

**BOARD PAPER – NHS ENGLAND**

**Title:** Patient and Public Voice

**From:** 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;
- 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 reflects on some of the related activities in the first year of NHS England and looks ahead to a few of the programmes being taken forward in the year ahead.

## Executive summary

During 2013/14 NHS England has:

- For the first time, [published data](#) at consultant level for ten surgical specialties and data on prescribing and referrals for cancer at a GP practice level.
- Through the [Friends and Family Test \(FFT\)](#) enabled over 2 million patients to provide feedback to the NHS on the services that they have received.
- Worked with The Tinder Foundation to [widen digital participation](#), including reaching over 100,000 people with digital literacy messages, and training over 50,000 in online skills. As highlighted in [this video](#) showing digital inclusion work with the Asian community in Leicester.
- Hosted the inaugural [Excellence in Participation Awards](#), showcasing exemplary practice in public and patient participation and insight.
- Received 360 degree feedback from Arm's Length Bodies and patient and public organisations, including the Voluntary Sector Strategic Partners.
- Launched the [care.data programme](#) to ensure that data can be linked and used to ensure that patients receive the highest quality care and the best possible outcomes.
- Begun to coproduce the [NHS Citizen](#) model as an innovative way of enabling people to engage with NHS England and hold the organisation to account. One of the four core elements of NHS Citizen is the concept of a 'Gather' space in which people can connect with others who share an interest or concern.
- Engaged all CCGs in a support programme to deliver personal health budgets and instigated an intensive training programme resulting in a jump from 25% of CCGs being ready to offer them to people eligible for Continuing Healthcare, to 76%. [This video](#) shows the impact that a personal health budget can have on an individual and their family

## Transparency and Data

1. During 2013/14 NHS England continued to demonstrate commitment to transparency for the health service. In the summer of 2013 data was published at consultant level for ten surgical specialties and the following winter saw the publication [on the NHS Choices website](#) of new information about prescribing and referrals for cancer, at a GP practice level.

**Hold health services to account**

You can help build better, more responsive, health and social care services – but to do so you need information about the performance of those services, and the challenges they face.

This section of NHS Choices aims to let you get the data that 'the system' uses to monitor and shape the services it provides. This information is open to everyone, but it may be especially useful to members of the public already involved in examining services and challenging them to improve. You might be a member of a local Healthwatch group, a councillor or perhaps a campaigner interested in care for a particular condition.

We will cover a wide range of organisations, including GPs, hospitals, local authorities and clinical commissioning groups. We'll be building up the database over time but there is already plenty to explore. See the panel on the right for details of just one of the highlights of the launch database. When looking at these indicators, it is important to consider the context in which services operate. Local knowledge of the services can help here. It is also generally a good idea to consider a range of indicators together – in order to get a fuller picture of performance.

If you want to choose a hospital or general practice please use our [service-finder](#).

**What do we publish?**

We publish a diverse range of data that covers topics such as:

- Patient experience
- Patient safety
- Patient outcomes

This data is the most up-to-date available in the NHS. The data is not a definitive view but may point the way to areas for further investigation, discussion and debate.

**How we display the data:**

We display indicators in a range of ways including rates and percentages. Where possible we display a performance category showing relatively worse, better and average performance.

Each of the indicators is paired with an information sheet that gives information about how the indicator is calculated, the period it covers, and issues related to its interpretation.

**New GP indicators released to the public (November 2013)**

NHS England is publishing data including statistics on unplanned hospitalisations, which can be used as a broad indicator of quality of care in the health system, as shown on the map below.

**Map Key:** ■ In the best 25% of CCGs ■ In the middle range ■ In the worst 25% of CCGs

This map shows unplanned hospitalisation for 'Chronic ambulatory care sensitive conditions for GP practices' aggregated and displayed by Clinical Commissioning Group (CCG). Click on a CCG to see further information for GPs in that area.

2. In 2014/15 NHS England have committed to the publication of additional consultant-level information on NHS Choices and to the roll out of work to develop new service level measures that will provide an at-a-glance summary of how well hospitals are performing in ten clinical areas.
3. In addition, a programme of work will be launched to help people to access and use health data and information so that they can better participate in conversations about the design and quality of their local services.

## Care.data

4. Every patient should expect the highest quality care. One of the most powerful ways in which the NHS can be sure that it is providing patients with the best possible care is by analysing detailed, joined-up, high quality information about illnesses, treatments, and outcomes.
5. Sharing information about the care patients receive when they visit their GP builds understanding of health needs and the quality of treatment patients receive. Care.data aims to link this data together with information from GP records, hospital records and information about other care settings.
6. In February NHS England acknowledged the concerns of patients, clinicians and the public around awareness of the care.data programme and decided to defer the extraction of GP data for 6 months.
7. One of the first steps was to establish an independent care.data advisory group. This group is chaired by Ciaran Devane, Chief Executive of Macmillan Cancer Support and one of NHS England's Non-Executive Directors. This group has already met on a number of occasions. Further information about this group is available on the NHS England website.
8. Common themes have already begun to emerge and, as a result, discussions have taken place with the British Medical Association (BMA), Healthwatch England, the Royal College of General Practitioners (RCGP) and the independent advisory group, on a proposal for a phased roll out of the GP data extraction process to begin in the autumn. This will involve a cohort of between 100 and 500 GP practices to trial, test, evaluate and refine the process ahead of a national roll out – for which no artificial deadline has been set.
9. In addition, steps have already been taken in making changes to the law. This will increase the protection of confidentiality and ensure there is greater transparency around the release of data by the Health and Social Care Information Centre (HSCIC). Over the coming months, the HSCIC will work to provide assurances over the safety of data collected, stored and shared, including the option of accessing data from a controlled environment, sometimes referred to as a 'data-lab' or 'fume-cupboard', for use by organisations requesting data.
10. A comprehensive communication and engagement programme is now

# HEADLINES

established to support this extension period to ensure that the views of patients, clinicians and the public continue to be listened to and addressed

## Patients online and in control

11. The vision for Patients Online and In Control is to unleash the power of people to manage their own conditions by providing them with the types of applications that allow them to monitor their lifestyle, such as activity and diet, and the added ability to view, merge and enhance their full NHS medical record with the information they are recording about themselves.

12. It has been well-documented that the NHS needs to become easier to do business with, giving patients the power to interact with NHS services in a way that is convenient to them. For example, enabling communication by telephone, email, text message or via the internet, and empowering people to directly book and change appointments, track the progress of tests and view results when it suits them.



13. Over the last year, NHS England has begun to make good progress in this regard. This has included working closely with GP colleagues to agree that offering the ability for people to book GP appointments and order repeat prescriptions online is a contractual requirement from 1 April 2014.

**tpp** **systemone**

**Avoid the queue**

**Book your next appointment online**

You can now view, book and cancel your appointments by logging on to a new service on the internet.

Manage your appointments quickly and easily wherever you are, 24 hours a day, 365 days a year.

14. Patient access to the summary information held in their GP medical record is also a contractual requirement. However, it is recognised that to meet the vision – to provide a set of rich and meaningful information – work is needed, and is underway, to develop safeguards and processes to allow patients to access and download their full medical record.

# HEADLINES

15. Effective from 1 April 2014, the national GP Systems of Choice (“GPSoc”) contract has been renegotiated to require software suppliers to provide the new functionality needed by GPs to enable them to meet their new obligations to patients.
16. During 2014/15, the Royal College of GPs and teams across England will support all GP practices to switch on these new functions and fully embed the enablers in their day-to-day interactions with patients.
17. In order to fully realise the vision, NHS England’s user experience (UX) principles are being applied to test the usability, design and functionality of these patient-facing tools. This will be tested and validated with patients and the public in order to ensure people are best able to use the technology to support them in their health-enhancing behaviour.
18. By March 2015, supported by examples and evidence of how this is working from ‘accelerator’ practices, and with the technical and operational capability enabled, a public awareness campaign will begin to publicise availability of these online services.

## **Widening Digital Participation**

### Overview

19. Today’s digital revolution has the power to transform healthcare for all. But those who make greatest use of health services, and those experiencing greatest health inequalities, are exactly those least likely to be online or to have basic digital literacy skills. It is estimated that 11m people lack basic digital literacy skills and 7m people have never been online. This includes many older people, people with disabilities and long term conditions, and those from socially deprived groups.
20. Alongside the ‘coming of age’ of ‘digital natives’ (people who have grown up with digital communication), increasing numbers of older people are also now active online. Many in even the most socially deprived communities now have smart phones, and simple to use tablet devices are making digital access easy for those with the most basic digital literacy skills.

# HEADLINES

21. However, there is still a significant section of the population who will not benefit from the opportunities of the digital revolution without support. This might include places they can go to get online, support in using online services, and training in digital literacy skills.

## Progress and achievements

22. To start to address these issues, NHS England is funding a Widening Digital Participation programme, working with a social enterprise – The Tinder Foundation – to deliver digital skills training to reduce inequalities and boost health literacy. Despite a delayed start to the contract, all performance targets for the first year of the contract (to 31 March 2014) have been exceeded.

23. A full evaluation report is currently being produced and will be launched at a stakeholder event on 22 May. Early findings suggest:

- 76% of people trained now feel more confident managing their health using online tools;
- 18% of people trained now feel more self-reliant and have reduced their use of the NHS.

24. Fifteen local flagship projects have been funded by the Widening Digital Participation programme to demonstrate the possibilities and opportunities presented by digital inclusion, working with local primary care and community groups. Examples include:

- This [video](#) showing digital inclusion work with the Asian community in Leicester.
- This [video](#) showing digital inclusion work with homeless people at York Street GP Practice in Leeds. The project won an Excellence in Participation Award at NHS Expo.
- The Mayfair Community Centre in Shropshire which provides digital skills training to older people in rural areas and has just won a [GSK/Kings Fund Impact Award](#)

# HEADLINES

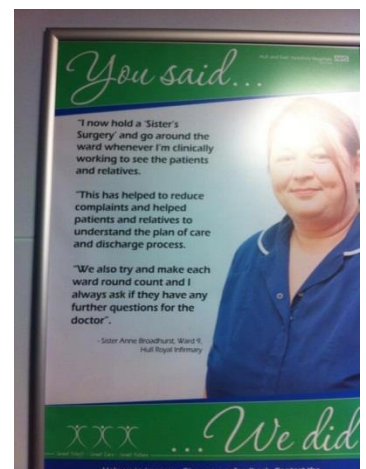
## Looking forward

25. All approvals have now been secured to extend the contract with The Tinder Foundation for 2014-15. In this second year, contract deliverables have been increased, and key targets for the coming year are:

- Increasing numbers trained in online skills from 50,000 to 80,000;
- Increasing numbers reached with information about how and where to get online for health from 100,000 to 120,000.

26. In addition, additional value for money has been secured by:

- Reducing the contract value from £1m in 2013-14 to £800k in 2014-15;
- Achieving 60% increase in activity for 20% reduction in cost.



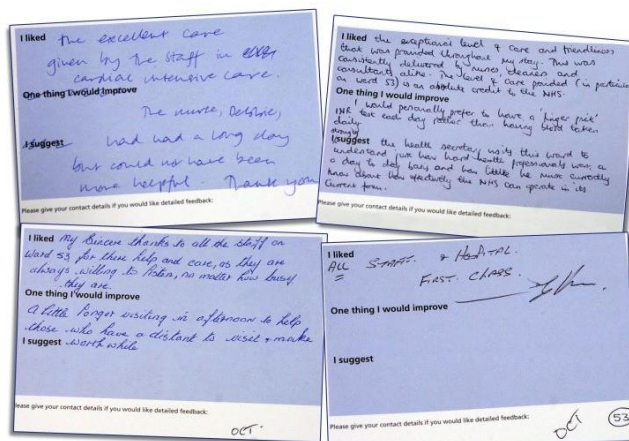
## **The Friends and Family Test**

27. Since the introduction of the Friends and Family Test (FFT) in April 2013, over 2 million patients have provided feedback to the NHS on the services that they have received. The free-text follow up questions offer a rich source of patient views that are being used locally to highlight and address concerns much faster than more traditional survey methods. On a daily basis, Trusts across the country are using feedback from the Friends and Family Test to improve services for patients. Examples of some of the changes made by Trusts include:

- Introducing medication cards for patients who are off the ward during drug rounds to alert them that their medication is waiting to be dispensed;
- Establishing a new dining area where patients can meet during mealtimes, to encourage mobility;
- Installation of full length mirrors to support patients who use a wheelchair.



# HEADLINES



28. An additional benefit of the Friends and Family Test is that it provides regular, real-time feedback to front line staff which has not previously been available. It is clear that FFT is having a positive impact on staff morale as much of the feedback indicates that patients have been very happy with the care provided.



29. The Friends and Family Test for staff will be undertaken by all Trusts from quarter one of 2014/15. It is **hoped** that Staff FFT will help to promote a big cultural shift in the NHS, **where** staff have further opportunity and confidence to speak up, and

where the views of staff are increasingly heard and acted upon.

10

30. Looking forward, the Friends and Family Test will be rolled out to all NHS funded services. This will provide every patient with the opportunity to provide feedback regardless of which part of the NHS they have interacted with. The roll out timetable is as follows:

- GP practices by end December 2014;
- Mental health services by end of December 2014;
- Community services by the end of December 2014;
- Outpatients and day cases, ambulance and NHS Dental services by the end of March 2015.

31. A commitment was made to undertake a review of FFT after six months of implementation to ensure that learning from acute Trusts was understood prior to the introduction of FFT to different settings. This review is nearing completion and will recommend any changes which could be made to FFT to further enhance its effectiveness.

## **Patient Participation**

### Personalised care and support planning and the 'House of Care'

32. Care and support planning encourages clinicians and people with long-term conditions to work together to clarify and understand what is important to that individual. They agree goals, identify support needs,

33. Looking forward, and in addition to this, NHS England will:

- Build on the new enhanced service for unplanned admissions in the GP contract, which includes a component on care planning, by producing clear guidance on personalised care planning. This will outline the high level principles of care and support planning, building on the work of National Voices, and provide guidance on how to deliver personalised care planning.
- Support the use of digital care plans, where plans can be shared across different systems and settings. This would support a more consistent approach and smoother transfer of information.

### Personal Health Budgets

34. A personal health budget is an amount of money to support a person's identified health and wellbeing needs, planned and agreed between the person and their local NHS team.

35. NHS England's vision for personal health budgets is to enable people with long term conditions and disabilities to have greater choice, flexibility and control over the health care and support they receive

36. National roll out of personal health budgets was announced on 30 November 2012, following the three year pilot programme in the NHS, which ended in October 2012 with the publication of an independent evaluation report, led by the

# HEADLINES

University of Kent. The NHS Mandate sets an ambitious objective that people with long term conditions who could benefit from one will have the option to hold a personal health budget, including direct payments. As a first step, from April 2014 people who are eligible for [NHS Continuing Healthcare](#) have a 'right to ask' for a PHB. There will be a 'right to have' from October 2014.

37. NHS England has a national delivery team in place to support CCGs as they develop the capability to deliver personal health budgets. NHS England works closely with [Peoplehub](#) a national peer network for people with personal health budgets who are instrumental and fundamental to the development of personal health budgets nationally, in a real example of how people have driven policy, delivery and taken control of their own lives.
38. For 2014/15, the delivery team will continue to offer a package of support to CCGs to enable them to respond positively to people and families who from October will have a 'Right to Have' a Personal Health Budget where they are receiving NHS Continuing Healthcare. In June 2013 a support programme was established and recruitment of CCGs into this programme began. From September an 'Accelerated Development Programme' started – 6 full day sessions across 6 months held 8 times around the country to learn how to introduce them well. 180 CCGs attended, with feedback at session 6 showing that 100% of respondents found the course helpful in supporting them to introduce personal health budgets locally.
39. At April 2013 there were no data available about readiness of CCGs implement personal health budgets. By September 2013 it was known that 25% of CCGs were ready to offer them. At March 2014, data shows that at least three quarters have confirmed they are ready (see figure below). Regional support is in place to mentor all CCGs, including those who may receive requests for personal health budgets but do not consider themselves ready.
40. NHS England will continue to support CCGs as they develop the capability and capacity to implement personal health budgets in NHS Continuing Healthcare and to ensure they stay connected to best practice so that the potential benefits of personal health budgets are realised. Working with In Control, the voluntary sector partner for this work, the focus on budgets for children will increase, which has been an area of lower level engagement so far. A development programme for the voluntary sector will also be rolled out to help them 'gear up' to support people to access personal health budgets.
- 41 The roll-out of personal health budgets beyond NHS Continuing Healthcare will commence, working with Peoplehub and a range of other stakeholders. This will include specific programmes to support commissioners in CCGs to begin to

develop their systems so that those who could benefit from a personal health budget are able to receive one. The early adopter programme for personal health budgets - 'Going Further Faster' - will be re-launched to demonstrate the business case for the scale up of personal health budgets and their extension into a wider population, including people with long term conditions and people who use mental health services

## Stakeholder Perceptions of NHS England

### Overview

42. As part of the 2013/14 Business Plan 11 point scorecard, NHS England committed to obtaining '360 degree' feedback from partners in order to review organisational health. Research Works Limited, an external and independent research agency, was commissioned in November 2013 to conduct qualitative research into perceptions and understanding of NHS England by both Arm's Length Bodies and Patient and Public Organisations as part of the 360 degree review.
43. The sample for patient and public organisations was drawn from voluntary sector organisations that NHS England maintains a relationship with, including from:
- the Voluntary Sector Strategic Partner Programme (22 partner organisations and consortia from across the breadth of the voluntary sector, funded in partnership with the Department of Health and Public Health England);
  - the Voluntary Sector and Social Enterprise Sounding Board (who provide early input into policy development and a 'sounding board' for the Department of Health, NHS England and Public Health England);
  - the Richmond Group (a grouping of the ten largest health and care charities); and
- other national voluntary sector organisations.
- Stakeholders praise NHS England for its enthusiasm in communicating with them; however. The volume of messages can feel overwhelming at times, and stakeholders want NHS England also to listen effectively.
  - Views on NHS England's commitment to public and patient engagement were polarised, with some seeing a genuine desire to engage, and others perceiving engagement to be tokenistic.

## The future

44. NHS England is currently considering feedback from the 360 degree process as a whole. However, some actions are already being implemented by the public voice team, including:

- Holding a meeting with voluntary sector partners in May 2014 to develop a 'commitment to collaborate' charter with the voluntary sector to include shared values and behaviours;
- Reviewing the routes used to communicate with patients and the public to streamline communications and make sure these are appropriate, timely and relevant;

## Spotlight – NHS Citizen Programme

1. NHS Citizen is being designed to bring the diversity of citizens' voices and views into the heart of NHS England's decision making, respond quickly to issues raised, work with citizens to solve some of the NHS's pressing problems and be held to account by citizens for their decisions.
2. The model for NHS Citizen is being designed in the open, and anyone who wants to take part can – everyone is welcome. Work on the model started in July 2013, followed by another public workshop in October 2013. Over the next few months more public workshops will take place around the country to improve and strengthen the design of NHS Citizen. Further information about how to get involved is available at [www.nhscitizen.org.uk](http://www.nhscitizen.org.uk) including details of all the



[Type text]