'*
- Showcases NHS England putting the principles of good public participation into practice at the Annual General Meeting (AGM) in September 2013;
- Update on progress relating to the workshop themes from the NHS

England AGM.

Actions required by Board members:

- To note and comment on activity that is underway across NHS England in support of the patient-centred approach and which demonstrates that the patient voice is being heard.

Patient and Public Voice Update

Introduction

1. This paper highlights to the Board key activity across NHS England in the field of Patient and Public Voice.

Context

2. This is the third paper in what is a regular update for the Board highlighting activity across NHS England which showcases a commitment to:

- transparency of information;
- enabling the active participation of patients in decisions regarding their own healthcare; and
- enabling active participation of the public in decisions about the nature of the NHS services they use.

3. Following papers presented to the July 2013 and September 2013 meetings of the Board, a new approach has been taken to the preparation, content and format of this paper. It is proposed that, for each meeting of the Board, the paper will include the following four sections:

- Headlines: two or three key patient and public voice 'highlights' from across NHS England – showcasing activities which have recently taken place.
- Spotlight: a focus on one particular patient and public voice activity which has been undertaken.
- Example: a case study, linked to the theme of the 'focus' activity, which demonstrates good practice in this area.
- AGM update: an update on progress relating to one of the workshop themes from the NHS England Annual General Meeting (AGM) in September 2013.

Headlines

Citizen's Assembly

3. NHS England is committed to pioneering a new approach to patient and public engagement in the health service, a 'Citizen's Assembly.'

4. Collaborating with Involve, Public-I and the Democratic Society we hosted two development days that built on the design work undertaken over the months with the Tavistock Institute and other partners. These two days focussed on shaping

and refining the concept, especially the approach to digital by default as a key mechanism for the public to hold NHS England to account.

5. The whole two days were streamed live on the web and had integrated digital conversations with participants from across the country, any beyond, contributing to the debates. The live stream and all the resources developed for and during the event are hosted **here**. A full transcript of the twitter conversation is available **here.**

6. The innovative and digitally integrated approach to the facilitation generated over **700** individual connections to the live web cast and through Twitter **7,039,627** Impressions, **3,892** Tweets and **469** participants. Whilst the issue of digital exclusion was hotly debated during the two days the increased reach this approach achieved demonstrates why we need to be more ambitious and innovative in our approaches to participation. We understand that this is the most successful digitally integrated participation approach undertaken to date. The challenge now is to maintain the momentum.

7. Refined during the two days the following purpose and principles were developed. Reflections, blogs and more detail on the discussions including a full discussion paper (that was redrafted overnight between days one and two) is available **here.**
    - The Citizen's Assembly has three main purposes:
        - to give citizens and organisations a direct transparent route for their voices to reach the heart of the NHS England decision making process, in a way that cannot be ignored;
        - to give the NHS England board and others a new source of evidence and opinion on the NHS now and future;
        - to give the public an open and robust accountability mechanism for the work of NHS England, and opportunities to participate in every aspect of the organisation's work; and
        - leads to action, quickly.

    - This can be better captured with a wider statement that it, within a wider system, exists to promote the best possible health and wellbeing for citizens now and in the longer term. This will be done by:
        - informing and influencing the big strategic issues and priorities;
        - informing and influencing the system conditions;
        - holding the system and board to account;
        - aggregating systemic issues, failures and successes;
        - informing and synthesising systemic monitoring and evaluation;
        - overseeing interconnectedness of system; and
        - scaling-up what's going right.

    - Why is it different to groups and structures which either already exist or have recently been formed?:

  - it's responsive and agile; ideas lead to action quickly;
  - it listens to everybody who chooses to participate – not the usual suspects;
  - it creates demands on the NHS Board and holds the board to account;
  - it galvanises and better connects already active people; and
  - it's about health, not illness.

- It *doesn't*:
  - replicate activities other orgs are doing: 'Let HealthWatch Be HealthWatch'
  - get bogged down in process.

8. Next Steps – the wealth of insight and material generated through these development sessions, added to the material already generated in previous events will be shared and further developed to agree, in an open, transparent and participative way, what the next steps towards establishing #NHSCitizen should be. Over the coming months we will work with collaborators to model how the approach would work in different scenarios, ensuring that it adds value and amplifies the power of citizen voice.

The Future of Health Conference

9. Organised by NHS England along with University College London (UCL) and the political information company Dods, the conference brought together more than a thousand experts to hear the views of the "people's panel". Led by Dr Martin McShane, the event enabled senior health and care professionals to hear, first hand, from patients – especially those with long term conditions – what was important to them, and where, often simple, improvements could be made

10. The People's Panel comprised 14 people with a wide range of long term conditions and expertise in their own health and care. Their insight, experience and feedback formed a central theme and reality check making sure that the whole conference aligned to have people - patients, people who use services, carers and families - at the centre of every conversation. We have committed to reconvening and building on the People's Panel at the Health Expo in March 2014 and really coproducing the design and format together with people.

11. We are indebted to the 14 people who gave us their time, expertise, experience and insight at some significant cost to their personal health and wellbeing. The Panels 'Forewoman' Anya DeIongh has captured the experience eloquently in her blog http://thepatientpatient2011.blogspot.co.uk/?m=1

12. The success and impact of this ground breaking approach is captured in **Jackie Ashley's article in the Guardian** on Sunday 6 October 2013. Where she

captures the impact of the event and identifies that we do still have work to do to really bring patients in to the design and creation of our work at the earliest possible stage.

Spotlight – publication of participation guidance

13. Launched at the NHS Commissioning Assembly on 25 November 2013, NHS England has published ***'Transforming participation in health and care'*** to support the effective commissioning of services for individual and public participation and to build insight. The guidance supports NHS England's vision for public participation, which is that every level of the commissioning system is informed by insightful methods of listening to those who use and care about our services.

Executive Summary: Transforming participation in health and care: overview

To help NHS England and clinical commissioning group commissioners fulfil their statutory duties and involve patients and the public effectively and systematically, NHS England will work with partners to:

Individual Participation

1. Ensure that every person with a long-term condition or disability has a personalised care plan supporting them to develop the knowledge, skills and confidence to manage their own health. NHS England will develop and implement a best practice standard that defines what good, personalised, digital care plans and planning processes look like, in order to support GPs and health professionals during 2014.
2. Launch a new certification process for entrepreneurs to easily offer on-line tools and services that support personalisation, to help commissioners to identify high quality suppliers.
3. Build a field force of practical support and help for commissioners, through the Patient and Public Voice Commissioning Support Programme, to introduce and roll out personal health budgets and approaches to personalisation so that anyone who can benefit will be able to have a personal health budget and care plan by April 2015.
4. Launch an online health literacy programme with The Tinder Foundation to train 100,000 people from disadvantaged communities by April 2014.
5. Launch 'Patients in control', a comprehensive programme including practical training, support and tools to support local communities to deliver Shared Decision Making, Personalised Care Planning and better self-management of their health.

Public Participation

1. Establish a national Citizens Assembly that will put a citizen voice at the heart of decision-making and hold the board of NHS England to account. We will also work with the British Youth Council and other children and young people's groups to establish a Children and Young People's Forum for NHS England.

Executive Summary: Transforming participation in health and care: overview

2. Launch a national 'Excellence in Participation Awards' scheme that gives status and profile to patient and public participation, promoting best practice. NHS England is working with patients and carers to develop this.
3. Set up a Participation Academy, a programme of learning and development for people who want to explore roles as patient and community leaders in health and care. Working with partners, including local Healthwatch and health and wellbeing boards, we will work with local communities to identify routes to reach a diverse range of people who can champion the health needs and interests of local communities and citizens.
4. Create a 'People Bank' where citizens and organisations can register their interest in participation opportunities across NHS England's activities and/or commissioners can identify interested people to engage with.

Insight & Feedback

1. Roll out the Friends and Family Test to cover all NHS services by the end of 2014/2015.
2. Publish the most useful data and insight through the Patient Insight Dashboard in a format that can be understood by patients, the public and local Healthwatch, by Autumn 2013.
3. Develop Patient Centred Outcome Measures to gather genuine insight from patients about the outcomes that matter most to them across a range of specialised conditions.

14. Produced as an interactive e-book, and in a distinctive, less formal style than traditional guidance documents, '***Transforming participation in health and care*****,**' aims to promote inclusivity and accessibility, and to provide core principles for effective participation, whilst encouraging local flexibility to use the most appropriate mechanisms for local populations. Published alongside the main document are a suite of online tools and resources, including case studies, the legal framework and onwards signposting to useful sources of further advice.

15. Although aimed primarily at commissioners of health and care services, the guidance will be of interest to local government, public health, social care, providers, patients and patient groups, including local healthwatch and self-advocacy groups. In light of this, versions will shortly be available in plain text (to support access for people using assistive technology) and in 'easy read.'

16. A comprehensive programme of support for implementation through commissioning support units is being developed so that commissioners, from CCGs and NHS England, have access to specialist skills and expertise that can build sustainable approaches to dramatically improving the ways in which we really put people at the heart of the NHS.

Example – putting public participation into practice at the AGM

17. As the leader of the NHS commissioning system, it is vital that NHS England not only supports clinical commissioning groups and others in effectively undertaking and commissioning public participation, but is able to demonstrate best practice and showcase innovation in this area. The recent Annual General Meeting (AGM) was identified as the ideal opportunity to put the principles of good public participation into practice, prior to their publication in the guidance outlined above.

18. On 12 September 2013, prior to its first AGM, NHS England invited citizens to take part in a series of 'Talking Health' pre-AGM workshops. This was a real opportunity to demonstrate openly the values, behaviours and culture of transparency and participation that NHS England seeks to embody.

19. The aim of the workshops was to work in partnership with people to explore topics of fundamental importance, relating to the following themes:

- A Call to Action – what does the future look like?
- Making a difference for those facing the greatest health inequalities.
- Developing Seven Day Services.

- Transparency and participation – unlocking the power of data and information.
- Improving end of life care.

20. Over 200 people participated in the pre-AGM workshops and 400 people registered for the evening AGM meeting. The audience included patients, the public, clinicians and other NHS professionals. Each workshop had a live Twitter chat which enabled hundreds more people to contribute their ideas, experiences and opinions to the debates – without travelling to London. One person tweeted *“Unfortunately I could not make @NHSEngland’s #NHSAGM, but thanks to twitter, it feels like I’ve been there”.* There were more than 4000 tweets using the workshop hashtags, with several workshop themes continuing an on-going discussion well beyond the AGM. In the case of #EndofLifecare the Twitter discussion continued for several days. We reached an estimated 200,000 individual Twitter accounts.

21. Representatives of the NHS England AGM Board attended each workshop and listened directly to what participants were saying. Scribes and graphic artists captured what people said, ensuring that everyone was included and that literacy or jargon were not barriers to participation. The key highlights (summarised here) from the discussions into the AGM public meeting with strong themes around greater partnership working with patients and the public to meet the future challenges of the NHS.

Picture: Martin McShane presenting on Person Centred End of Life Care

AGM update

22. Each paper will include an update on progress relating to the workshop themes from the NHS England Annual General Meeting (AGM) in September 2013. It is intended to publicly feedback on progress in relation to the workshop themes at EXPO 2014, using a “you said…we did…” format. This approach will enable NHS England to be held accountable for the discussions and activities developed in the AGM workshops. It will also enable us to continue a transparent dialogue with patients and the public.

23. Key points raised by participants at the AGM, and commitments / responses from NHS England are as follows

Call to Action:

25. There is a need to focus on preventing ill health and improving well-being to ease the burden on the NHS. *The NHS England Call to Action team have begun engagement on prevention and focused the first national event on* 7/10/2013 around the theme of prevention. The event brought together *informed patients, the public and staff from across the health, social care and voluntary sector who explored a range of future options and issues around preventing ill health.*

26. The Call to Action should address and involve communities, not just patients, in future plans for the NHS. *NHS England will ensure that both patients and the public are invited to all of the national events to ensure that whole communities have an opportunity to have their say. Communications with clinical commissioning groups and NHS England area teams are also reinforcing messages for ensuring participation at a local level.*

27. Issues of access and continuity in the care of long term conditions must be considered as part of the national Call to Action discussions. *One of the national Call to Action events will focus on 'Putting Patients in Control'. At this event NHS England will work with patients and the public to explore how the NHS can understand what people feel is of greatest importance in their own care and how they would like to be more in control of their own health management.*

Health Inequalities:

28. Good data is essential for informed decision making and should be used to ensure that those who experience the greatest health inequalities are receiving high quality care and services. *NHS England is committed to building this approach to managing our data and using expert by experience-led research and community insight to shape healthcare improvements.*

29. Integrated care is really important - joining up services, agencies and individuals across geographical boundaries to provide seamless care. *This was the theme of the recent NHS Values summit in Greater Manchester where we worked with patients and the public to develop new approaches to ensure that this happens.*

30. Many of the barriers to accessing and receiving good healthcare come from the need to change attitudes. *NHS England is committed to growing and supporting a positive culture in the NHS. We will challenge and influence staff attitudes to individuals and groups facing health inequalities. We are encouraging NHS staff and community members who are experts by experience to become champions and volunteers who will "walk in the shoes" of seldom heard groups, they will listen to people, value the lived experience and work in partnership with people to co-produce improvements to services.*

Seven day services:

31. The Seven Day Services team used the AGM workshop to gain patients' perspectives. Whilst the workshop comprised a mixed group of stakeholders including professionals, everyone in the room was able to think of their experience as a patient or that of their loved one.

32. Some key themes emerged and had a strong impact on the policy team. The team members present were able to relay these views to the wider 7 Day Services team. Both the AGM itself and the strong output from the workshop will certainly have a tangible impact on the forthcoming NHS Services, Seven Days a Week Forum review.

The themes were:

33. Representatives of patients and the public felt that the debate around providing equal access to care, seven days a week often results in a polarised argument around centralisation v localism. This, they felt, mislead the public into thinking it was a choice between local provision or having to travel for care in specialist centres. Instead, the focus needs to be on appropriate integration of services. We need to promote thinking that this is not about 'bricks and mortar' provision but about people receiving the right care at the right time and by the right person. This would result in a focus on improved outcomes and patient experience, which is the most valid approach.

34. *As a result of this feedback, the Seven Day Services team takes additional care to articulate the debate around seven day services in such a way that promotes the concept of integration and challenges thinking which is focussed only on centralisation. This is reflected in our media and communications planning in order to ensure that the public and other key stakeholders are presented with information that best represents the issues. In addition, Fiona Carey, who articulated this point so well in the workshop, has been asked to provide a 'Patient's Foreword' for the forthcoming Forum report, due to be published by the end of Autumn.*

35. The workshop participants expressed a strong desire to be involved in the shaping the next phase of the NHS Services, Seven days a week programme. This should include frank discussions about the issues involved and a fully transparent approach. Public and patients want to be involved in the tricky issues and understand the opportunities and challenges.

   - *This is now feeding in to the engagement planning for the next phase of the NHS Services, Seven Days a Week programme. Ideas currently being tested include a dedicated patient, public and caregiver steering group, involved in decisions around scope and helping to shape delivery. This would be in addition to broader patient, public and carer engagement. It may include patients / carers that have themselves had a poorer experience at the weekend, so that the real 7DS issues from a patient perspective are considered. Contributors will be influential in deciding how best we engage with and inform the wider public. The engagement plan will identify the need to maintain full transparency and ensure that patients are fully informed of all issues. This model could be replicated locally, based on the groups feedback that locally driven change is key –NHS Improving Quality's 7 Day Services Early Adopters Programme presents an ideal opportunity for this.*

36. A number of people in the workshop highlighted the need for young person involvement in future planning. Examples were given of poor experiences of care by young people and the need to tailor provision to their needs. It was highlighted that young people had a unique perspective on the world, which would bring new ideas and innovation on some of the challenges, for example reconfiguration. In addition, it was the right of young people to have strong involvement as ultimately, they should decide the future of their NHS. During the fish bowl session, a young person from Whizz Kids responded to the issue of 7 Day Services and was clearly worried and outraged by the current situation. This had a very powerful impact on the team.

   - *The team will ensure that in the next phase of the programme, the views of young people are fully considered. This will be reflected in our future engagement plan which will be published as an appendix to the main report.*

Transparency and Participation:

37. Do not build digital products that use up all of our data or incur costly charges. *NHS England has adopted the founding principle that visitors to NHS Choices will be able to access the site via mobile devices without significant data use or charges.*

38. Although digital access to information is important, we must not forget those who are not online. *NHS England has committed to only developing digital tools and options that have 'real-world alternatives' – no-one will be forced to 'go digital' in health; and we have launched a £1m programme to widen digital participation across England.*

39. NHS England should be clear about how patients' information will be used, communicate safeguards and support people to understand the data. *We are planning a national awareness programme to ensure that patients and the public understand how information is used for wider purposes, the benefits this can bring and their choices including their right to object and have their objection respected. We are also talking to voluntary sector partners to help us understand concerns better and respond to them appropriately.*

40. NHS England should simplify and use existing channels for patient and public participation, reduce complexity of language, and empower patients. *We are planning to support patient empowerment through developing a Patient Leadership Academy and range of other actions outlined in our recently published participation guidance 'Transforming Participation in Health and Social Care'. This guidance includes the principle that we will use plain language, and will openly share information, and we are working to make this a reality in all our involvement activities, and to support CCGs to do the same.*

End of Life:

41. Communication is really important. The terminology or language used is less important than the way in which staff communicate with patients and their families. It is important be culturally sensitive and use clear and open language. Professionals need to have the skills to be able to discuss, in a clear way, all aspects of End of Life care including supporting decision-making.

42. It is essential to focus care on the individual, including continuity and consistency of care, clear communication between professionals, de-medicalising death and dying, and care right through to end of life, including care after death.

43. Do more to recognise that enabling a loved one to die at home can cause enormous strain to carers and families.

44. Other key priorities (highlighted as part of conversations on Twitter) include: timely access to home care and palliative care services; advance care planning for non-cancer diagnoses; the need to tackle variation and inequities; funding and commissioning approaches for care homes.

45. *NHS England will consider all of these issues as part of the review and refresh of the End of Life Care Strategy that is currently underway. In addition, further feedback will be sought, and patient and public participation undertaken. Where appropriate, feedback is also being used to inform the response to the independent review on the Liverpool Care Pathway and its recommendations about care in the last days of life.*

Please follow the link below to access the Participation Guidance described in this document:

http://www.england.nhs.uk/wp-content/uploads/2013/09/trans-part-hc-guid1.pdf

Tim Kelsey

National Director for Patients and Information

October 2013