

**BOARD PAPER - NHS ENGLAND**

<b>Title:</b> Patient and Public Voice
<b>Clearance:</b> Tim Kelsey, National Director for Patients and Information
<b>Purpose of paper:</b>  NHS England is committed to: <ul style="list-style-type: none"><li>• promoting and upholding the values, rights and pledges enshrined within the NHS Constitution;</li><li>• putting patients and the public at the heart of everything it does;</li><li>• promoting and embedding a truly customer focused culture within the NHS;</li><li>• 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).</li></ul> 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 three of the workshop themes from the NHS England Annual General Meeting in September 2013 is also included.
<b>Key issues and recommendations:</b>  This paper: <ul style="list-style-type: none"><li>• highlights the forthcoming Expo, and developments with Care.data, your health online and specialised commissioning;</li><li>• updates on current thinking with regards to the <i>Patients in Control</i> programme;</li><li>• details activities and commitments as part of Children's Takeover Day;</li><li>• outlines progress to date with the digital inclusion programme;</li><li>• Provides an update on developments since the AGM on three workstream areas.</li></ul>
<b>Actions required by Board Members:</b> <ul style="list-style-type: none"><li>• 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.</li></ul>

# INTRODUCTION AND CONTEXT

## 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 fifth 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.

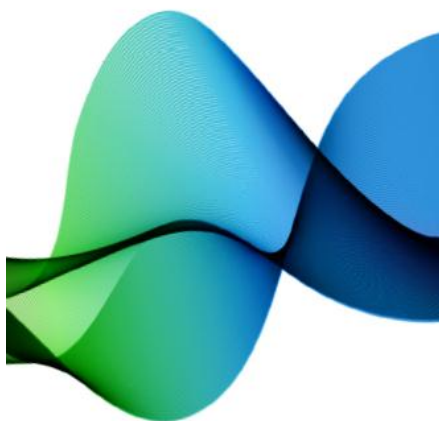


## Headlines

### ***Care.data – your information improving health and care for all***

4. Every time someone goes to hospital, the NHS collects information about them to help improve care for everyone. For example, information is used to check the safety of different hospitals, to compare the quality of care across the country, and to help plan new health services. All patients have been benefitting from information such as this for decades, but at the moment the NHS is missing information about much of the care provided outside hospital. This is a problem because it means no-one really knows how well all the different parts of the NHS and social care are working together.
5. To help tackle this problem, the NHS is going to start bringing together this missing information to get a better, more complete, picture of the care being delivered. This will mean that information is available about the quality of care that patients receive as they move between all the different parts of the NHS and social care. Data will indicate where the NHS needs to invest more in different parts of the country and in treating different diseases and conditions. It will also be clearer where the NHS is providing excellent care and where there may be local problems.

6. In January, NHS England and the Health and Social Care Information Centre are sending a leaflet to every household in England explaining how the NHS uses information about us to help improve care for everyone. The leaflet makes it clear that patients have a choice: if they do not want information that identifies them to be shared outside of their GP practice, they should ask the practice to make a note of this in their medical record. This note will prevent their confidential information from being used other than in special circumstances. Information from other places where patients receive care, such as hospitals and community services, is collected nationally. Patients should also let their GP practice know if they want to prevent the information from those places being shared. The practice will make a separate note of this in their medical record.



This leaflet contains important information about your health records.

You, and everyone who lives with you, should read this leaflet carefully. It is important that everyone knows how we share, protect and use information about their health. You have a choice.



7. A dedicated patient information line, which patients can call if they have any queries or concerns, is also being launched (0300 456 3531).
8. This is an opportunity for each of us to help the NHS deliver high quality care for all.

## ***Your health online***

9. For patients and the public in England, the NHS will always be there for those who need medical treatment. However, many people now manage their daily lives using telephone and tablet technologies. NHS England's vision is to unleash the power of people to manage their own conditions by providing them with applications that allow them to monitor their lifestyles, for example activity and diet, but with the added ability to view, merge and enhance their full NHS medical record with the information they are recording about themselves.

10. As well as contributing to their own medical records, the aim is also to give people the ability to transact directly with the NHS using technologies that allow them to book and rearrange appointments, order repeat prescriptions, track the progress of test results, contact their GP or hospital electronically with a query, provide electronic feedback and even switch GP provider. This is part of the ambition to put people in control of their care, but there will also be safeguards in place, including that their doctor or carer also has access to this information and can intervene and support as required.



11. The first step to achieving this vision is to give patients the ability to book appointments online, order repeat prescriptions and access their GP record **from April 2014**. This commitment has been included in the 2014/15 GP contract and work is currently underway to define in detail what the 'GP record' will constitute, for example how much historical data is meaningful and whether there is a time delay to allow a GP to 'manage' how the impact of certain test results are communicated. **By March 2015**, the facility will be available everywhere and work will take place with patient groups to build awareness and measure the effectiveness and value of these services to inform their ongoing development and widespread adoption.

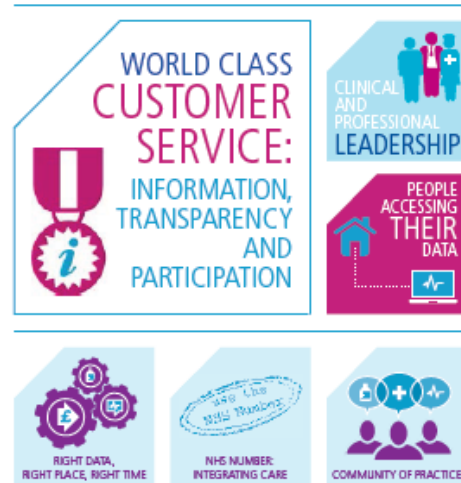


12. However, in order to achieve the vision that patients and clinicians will have access to a FULL medical record, greater strides must also be made in the achievement of safe, digital record keeping in secondary care, as a precursor to integration of those records with the GP record.

13. In mid-2013 the £260m '[Safer Hospitals, Safer Wards](#)' technology fund was launched, £218m of which was awarded to NHS Trusts for 234 projects in December 2013. The projects that have been funded range from explicit creation of digital care records at Calderdale and Huddersfield NHS Foundation Trust (FT), to implementation of e-Prescribing systems at Birmingham Children's Hospital NHS FT, to delivery of multi-organisational proposals to create integrated digital care records across care settings in Bradford, Bristol and Cumbria.

## SAFER HOSPITALS SAFER WARDS

Achieving an integrated digital care record



14. A further £250m has been made available for a second tranche of the fund, with an increased emphasis on delivering integrated care records between health and social care, which will be launched in early February. All allocated funds must be match-funded by NHS Trusts making the total expected investment in digitisation, e-prescribing and integrated care records over £1 billion.



## Health and Care Innovation Expo 2014

15. On 3 and 4 March 2014 NHS England will host the Healthcare Innovation Expo in Manchester, which will bring together 10,000 people from across health and care and the voluntary and community sector to inspire change and improvement in NHS and care services. Designed to share learning and promote NHS renewal, the event aims to activate people to do something new and different when they go back to their own organisations and communities. This will be a truly exciting opportunity to see and experience the latest innovations in health and care and to understand the opportunities to really engage in a people-centred, #peoplepowered NHS fit for the future.



16. To register for your place and find out more visit <http://www.expo.nhs.uk/>

## Specialised Commissioning – transparency and participation

17. Communication and engagement support for NHS England’s specialised commissioning function covers a broad remit. The key focus since April 2013 has been to develop a web presence for specialised services, including individual pages for each of the 75 Clinical Reference Groups (CRGs). These now house key commissioning documents such as service specifications and clinical policies. Successful recruitment to the CRGs has also been managed via the web and these pages continue to be developed to better showcase the breadth of work taking place across the specialised services landscape. Each CRG has representation from commissioners, clinicians, patient organisations and individual patients or carers as well as other stakeholders. CRGs are developing a strong culture of listening to patients.
18. Other key pieces of work more recently include: the launch of Commissioning through Evaluation; the recruitment of Chairs and patient / public members to the Clinical Priorities Advisory Group and Rare Diseases Advisory Group; promotion of work to develop a vision for innovative radiotherapy services; and continued support for the Specialised Services Patient and Public Voice Assurance Group.





19. In 2014 the focus shifts to supporting the development of the specialised services five-year strategy. This is work which started in December 2013, during the strategy scoping phase, but which will intensify during the early months of 2014. This will include engagement events at area team and programme of care level, a three-month public consultation, and will culminate in the publication of the strategy itself in July. NHS England will also be publishing the results of its exercise to determine provider compliance with service standards, a significant piece of work which will be supported by communication and engagement.
20. We are keen to involve as many people as possible in this work and are doing this in a number of ways including a series of engagement events to develop the overarching mission and vision and a focus on how individual services can provide real value for money.
21. We are now inviting patients, the public and professionals to submit [ideas of how changes could be made to specialised services](#). The type of change proposals sought include changes to a service, system or pathway which can improve or make efficiencies for the benefit of service users. The proposals should explain the root cause of a problem and how improvements could be made. Proposals should be presented in a clear and succinct way. These proposals will be used to define the service-level goals and objectives and ensure alignment to the overarching mission and vision as it is built over the next few months.
22. We want to hear from everyone who can propose a service change that can be implemented at scale across the whole of a specialised service, and are encouraging joint submissions from patient, public and professional groups working together.



## ***Widening Digital Participation Programme***

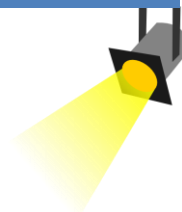
24. Today's digital revolution has the power to transform healthcare for all. But those who make greatest use of health services, and those experiencing greatest health inequalities, are exactly those least likely to be online or to have basic digital literacy skills. This includes many older people, people with disabilities and long term conditions, and those from socially deprived groups.
25. In response, NHS England has committed in its Business Plan to a programme of widening digital participation, specifically "Reducing inequalities: 100,000 citizens trained in basic online skills to boost health literacy." The programme includes:
  - Establishment of a network of community hubs in deprived areas providing training in online skills and assisted digital support in accessing online services;
  - Development of online training tools on health information and transactions;
  - User testing of digital products and services with less digitally skilled users;
  - Building the evidence base on the contribution of digital literacy to increasing patient empowerment and reducing health inequalities.
26. A contract to deliver the programme has been awarded to the leading digital inclusion and skills agency, the [Tinder Foundation](#) (a social enterprise) which manages UK Online Centres and works with community partners to support digital skills. Under the contract, by March 2014, 100,000 people will be reached with digital literacy messages, 50,000 will be trained in online skills, and 1,000 volunteer digital champions will be recruited. To date over 32,000 people have been trained and a network of local flagship sites has been established to share good practice. The initiative has been warmly supported by the Royal College of GPs and will feature in their upcoming publication on health literacy.
27. This is not a top-down initiative. In addition to the contract with The Tinder Foundation, funding has been distributed as small grants to innovative local primary and social care organisations. These are acting as flagship sites working with local deprived populations to provide digital access and boost digital literacy skills.



# HEADLINES



28. Small grants have also been made to support innovation through smaller creative digital companies including Breezie, Finerday and Tyze. These are developing simple tablet-based interfaces for health information and services, particularly for older people.
29. The initiative will be showcased at the Informatics Services Commissioning Group 'Open House' on 21 January and at the Expo in March 2014. A business case has been prepared for continuing funding in 2014-15 to enable increased numbers of digitally excluded people to be trained and benefits realised.
30. Video case studies are being made as part of the programme, including this video of 78 year old Norah from South Yorkshire talking about how getting online has transformed her life and her health.
31. Deliverables are monitored transparently and in real time through a public dashboard at <https://public.ducksboard.com/icBH-7JEYIAQgNuLgVhC/>



## Spotlight – patients in control

32. The 'Patients in Control' programme aims to deliver the Mandate commitment that the NHS becomes “dramatically better at involving patients and carers in decisions about their care and support.” Jointly owned by the Medical, Nursing and Patients and Information directorates of NHS England, 'Patients in Control' includes projects and priorities relating to “patients and carers in control of their health, wellbeing and care.”
33. Historically, policies and programmes aimed at making the NHS more personalised and person-centred have been treated separately with no overarching vision of what individual patient participation means across the NHS. NHS England sought to change this with the launch in September 2013 of *Transforming Participation in Health and Care*, setting out the new legal duties relating to individual and public participation placed on the NHS by the Health and Social Care Act 2012 and providing guidance.
34. *Transforming Participation in Health and Care* sets out at a very high level what is meant by individual participation ('Patients in Control') using three broad themes: self-management, shared decision-making, and collaborative, personal care planning for people with long term conditions. NHS England will be building on this to create a clear and transparent vision for what individual participation and “patients in control” means across the NHS.
35. For 2013/14, there are a number of specific workstreams looking at particular aspects of patient participation and personalisation, including:
  - Personal health budgets;
  - Personalisation for children and young people and maternity services;
  - Shared decision making and Patient Decision Aids;
  - Quality information including The Information Standard;
  - Health Literacy and patient activation (supporting patients and the public to best make use of health information, and how clinicians can make sure that patients understand messages about their health and care);
  - Peer support and self-management;
  - Researching and demonstrating the benefits and outcomes of patient participation;
  - Working with the Royal College of GPs, National Voices and other stakeholders to create a national coalition for long term conditions built around the house of care;
  - Improving understanding of patient participation;
  - Measurement / incentives.



## **Example – Children’s Takeover Day**

36. Led by the Office of the Children’s Commissioner, Takeover Day gives young people the chance to work with adults for the day and be involved in experiencing and learning in ways that connect them with the world of work and raise their personal aspirations for the future. NHS England’s aims for Takeover Day were to:

- Increase young people’s understanding of NHS England’s role;
- Provide assurance that the opinions of young people are valued and respected;
- Increase aspirations, skills, knowledge and inspiration.

37. On Friday 22 November members of the Young People’s Parliament from the Cooperative Academy of Leeds came in to Quarry House. Bill McCarthy, National Director of Policy, Liz Eccles, Director of Corporate Development, and Neil Churchill, Director for Patient Experience, took part in an insightful discussion that explored young people’s experiences of health services and developed some imaginative improvement solutions.



38. On Thursday 28 November young people really took over. Working with the Young People’s Health Partnership – one of our national voluntary sector strategic partners including Addaction, Association of Young People’s Health, Brook, CLIC Sargent, StreetGames, and Youth Access – young people came from all over the country to participate in a day’s workshop to explore their views and experiences of the NHS and concluded with a powerful presentation to the Executive Team.

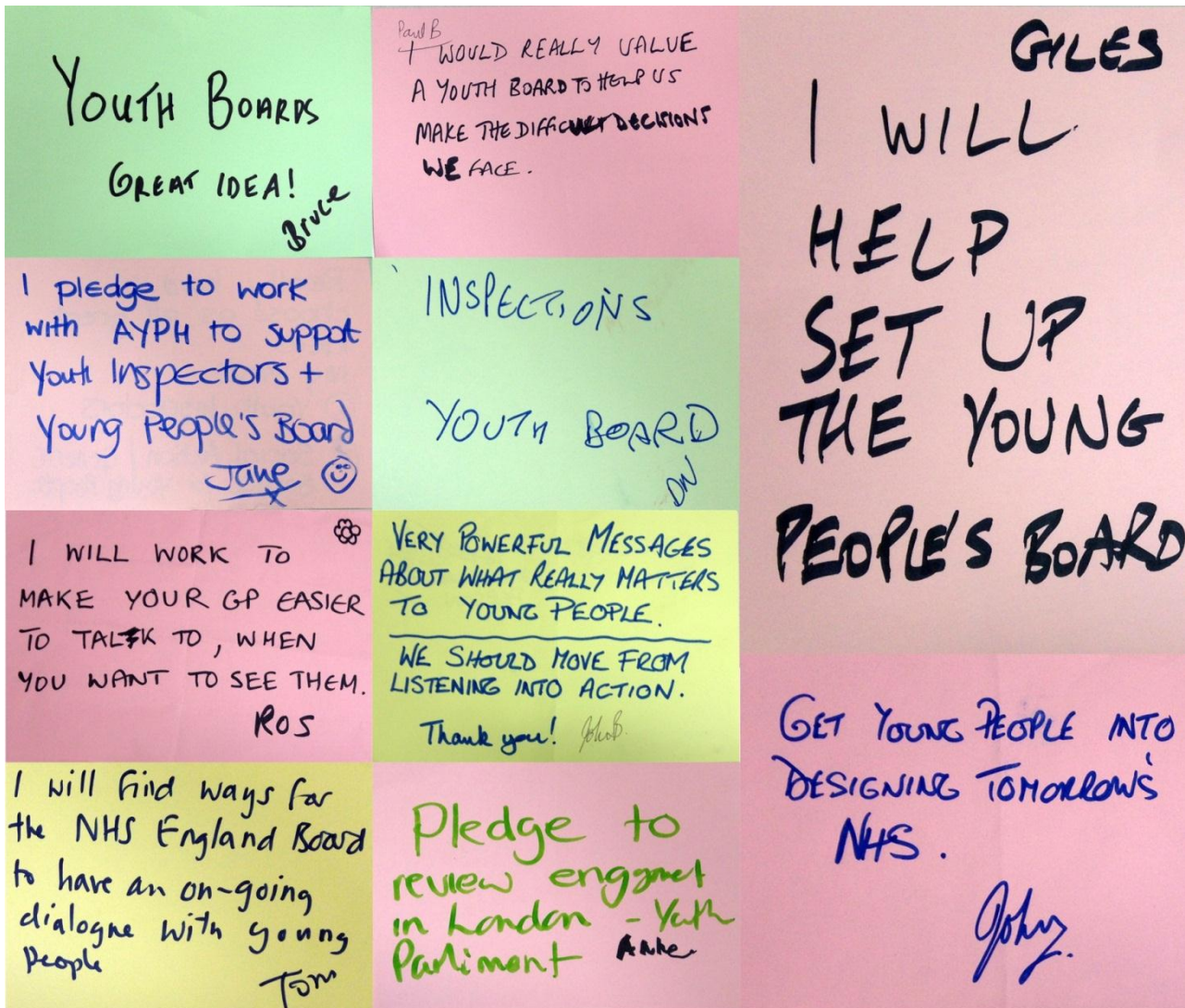


The ‘Twitter story’ from the day is presented [here](#) Olivia Butterworth, Head of Public Voice, has also written a Blog about Takeover Day which is published on the NHS England [website](#)

# SPOTLIGHT



39. To conclude the day the Executive Team were asked to say a word, make a pledge or commitment or simply reflect on what they had heard:



40. The two strongest suggestions were to establish 'Youth Boards' and to have young inspectors involved in assessing whether services were really delivering high quality and appropriate support for young people, this was welcomed and a number of Directors committed to exploring ways to make it happen. Pledges and comments included:

- Ros Roughton, Director of Commissioning Development, "I will work to make your GP easier to talk to, when you want to see them."
- Sir Bruce Keogh, 'Medical Director, "Youth Boards...great idea!"
- Sir David Nicholson, Chief Executive, "Youth Boards and inspectors."



## AGM update

41. 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.
42. The following gives an update on the progress made around key areas for three of the topic groups from the AGM. An update on progress around the End of Life workstream was included in the December paper, and Health Equalities and Inequalities will be the focus of the next paper.

### ***Transparency and Participation:***

43. Progress has been made with the three key discussion points raised at the AGM, as follows:
  - a) Although digital access to information is important, NHS England must not forget those who are not online
    - *As outlined above, the importance of ensuring that those who are not online are not excluded from access to information and opportunities for participation is recognised.*
    - *Work is underway both to increase the number of people with online access to health information and to support participation and communication in ‘offline’ formats.*
  - b) NHS England should be clear about how patients’ information will be used, communicate safeguards and support people to understand data
    - *In January 2014, a leaflet about information sharing will be delivered to every household in England to ensure that patients understand and can make choices about how their information is shared for purposes beyond direct care.*

- *The procurement process for a patient information line has recently been completed – this will support individuals who have questions or concerns.*
  - *Wide-ranging stakeholder engagement activity has taken place, including with patient groups, to help cascade messages about the benefits of using data to improve the health and social care service for the benefit of all patients.*
- c) NHS England should simplify and use existing channels for patient and public participation, reduce complexity of language, and empower patients.
- *One of the commitments made by NHS England at the AGM was to do more to involve children and young people in core business. In response, a Children and Young People’s forum is being established to help shape health services, in partnership with the British Youth Council. Other activity in this regard has included Children’s Takeover Day (see above).*
  - *A recent milestone to get citizen voice at the heart of decision-making has been completing a transparent process to recruit lay chairs and patient and public members of the Clinical Priorities and Rare Diseases advisory groups. More information about activity with regards to the commissioning of specialised services is highlighted above.*
  - *As outlined in the December 2013 paper, engagement activity is also underway to inform the development of an information standard for accessible information. This includes surveys in a range of formats and workshops to support service users to get involved. For more information visit [www.england.nhs.uk/accessibleinfo](http://www.england.nhs.uk/accessibleinfo)*
  - *The public voice team are also developing the ‘People Bank,’ a key tool to simplify and support participation. This Bank will link patients and members of the public to participation opportunities and ways to become more involved in NHS England’s work.*

## **Seven Day Services update:**

44. Progress has been made with three key themes raised at the AGM, as follows:



- a) Concerns were raised at the AGM that there was some misunderstanding about what equal access to care seven days a week meant, particularly in terms the impact on local provision of care
- *As a result of this feedback, additional care is being taken to ensure that communication about seven day services includes messages supporting integration, networking and collaboration, and challenges the tendency to focus on 'centralisation.'*
  - *On 16 November 2013, the seven day services team and NHS IQ hosted an engagement event which brought together over 300 stakeholders including patient and public representatives. The event was co-chaired by Professor Sir Bruce Keogh and Fiona Carey, a patient representative. In contrast with much of the recent focus on urgent and emergency care, the event focused on the whole patient pathway / experience and on integration, since feedback at the AGM had highlighted the importance of 'seamless care.'*
- b) Participants were keen to continue to be involved in the programme
- *An Engagement Strategy has recently been developed by NHS IQ who will work with NHS England to test out ideas on how best involve patients and the public.*
  - *This engagement will be carried out in collaboration with Healthwatch, nationally and locally. It will reach out to individuals and patients' networks, such as National Voices, and condition focused patient forums.*
- c) It is essential to involve young people in future planning and to ensure that services meet young people's needs
- *Central to NHS IQ's Engagement Strategy is the intention to proactively involve young people in decision making. Targeted engagement will be undertaken through outreach activity, aimed at gaining the views of specific groups within their own communities.*
  - *On 08 November 2013, members of the team joined a WebEx discussion with clinicians in training and young leaders. This was the first of a number of similar initiatives that will be carried out by NHS*

*England and NHS IQ as the work around seven day services progresses. The team heard some excellent feedback from the young people involved, including first-hand experience from young clinicians in training. All expressed an interest in on-going involvement.*

## **Call to Action update:**

45. Since the AGM, the NHS England Call to Action team have been working to produce a 'thought leadership' product which focuses on prevention, informed by outputs from a recent event in Birmingham. Once approved, this will be disseminated to clinical commissioning groups (CCGs) in order that they may use it to support the development of their 5 year strategic plans.
46. On 25 November 2013 the second national A Call to Action event took place in Manchester, focusing on Valuing Mental and Physical Health Equally. The event was attended by a number of public representatives as well as experts by experience and leading thinkers, to ensure that communities and patients have their say in the debate.

## ***“Improving General Practice – A Call to Action”***

47. Between August and November 2013 the first phase of a national debate took place on the transformation of general practice services, including how they can become part of a more integrated set of wider primary care services. This was supported by the publication of “Improving General Practice – A Call to Action” which set out the challenges that general practice will need to meet in the future, and a series of questions about what actions might be needed nationally to enable local strategies to be delivered. Area teams and clinical commissioning groups (CCGs) have held various local engagement events, and supplemented this with additional local material. For example, “Transforming Primary Care in London” was published in November setting out the particular challenges and opportunities for primary care in London.
48. As well as local events, a national stakeholder event took place in October 2013, alongside an online questionnaire at [www.england.nhs.uk](http://www.england.nhs.uk) Insight was also gathered from a review of responses to the GP Patient Survey and of complaints that NHS England has received directly from the public since April 2013. Children and young people also shared their experience of general practice services directly as part of Children’s Takeover Day (see above). In addition, the Department of Health (DH) has been carrying out a national

# AGM UPDATE

engagement exercise on how to improve services for vulnerable older people – NHS England will work with the DH to identify how best to support general practice to meet the issues identified.

49. A clear and consistent message from stakeholders was that “to do nothing” is not an option. Steps have already been taken to address some of the issues identified, both by the public and by the profession. This has been reflected in the recent set of reforms to the GP contract, and the approach taken to allocations published in December. Consideration is also being given to: how improvements in access to general practice can be made through making best use of the Prime Minister’s Challenge Fund from April 2014; how to make it easier for area teams and CCGs to jointly commission services; and how it can be made easier for providers to come together across primary care and wider community-based services, including social care, to deliver an integrated service. Raising quality across general practice and responding effectively to provider failure have also been significant themes arising from engagement.
50. This month, a report will be published of an independent analysis of the responses to the questionnaire (as well as the full responses made by organisations) and a report on emerging findings. These early reports will help to frame local discussions about developing integrated primary care strategies as part of the 5-year strategic planning cycle. But there is more to do, particularly around public engagement and improving the patient and public voice at both national and local levels. Thanks are due to National Voices, who hosted a workshop with a number of voluntary and community sector groups in December to help develop the vision for general practice services. In the next quarter, the intention is to work with partners in the voluntary and community sectors to build the vision and strategic framework further, to build confidence that the approach meets the needs of patients, and secures best value for money for taxpayers.

