Title: Patient and Public Voice

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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;
- 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 patient and public voice activity. An update on progress relating to the Health Inequalities workshop theme from the NHS England Annual General Meeting in September 2013 is also included.

Key issues and recommendations:

This paper:

- highlights NHS Choices and digital services especially patient record access online and launch of the new vendor market
- outlines the latest developments with the *Friends and Family Test*
- details feedback from the Informatics Services Commissioning Group Open House event on 21 January
- updates on current thinking with regards to the *NHS Citizen* programme
- provides an update on developments since the AGM focusing on Health Inequalities

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.

Introduction

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

Context

2.   This is the sixth 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.   Each paper includes 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 or more of the workshop themes from the NHS England Annual General Meeting (AGM) in September 2013.

Headlines

Health and Social Care Digital Service

- 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 40 million visits per month. This evolving landscape requires that our approach to digital participation be much wider than the current offer. Health and social care services have several digital propositions and they all need to come together to deliver an improved outcome to enable patients, service users and the public to better inform themselves, get involved and be engaged in their health and care.

- The Health and Social Care Digital Service (HSCDS) will be a world leading, multi-channel service that will harness the power of technology to create a 'front door' to transform the way the public engages with health, public health and social care services in England. HSCDS will empower patients and the public to live healthier and better informed lives through the use of cost effective, relevant and personalised digital channels for their health and care needs. Delivered through mobile phone apps, SMS, telephone and online channels, it will support and enable people to access information, provide feedback, carry out transactions and more fully participate in their health and care services.

- All this change represents the evolution of a site rather than the creation of a new entity. It is imperative that we maintain the existing traffic while improving the user experience. NHS Choices will build on the success of the current Government Digital Service and benefit from lessons learned in delivering digital engagement.

- The evolution of NHS Choices will be significant, not only in terms of the technical and user-centric evolution, but also in terms of its workforce. It is anticipated that usage of the site will double or triple what it is today over the next three years. The HSCDS will:

  - Directly connect people to information about health, care and associated services to help them to make informed decisions about their needs, such as choosing when and where to access care and advice.

- Provide a range of simple, relevant and timely online services to enable people to carry out health and care transactions online, such as booking appointments, ordering repeat prescriptions or accessing their digital care record, when and if they wish.

- Provide a service for individual participation in health and care and the opportunity to connect to supportive communities and third party services. This might include managing a long-term condition with online tools, and connecting to others with the same condition for peer support and advice.

- Enable people to feedback about their experiences of health and care and ensure that they are listened to and their comments acted upon.

- Facilitate access to HSCDS information for third party organisations and developers, enabling them to create innovative products for consumers to further improve the variety of tools and services available.

- As of February 2014 every GP practice profile on NHS Choices displays the range of online services that they provide and easy access to, for instance, repeat prescription ordering and appointment booking online, once they have registered. The display also links to supporting material explaining the on-line services and how to sign up for them.

- The public preview (Beta) of the online channel was launched at the NHS England Health Innovation EXPO on 3 and 4 March. This highlighted the new look and feel for NHS Choices and features being developed across the following priorities:

  - Relieving pressure on primary care and A&E services
  - Supporting people living with dementia and their carers
  - Promoting greater transparency and choice over services and treatments
  - Encouraging and stimulating market involvement and innovation, through the development of a robust and open technical platform.

NHS Choices and HSCDS delivery timeline

Personal Health Records

- Another key development associated with the HSCDS relates to Personal Health Records (PHRs). PHRs can help shift the relationship between patients and clinicians through increased access and ownership of relevant health information.

- Building on the broad level objective of supporting the Small and Medium Enterprise (SME) market work is underway to consider the supplier and commercial models needed to foster a PHR marketplace within NHS Choices. NHS England is working with the GP System of Choice team and techUK on these commercial models while also giving consideration to factors such as the technical architecture and long-term vision for PHRs in order to ensure that a viable market is created.

- Defining the vision and delivery models for PHRs is underway.
  During the spring of 2014, a series of workshops and working groups with stakeholders are being held to develop the vision, architecture and commercial models. NHS England and the Health and Social Care Information Centre (HSCIC) are working collaboratively to develop the vision for PHRs within the HSCDS landscape, and to understand which commercial models can be used to drive citizen uptake of PHRs.

Friends and Family Test Update

- The NHS Friends and Family Test is based on a simple question that ensures that local hospitals and the public get regular, up to date feedback on what patients think about their services.

- The purpose of the NHS Friends and Family Test is to improve patient experience. It is about much more than a score. It acts as a catalyst to ask 'why? – why have patients awarded us this score?' Trusts are collecting hundreds of pieces of detailed feedback from patients every day and it is this insight that is enabling Trusts to make positive changes and celebrate success.

- Publishing the results of the NHS Friends and Family Test signals an ongoing commitment to transparency in the NHS. Transparency is the lever by which customer services will be transformed and is at the heart of NHS England's drive to improve quality for patients.

<u>Inpatient and A&E services</u>

- The NHS Friends and Family Test (FFT) was implemented on a national basis across all acute hospital inpatients and accident and emergency departments on 1 April 2013. Data is now reported and published on a monthly cycle. The total number of responses to date for the inpatients and A&E FFT (April to December 2013) is 1,581,370.

Headline figures: inpatient and A&E

	Nov	Dec
National combined score (including independent sector)	65	64
National combined score (NHS trusts only)	64	64
National combined response rate (including independent sector)	20.9%	19.9%
National combined response rate (NHS trusts only)	20.6%	19.7%
National inpatient score (NHS trusts only)	72	71
National inpatient score (including independent sector)	73	72
National inpatient response rate (NHS trust only)	31.1%	28.5%
National A&E score (NHS trusts only)	56	56
National A&E response rate (NHS trusts only)	15.2%	15.3%
Number of negative scoring NHS trusts - inpatient scores	0	0
Number of negative scoring trusts - A&E scores	0	1
Number of negative scoring wards	36	38

- After the first six months of the inpatient and A&E implementation, a review is underway. This is due to report in April, and will inform the development of FFT in other service areas.

<u>Maternity services</u>

- In October 2013 the FFT was rolled out to all NHS-funded maternity services. The first results of this data were published on Thursday 30 January 2014, alongside the latest monthly inpatient and A&E data.

Women are asked four questions at three maternity touch-points:

- One question just before birth (about experiences of antenatal care);
- Two questions soon after labour and birth (about experiences of birth and the postnatal care received in hospital/place of birth); and
- One question at the end of the maternity pathway (about experiences of postnatal care).

- This is the first time that we have collected maternity FFT data and the first time that FFT has been applied across a pathway. We have published a response rate for the birth question (question 2) as the number of women giving birth is a clearly identified and counted population. For the other touch-points, women may access services in a variety of ways and with different providers which introduces additional complexity.

Headline figures: maternity

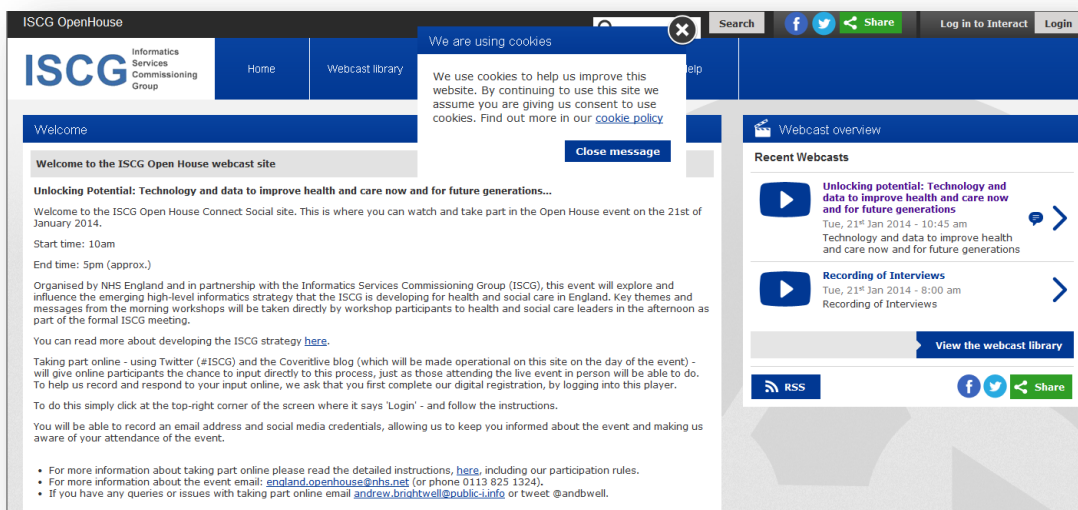|	Nov	Dec
National score - Question 1	65	63
National score - Question 2	77	75
National score - Question 3	66	66
National score - Question 4	72	74
Response Rate - Question 2	19.6%	19.1%
Number of negative scoring sites - Question 1	3	3
Number of negative scoring sites - Question 2	1	1
Number of negative scoring sites - Question 3	1	4
Number of negative scoring trusts - Question 1	1	2
Number of negative scoring trusts - Question 2	0	1
Number of negative scoring trusts - Question 3	0	1
Number of negative scoring trusts - Question 4	0	3

Other services

- The NHS Friends and Family Test will be rolled out across all NHS services by April 2015. NHS England is committed to introducing the Friends and Family Test to General Practice and community and mental health services by the end of December 2014 and to the rest of NHS funded services by the end of March 2015. Guidance for other services is currently under development, including Acute Outpatients and Day Cases, Mental Health Trusts, Community Trusts, and Primary Care, as well as the introduction of a staff-focused FFT.

- A process of testing the implementation of FFT across a range of services in a geographical area is about to launch, which will inform the wider implementation across the whole of the NHS, looking at the interaction between services.

- The process of setting up broader review of the patient feedback architecture is also being considered, including FFT in the context of other insight mechanisms, such as the national patient survey programme. This will start in the next few weeks.
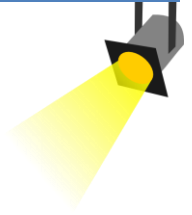
Spotlight – Open House Event

Informatics Services Commissioning Group (ISCG) Open House event

- NHS England is a member of the ISCG, which develops informatics strategy for the health and social care system in England. This group is chaired by Tim Kelsey, National Director for Patients and Information, NHS England. From April 2014, the ISCG will be renamed the National Information Board.

- NHS England hosted an Open House participation event on 21 January on behalf of the ISCG providing an opportunity to develop the informatics strategy in a transparent and participative way. Patient leaders were involved in planning the event which was intended to move beyond information-giving to shaping and building strategy together.

- On the day, a range of stakeholders from across health and social care, including patients, carers and voluntary sector representatives, took part in facilitated discussions focusing on four different areas of informatics:

  - linking patient records across health and social care;
  - delivering IT services with a direct impact on citizen experience such as NHS Choices;
  - comparative data - introducing care.data;
  - patients, nurses and technology.

- Key themes were fed back and discussed with the ISCG Leadership Group as the first item on their meeting agenda. *A clip will now be played noting some key views about the themes discussed.*

- Building on learning from previous digitally integrated events, the ISCG Open House was webcast and enabled digital conversations to take place with participants across the country and beyond. The live stream and all of the resources developed for and during the event are hosted here. A transcript of twitter highlights is available here.

SPOTLIGHT

- As with previous events such as NHS Citizen and the AGM, the digitally integrated approach greatly extended the reach of the meeting, generating over 1628 individual connections to the web cast and through Twitter 3.7m Impressions, 1,591 Tweets and 378 participants, with #ISCG trending on the day of the event.

- Key themes from the event:

    o The need to maintain communication and engagement with patients, patient groups and clinicians in relation to informatics, on an ongoing basis.
    o The importance of using plain English and of recognising that much of the language around informatics is difficult for many people to understand. Discussion should be connected to patient experience, stories and benefits.
    o "Convenience" was a consistent message from each workshop. People should be able to have access at any time, in a way that suits them best, rather than at a time and way that suits health and care services best.

    o Participants expressed a strong desire to be able to complete more online health transactions including accessing their own health records.
    o There were strong and consistent views that individuals must be involved in the decision-making that affects their care and that their views and experience should be reflected in how data is shared and how the programme of work is taken forward.
    - Perceptions around data security, especially relating to personal health records, were of critical importance to participants. Citizens need to be completely reassured about how, and with whom, personal data was being shared.
    - Participants' views were that cultural change is required – both with individuals understanding that their data might be shared, but also clinicians and other professionals being willing to share.

- The insights and suggestions from this event are being used to inform the ISCG strategy and implementation of the relevant work programmes. Event participants have been invited to continue to be involved in the design of an

accountable and transparent approach to embedding participation in the ongoing work of the National Information Board, and also to maintain their involvement in different informatics work programmes.
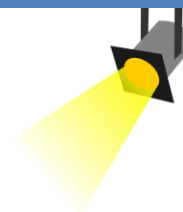
Example - NHS Citizen Programme

- The public voice team is currently travelling across the country gathering ideas, feedback and comments on the latest plans for NHS Citizen and how it could work locally. To date, three regional events have been held, in Leeds, Birmingham and Sunderland.

- An iterative management process is being used which holds the vision and model, the research and learning questions and the programme's critical path in public. A two-three month sprint-testing process of different elements of the NHS Citizen model (pictured below) is now taking place where at the end of each testing phase the components of the model are being refined and adapted.

- Each of these two to three months sprints will include testing bits of the system, and as the year goes on this will increasingly move to whole system tests. These will be designed to ensure that we, and all partners and participants, can learn from the process and iterate the design to make it work better.

- Key learning from the regional events has been:

  - NHS Citizen needs to reduce not add to complexity.
  - It needs to provide a simple visible point of entry for any citizen who wants to affect NHS England decision making – it needs national profile and door openers to help orient people at the edges of the system.
  - The 'Gather' has to be something that works at local and national level.
  - Further exploration is needed as to how to bring off-line discussions into the discover space. Conversations at the
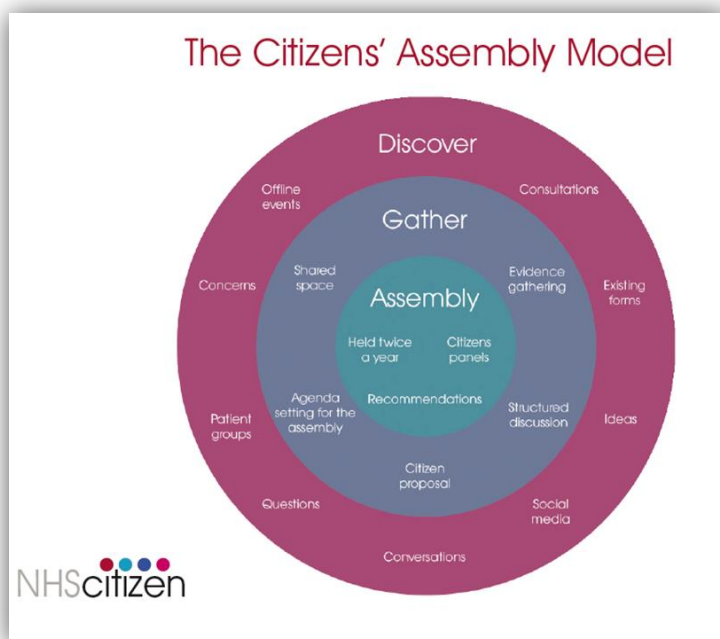
Sunderland event also made clear that consideration is also needed as to how online and off-line mix in the gather space as well.

- It will be important to visibly measure the impact of NHS Citizen.
- Participants suggested the creation of examples of what an NHS Citizen 'journey' might look like for an issue or individual therefore making is real to people.

- NHS Citizen was officially launched by Tim Kelsey, National Director: Patients and Information, Lord Victor Adebowale, Non-Executive Director, and Ciaran Divan, Non-Executive Director, on the Community Stage at the NHS England Health Innovation EXPO on 3 and 4 March.

- There are a number of ways people can get involved:

  - Coming back to the Involve blog and project page which will be updated to provide a high-level summary of what is happening;
  - Visiting the NHS Citizen blog;
  - Visiting the NHS Citizenspace for conversation and debate;
  - Attending a workshop or events either in person or online; and
  - Following @NHSCitizen and join the conversation with #NHSCitizen on twitter.

AGM update

- 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. This paper focuses on developments around the health inequalities theme.

Health Inequalities

- At the AGM in September several statistics were shared with the workshop attendees relating to health inequalities experienced by patients and the public resulting in an estimated cost to the NHS of £5.5 billion (Institute of Health Equity). Statistics shared included that homeless people are over nine times more likely to commit suicide than the general population and 80% of street workers report using heroin.

- Good data was a key theme emerging from discussion at the AGM workshop. Participants agreed that data was critical to ensuring informed decision making and should be used to ensure that those who experience the greatest health inequalities are receiving high quality care and services.

- A data sub-group has now been established in partnership with the Equality and Diversity Council and Commissioning Assembly Health Inequalities group and is chaired by Bill McCarthy, National Director of Policy. The aim of the group is to ensure a coordinated approach to the collection and use of data. This will help to

eliminate unfair variation and ensure NHS services achieve good access, health outcomes and experience for all with a particular focus on those currently experiencing the greatest health inequalities.

- To build on NHS England's commitment to use patient stories, experts by experience and community insight, a community research pilot is commencing in Greater Manchester. This will draw on community researchers with lived experience of homelessness, destitution, asylum seeking, sex work, recovery from addiction and mental health issues.

- Feedback from service users has shown that 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 which provided an opportunity for professionals, patients and the public to develop new approaches to ensure that this happens.

- Following the Summit, a group was convened to take forward joint work with local communities to establish a lasting post-event legacy. Volunteers with 'lived experience', community members, patients, and voluntary sector organisations are working together with health professionals to support improvements to integrated healthcare across Greater Manchester. The group examined Greater Manchester's Joint Strategic Needs Assessments (JSNAs) through an equality and health inequalities lens and identified some gaps in identifying and meeting health need in regards to some of the most disadvantaged groups. The group is also working to define 'what good looks like' for those experiencing the greatest health inequalities. A JSNA template is being developed for Clinical Commissioning Groups (CCGs) and Health and Wellbeing Boards. This template will be used to trigger the inclusion of the health needs of diverse communities, disadvantaged groups and people living in vulnerable circumstances. The template and more information about this initiative will be launched at an NHS Expo workshop in partnership with the Commissioning Assembly Health Inequalities sub-group.

- A number of initiatives are underway to remove barriers to accessing and receiving good healthcare by seeking to change attitudes. The staff attitudes that were described by patients as a barrier to individuals and groups facing health inequalities are being positively challenged. Groups such as the Greater Manchester Values Summit group are being formed with a commitment to respect, empower and positively support the community members and lived experience volunteers. This is can be a steep learning curve for staff, requiring them to 'walk in the shoes' of groups who may be termed 'seldom heard.' The aim is for staff to think about how can they equitably share power and model positive behaviour, truly valuing and working in partnership with people to co-produce improvements to services.

- The valuable work to change attitudes and shift the professional/patient power balance was profiled recently at Expo. This included approximately 40 patients

and community members with lived experience running the 'street of care'. This included a pop-up wellbeing café run by asylum seekers and refugees.

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March 2014