

BOARD PAPER - NHS ENGLAND

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 demonstrate 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 progress made with the rollout of the Friends and Family Test and its impact to date;
- showcases an example of an organisation using the results of the Friends and Family Test to improve the patient experience;
- updates on progress relating to End of Life care – one of 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

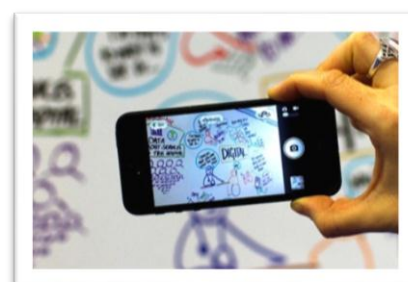
Introduction

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 fourth 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 presentation of papers in July and September, commencing in November 2013 and for each subsequent meeting of the Board, the paper will include the following four sections:

- Headlines: two or three key patient and public voice 'highlights' – 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

Engagement activity launched for accessible information

4. Led by the Patients and Information Directorate, NHS England has commenced a



programme of work to develop and implement an Information Standard for accessible information. An Information Standard is a framework of requirements and recommendations to which health and social care organisations must have regard.

5. Once implemented, this Information Standard will mean that disabled patients, service users and, where appropriate, carers, receive information in formats that they can understand, and that they receive appropriate support to enable them to communicate, which may include advocacy.
6. Hosted at www.england.nhs.uk/accesibleinfo engagement activity is underway to inform the development of the standard. This includes a survey for patients, service users and carers in Easy Read and British Sign Language video, alongside online and standard print versions. Face-to-face engagement events are also taking place alongside key partners such as the RNIB and CHANGE to ensure that the activity is as accessible and inclusive as possible.



7. Engagement will continue into February 2014, when feedback will be used to shape the specification for the standard itself, as well as contribute to assessment and evaluation of impact.

Congenital heart review

8. As NHS England progresses with the national review of congenital heart services for children and adults, John Holden (Director of System Policy) is writing a regular blog to maximise transparency and ensure that those with an interest in the review are kept informed of progress and given the chance to get involved as appropriate.
9. The latest blog, number 12 in the series, was recently published on the NHS England [website](#) It updates on a range of recent engagement activities and on-going discussions with interested parties, including the Patients and Public Group meeting on 12 November, which brought together local and national charities. The slide pack for this event, which includes questions added on the

day, is also [available](#) The Policy Directorate has committed to continuing to learn from this and other events to improve engagement in the future.

Gender identity engagement

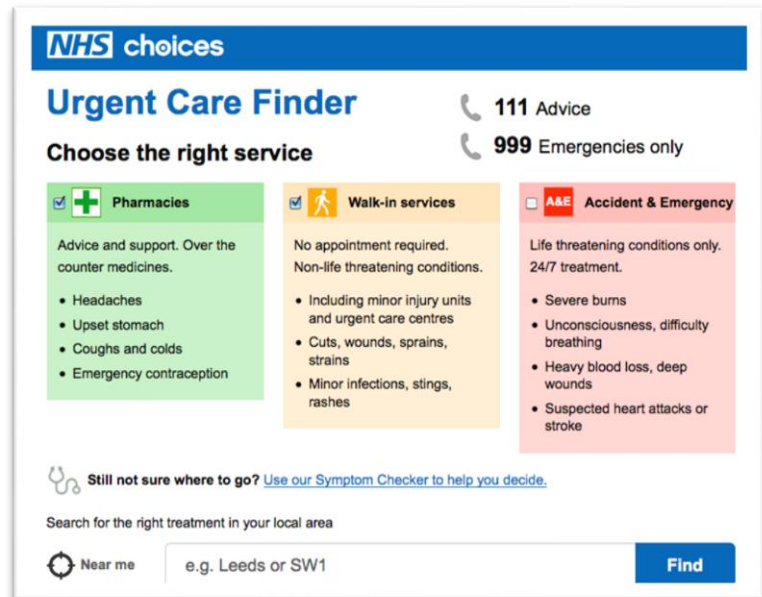
10. Following an initial workshop in June, commissioners and providers of gender identity services came together with people from the trans community for the first time on 07.11.13. The event followed the publication of the [interim protocol for gender identity services](#) and was the opportunity for NHS England to update on progress and for all participants to lay the foundations for partnership working in the future. Comments from attendees included, “I appreciated the positive ethos: the opportunity to make fresh start and to put in place policies and structures that will achieve national consistency of treatment and care.”
11. Following the workshop, a [Gender Identity Network](#) has been established, providing an online forum where people can ask questions and share information with their peers. It will also be a place to post views and ideas which will be forwarded on to the relevant groups and meetings which will include Clinical Reference Group (CRG), Gender Identity Services Review.

Participation Awards

12. Launched earlier this month, the NHS England Excellence in Participation Awards celebrate the outstanding contributions of people and organisations across the country who are transforming people’s lives, improving health and care services and putting patients, carers and communities at the very heart of healthcare.
13. The awards will contribute to a culture of excellence and achievement across individual and public participation in health which can then be celebrated and shared nationally.
14. There are a range of award categories all designed to recognise and celebrate outstanding people and organisations. Winners will be announced at Health Innovation EXPO 2014. [Visit Website](#)

NHS Choices

15. Since its launch in 2007, NHS Choices (www.nhs.uk) has successfully delivered rich health and care information and content to a growing demand of over 30 million visits per month (36 million visits in October 2013).
16. In November 2013, NHS Choices will publish General Practice level indicators as part of its accountability view. This information is currently available to commissioners and practices and will enable members of the public to participate more fully and equally in conversations about the design and quality of health and care services by accessing information previously only available to commissioners and providers.
17. In December 2013, NHS Choices will launch a dementia email service. This service will improve the information for people immediately following diagnosis, NHS Choices will shortly pilot an email toolkit for anyone whose spouse, relative or friend has just been diagnosed with dementia, delivering access to a library of the very best online content, sourced from NHS Choices and other high quality sources.
18. From February 2014, NHS Choices will launch user-centric beta products supporting people to choose the most appropriate urgent care services and identify an appropriate general practice based on relevant data about performance and quality.



Spotlight – Friends and Family Test Update

19. Launched on 01 April 2013, the Friends and Family Test (FFT) is a simple single question which asks patients whether they would recommend the NHS service they have received to friends and family who need similar treatment or care. To date more than a million patients have provided feedback through the Friends and Family Test.

20. The real strength of FFT lies in the follow up questions that can be attached to the initial question. These provide a rich source of qualitative patient views that can be used locally to highlight and address concerns much faster than more traditional survey methods.

21. The free text responses allow providers to look at the specific issues being raised by service users, to identify areas for improvement. NHS England does not see the responses to these questions, and we do not publish them (Trusts are able to publish anonymised responses if they decide to do so).

22. The responses to the FFT question are used to produce a score that can be aggregated to ward, site, specialty and trust level. The scores can also be aggregated to national level. In future the nationally aggregated FFT score will be used as an indicator in the Outcomes Framework.

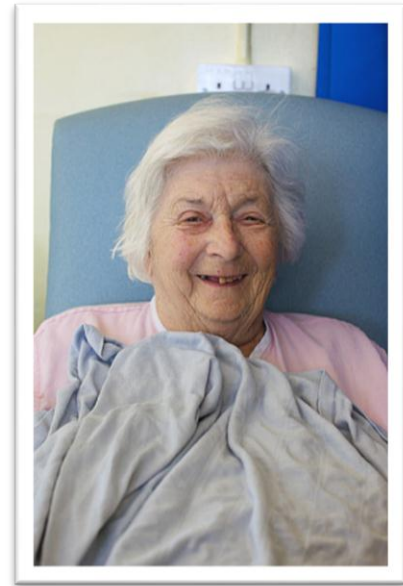
23. On 30 July 2013, the first three months results of the FFT for all acute hospital inpatient and accident and emergency departments were published. This was the first time that FFT results were made available at a national level. We are committed to publishing the scores every month.

24. Since 1 October, FFT has been live in maternity services (the first quarter's data will be published at the end of January 2014). We are committed to introducing FFT to general practice and community and mental health services by the end of December 2014. By April 2015, all NHS patients will be able to provide feedback via FFT.

25. We do not publish the scores in league tables, but the data is published on the NHS England website in a way that allows data analysis, including constructing alternative scoring methods and direct comparisons between providers on a national and regional basis.

26. As of this month, over a million patients have provided feedback using the Friends and Family Test, representing a real step change in the way that the NHS records patient experience data and uses this data to drive improvements.

27. Many Trusts have embraced FFT and have sought to build upon and add value to the insight it offers into patients' experiences. For example, some Trusts are at the early stages of mapping themes from FFT and comparing this to other patient experience data such as complaints, in-patient survey and other



surveys as well as triangulating patient experience data with the staff survey and safety measures for example the safety thermometer and others, while some Trusts are developing dashboards which include FFT.

Example – FFT at the Hillingdon Hospitals NHS Foundation Trust

28. The Hillingdon Hospitals NHS Foundation Trust recognised a theme in some of the feedback received through FFT relating to noise and light at night across a number of different wards, along with some comments related to responsiveness to need at night. In response, the 'Comfort at Night Campaign' was launched, supported by the Director of Nursing, with the aim to, "Create the right conditions to reduce sensory overload and enhance comfort at night."



29. An action plan has been developed, which includes:
- setting and achieving a standard for main ward 'lights out' or dimmed at night and 'lights on' the morning;
 - working towards changing all waste bins in or close by sleeping environments to 'silent closing' models;
 - supporting patients to maintain their own 'normal' personal hygiene routines, such as cleaning teeth and soaking dentures before bed;
 - ensuring that there are sufficient pillows and blankets available;
 - disseminating messages to staff through screen savers highlighting the importance of lower voices, being aware of the impact of staff conversation in an environment that is quieter, especially when close to sleeping areas, and ensuring that shoes adhere to uniform policy and do not create noise.

AGM update

30. 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.

31. The focus for this paper is on End of Life care, one of the workshop topics. This is timely, as the response to the report of the independent review of the Liverpool Care Pathway has a strong focus on communication and improving care in the last days of life.
32. Currently, NHS England is carrying out a public engagement exercise in conjunction with its partners on the Leadership Alliance for the Care of Dying People, about the desired outcomes for care in the last days of life, guiding principles and what this means for dying people and their families. So far, this engagement exercise has involved 14 face to face workshops with professionals and the public, a survey for online feedback and involvement of voluntary organisations across the sector.
33. A second wave of public engagement will target specific groups such as those working with people with learning disabilities and people from black and ethnic minority communities. The engagement exercise finishes on 06 January 2014, following which analysis of the feedback will inform a further revision of the document on outcomes, guiding principles and what this means, due to be published in late February 2014.



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December 2013