BOARD PAPER - NHS ENGLAND

Title: Review of NHS Citizen and the NHS Citizens Assembly at the AGM

From: Lord Victor Adebowale; Non-Executive Director

Ciaran Devane; Non-Executive Director

Tim Kelsey; National Director of Patients and Information

Purpose of paper:

- To describe the outputs of the NHS Citizen Assembly discussions held on 18 September 2014.
- To set out the next steps for the development of NHS Citizen as we progress to establishing the operational model from April 2015.
- To propose the establishment of a Board task and finish group including executive and non-executive directors to make recommendations on how NHS England can set a new standard for patient and public participation in its decision making processes – with particular focus on improving citizen engagement in specialised and primary care commissioning.

Actions required by the Board:

The Board is asked to consider

- the response and actions to follow through on the discussions held at the first NHS Citizen Assembly;
- the next steps for the development of NHS Citizen and agree in principle the requirement for resources in 2015/16 to enable the business model to be further developed; and
- the establishment of a Board task and finish group with a particular focus on specialised and primary care commissioning over the next few months to demonstrate implementation of the NHS Citizen approach.

Review of NHS Citizen and the NHS Citizens Assembly at the AGM

NHS Citizen: setting a new standard for patient and public participation

1. On September 18th 2014, over 200 patients, carers, activists, volunteers, voluntary sector and public services workers met face-to-face with the NHS England Board at the inaugural NHS Citizen Assembly. This meeting coincided with the NHS England Annual General Meeting (AGM), and was in essence the first full scale test of the Assembly process, taking issues that had been identified by citizens through a systematic process into detailed discussions with participants and Board members.

2. A full report of the Assembly and the five issues that were discussed is included as Annex 1. A critical part of the process is for the Board to consider how NHS England will address and progress the issues identified. The lead Executive Directors reflected on the discussions during the first part of the AGM and since then further work has been undertaken to consider in more detail what further action could be taken forward. Annexes 2 – 6 set out these considerations in more detail.

Recommendations

3. The Board is asked to:

   - agree the response and actions to follow through on the discussions held at the first NHS Citizen Assembly;
   - note the next steps for the development of NHS Citizen and agree in principle the requirement for resources in 2015/16 to enable the business model to be further developed; and
   - agree the establishment of a Board task and finish group with a particular focus on specialised and primary care commissioning over the next few months to demonstrate implementation of the NHS Citizen approach.

The NHS Citizen Assembly – what next for the issues discussed?

4. The five topics discussed at the test Assembly varied from broad and diverse issues that ranged across a number of areas such as access to services, to more defined and specific issues that affect particular communities such as gender identity. This variation allowed the Assembly process and NHS Citizen more generally to consider how issues need to be framed and prepared in order that focussed dialogue can lead to tangible actions that create change.

5. The full report of the Assembly is included at Annex 1 this details both the process and the discussions. It is evident that making progress to agreeing potential solutions was a challenge as, in most cases, whilst there was broad agreement about the issues, moving to action required more time and debate. Many potential solutions were bigger than NHS England's remit and require

cross system leadership or are political in nature.

6. Since the Assembly the detailed content of the discussions and the issues identified have been reflected on and Annexes 2 – 6 contain a more detailed response. Specific actions the Board is committed to pursuing in relation to each issue are set out in the annexes and summarised below: -

6.1 *Access to Services – Annex 2*
This is a critical and complex issue and the NHS Citizen discussion was wide and varied. We need to learn more about how communities want to access their health and care and we need to make sure that NHS services and support are fully accessible, especially to people who are vulnerable, isolated or marginalised in society. This must be an ongoing conversation through NHS Citizen, particularly to explore how we can improve access to primary care. We propose to prioritise this as a focus for the next six months working with NHS Citizen to develop work together.

6.2 *Self-Care and Personalisation – Annex 3*
Developing personalised services and support that enable people to self-care was a timely discussion and a good example of where collaboration between NHS England and citizens can produce richer ideas and solutions together. The NHS Citizen discussion was clearly defined and, as such, our response is more detailed with clear commitments to action.

We propose that NHS England supports the development of a national model for co-production, using the NHS Citizen approach, working through the arrangements being set up for the Coalition for Collaborative Care (2015-17).

The model will be based on:

- research into the barriers of co-production;
- training for co-production right across different levels of the NHS, from GPs to commissioners and at national and local levels; and
- measurement and incentives.

6.3 *Mental Health – Annex 4*
It is now NHS England's responsibility, working with partners, to address parity of esteem in a systematic way. The government's mandate for 2013-15 set NHS England the task *of putting mental health on a par with physical health, and of closing the gap between people with mental health problems and the population as a whole.*
a. NHS England would like to work with the NHS Citizen Assembly and other groups to agree a 'dashboard' of what real parity would look like to them.
b. NHS England will engage with the NHS Citizen Assembly to develop a 'roadmap; to parity between now and 2020.
c. NHS England will engage in the mental health intelligence network

programme, which like cancer and cardiovascular conditions, means that citizens can be provided with the information across the pathways in their local communities so that they can ensure that commissioners and providers of care have user voice and coproduction at the heart of plans and parity assurance processes.

6.4 Children and Young People – Annex 5

We recognise how important meeting the health, care and wellbeing needs of children and young people is not just for their own benefit but for the future of our communities and society as a whole. We will continue to support the NHS Youth Forum, which provides a vehicle to reach out to young people and to hear their views both through face to face meetings and the connections via social media. The forum is delivering on three core objectives around communicating with health professionals, young people's mental health and sexual health.

6.5 Gender Identity – Annex 6

We have started to address the issues raised by trans and other gender-diverse people and, in doing so, we have developed a dialogue with these communities to support and inform us in the development of a new specification and policy, and to develop a continuous process to improve our understanding of their needs.

We will continue productive and influential engagement with these communities and, in doing so, improve participation and access to information through events and on-line information, enabling people to access accurate and up-to-date information on the full range of services available to them.

We have established a taskforce that has started working to bring together the issues identified by service users, commissioners and service providers into a coherent and comprehensive action plan. This plan aims to address problems in accessing help with gender incongruence-related healthcare needs and develop the necessary service provider capacity to deliver this in a timely and effective manner.

7.   The Board is asked to agree these actions and commit to monitoring the progress with a view to reviewing in six months and following up at the next AGM.

Supporting the development of NHS Citizen

8.   NHS Citizen is an initiative to test new approaches to maximising the public accountability of NHS England and the active participation of patients and the public in its decision making. It is a collaborative model which engages individual citizens, voluntary and community networks and national partners. The process of designing NHS Citizen started in July 2013 and has been undertaken in partnership with four independent organisations commissioned

by NHS England: The Tavistock Institute, Involve, The Democratic Society and Public-i. The initiative was officially launched last March at the NHS Expo by NHS England non-executive directors Lord Victor Adebowale and Ciaran Devane with Tim Kelsey.

9. NHS Citizen has developed a virtual network through its website (www.nhscitizen.org.uk) and via social media including twitter (@nhscitizen/ #nhscitizen) and other channels such as live webcast workshops and design days across the country. This has involved:

   - 8 one day workshops and 4 two day development events covering Birmingham, Bristol, Cambridge, Exeter, Leeds, Liverpool, London and Sunderland - directly involving over 800 people
   - National events including NHS Values Summit, NHS Expo 2014, Wellbeing Conference, Voluntary Sector Health and Social Care Conference
   - 464,560 webcast 'hits' and 2,056 individual views
   - 42,693,651 twitter impressions, 21, 680 tweets from 2,687 individual participants

10. The focus for 2015/16 – as confirmed in the Five Year Forward View - is to take NHS Citizen to 'scale'. This is key to NHS England's core purpose of ensuring the patient and public voice is central to and has influence in the commissioning and development of services – and to our values of transparency and co-production.

11. To take NHS Citizen forward and implement the model as co-designed with citizens, we anticipate the following key developments during 2015/16 to establish the long term framework for implementation. This will include:

    - developing the prototype online network
    - to build broader citizen and community involvement and awareness of the opportunity to participate
    - to develop a programme of training and coaching for NHS England staff so that the NHS Citizen pro-active approach to genuine dialogue and citizen participation can be embedded in the culture of our organisation
    - to support the replication of this approach at CCG level so that accountability and participation is comprehensive across the commissioning system
    - To develop clear routes through which citizen participation and influence is connected and able to affect change across the system enabling local and national issues to be addressed in the right place

Setting the standard for patient and public participation: the role of NHS England

12. NHS England needs to set a new standard for patient and public participation in its own culture and operations – building on the values and behaviours modelled through NHS Citizen. Focussing on specific issues will help us to understand how we can develop an authentic culture of public participation and empowerment in the co-production of key decisions and policies.

13. Independent reviews of the NHS by both Sir Robert Francis and Don Berwick have exposed an environment in which patient and public participation is often token and they have called for a cultural transformation. To quote Berwick: *'patients and their carers should be present, powerful and involved at all levels'*. NHS England must collaborate with citizens utilising their expertise and building on the assets local communities have to offer. It should be as fundamental in our operations as our business commitment to other citizen rights in the NHS Constitution, such as timely access to health services.

14. We now need to ensure NHS Citizen is a core part of the way NHS England enables public participation and ensure that it is supported, without seeking to control, to make the step change in public involvement.

15. NHS England has articulated its vision for a transparent and participative future for the NHS, but to date this has been imperfectly executed. We propose the establishment of a Board task and finish group to work with NHS Citizen and other partners to develop a framework that should determine how NHS England makes concrete its ambition for co-production and participation, that can shape its commissioning behaviours and the way it supports those of CCGs. This would set out the role each directorate should play in making NHS England an exemplar, and – indeed – in how NHS Citizen contributes to the Board's review of the leadership, performance and culture of the organisation. We propose this group, working closely with colleagues in the field force, focus on proposals to foster a comprehensive approach to public participation in key areas – particularly around specialised services and primary care commissioning.

16. Key considerations include:

- How does the NHS Citizen model best link with and support front line public participation around specific local and area based issues?
- Do we have a clear enough understanding of the practical support – resources, capability, systems, infrastructure – needed to embed a more systematic public participation approach?
- How are cultural barriers to a new model of working manifesting themselves in practice and what do we need to do to address these?
- Do we have the right system levers and incentives to make comprehensive public participation easier to achieve and mainstreamed as a priority?
- What can we do to more clearly articulate the benefits of such an approach, with practical examples of where it has worked well and led to:
  - more effective delivery of local service plans with better public support and engagement;
  - equitable access to services by all sections of the community;
  - improved health outcomes and reduced inequalities.

17.   Several Area Teams have already volunteered to become involved in this work – and some are already testing the NHS Citizen model to encourage local participation. Durham, Darlington and Tees Area Team, for example, is organising a local event this month. It will be open to anyone with an interest in participation through an NHS Citizen approach and will be targeting key stakeholders including CCGs, Health and Wellbeing Boards, local Healthwatch and voluntary groups. The key aim of this initial event will be to scope out existing participation and engagement mechanisms to determine how NHS Citizen can connect with local people in different, more effective and impactful ways. We propose that the Board task and finish group test emerging proposals with the full NHS England Leadership Forum session in January before coming back to the Board with proposals for implementation.

Lord Victor Adebowale; Non-Executive Director

Ciaran Devane; Non-Executive Director

Tim Kelsey; National Director of Patients and Information

Assembly test 18th September 2014 Report

Version number

About the event

On Thursday 18th September NHS Citizen ran its first full-scale test of the Assembly Meeting, during which participants discussed agenda items chosen by citizens through the Gather process. The test coincided with NHS England's AGM, which took place after the NHS Citizen event. The first part of the AGM was informed by discussions held at the Assembly Meeting. This short report could not possibly capture the richness and depth of the numerous conversations that developed during the day, but it tries to convey the flavour of the event and highlight the key points, questions and problems, based on the notes taken by participants and social reporters. Another report will soon be released that reflects on learning from the process for the NHS Citizen team.

Over 200 patients, carers, activists, volunteers, third sector and public services workers met face-to-face with the NHS England Board in an informal and deliberative setting, coordinated by experienced facilitators. The participants were self-selected and mostly had a history of active participation in the health system, through employment or personal experiences as patients or carers. Several young people, many already active within NHS England's Youth forum, took part. This was a significant achievement since youth voices have been largely absent from previous design workshops. The NHS Citizen team seeks to build on this in the future to reach out more to young people and other groups that tend to engage less with traditional NHS bodies.

Participants joined different "issue groups" based on their own interests, expertise and/or personal experience. The issue groups were: Access to Services; Mental Health; Young People and Healthcare; Gender Identity; and Self-care and Personalisation. These issues were chosen from more than 80 that were submitted to the Gather process in August. People were able to flag (propose) issues online, which were then posted on an online platform, where they could be voted up or down and commented upon by anyone signing up for the site. A panel of three people then selected the five issues for the Assembly Meeting from all of those on the site, basing their judgement on a set of criteria, which included whether the issue fell under the remit of NHS England. The panel grouped issues together to try to get as many onto the assembly agenda as possible. The topics were then reposted online, for further refinement. Participants who had flagged issues through Gather volunteered to present the issue at the Assembly Plenary and within the relevant issue group, explaining what compelled them to raise it and why it was important to them.

Assembly Information Packs were created for each issue to help everyone taking part in the NHS Citizen Assembly discussions. This information was intended for use alongside the personal and professional experiences and knowledge of participants. NHS Citizen commissioned NHS England to provide the content that formed each document. This was the first time these Information Packs had been produced and they were developed in a very short space of time. The Information Packs were made available online and circulated among participants before the event.

The plenary

The Assembly Meeting started at 10.30 am with Olivia Butterworth (Head of Public Voice at NHS England) welcoming Assembly members who had travelled from all over the country to the Queen Elizabeth II Conference Centre in Westminster.

After the introduction from Olivia, four presenters from the NHS Citizen team[1] offered some

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[1] Anthony Zacharzewski, Camilla Child, Catherine Howe and Simon Burall, from the four partner organisations responsible for developing NHS Citizen.

background on the NHS Citizen design process to date and how NHS Citizen aims to enhance citizen voice. A short film created by Access Dorset to introduce NHS Citizen helped provide an overview of the project. The team shared the NHS Citizen ambition to provide a bridge between local and national health and social care, tapping into the conversations, resources and networks that already exist and encouraging new ones, as it reaches out to those people that tend to engage less. The rationale behind this ambitious and dynamic project is linking together all these different voices to encourage a deliberative debate between citizens and institutions and help them produce solutions together. At the national level, the Assembly Meeting will be the key stage where different local voices get together to talk directly to the NHS England Board. For NHS Citizen to function effectively, culture change among citizens and professionals is crucial. Facilitating co-production of services and a more collaborative approach is therefore an essential part of NHS Citizen's work.

Before moving into the main part of the day, five participants who had engaged in the Gather process started conversations about each topic with a short presentation, reflecting on their own experience of the health system:

- Michael Vidal introduced the **Access to Services** issue, focusing on the level of funding for primary care.

- Andrew Colleran introduced **Self-care and Personalisation**, by recalling his personal experience as a carer for his wife and stressing the need for joined up care.

- Rosemary Wilson talked about **Mental Health Services** and how she suffered from stigma and misdiagnoses, because of the lack of awareness and training among medical staff.

- Tom Yems, from the Youth Forum, offered an introduction to the **Young People's Healthcare** issue group, by talking about young people's priorities on sexual health and mental health and how young people need to be involved in the conversations and decisions that concern them.

- Nic Bray shared his experience of discrimination against transgender people in the health services, offering some important insights on the **Gender Identity Services** issue.

The issues

Based on their interest and/ or expertise, participants joined different rooms, each discussing one of the issues presented in the plenary and facilitators guided them through deliberative conversations in mini-plenary and small group discussions. Participants tried to 'unpick the issue', by raising key questions, imagining the future they would like and identifying main challenges and barriers to getting there.

After lunch participants highlighted key questions and began to reflect on possible solutions and approaches. NHS England's Board members joined the different issue groups in the afternoon sessions. They took part in the conversations and listened to people's concerns, questions, and ideas.

Towards the end of this session, a few participants in each group volunteered to present the main points raised in their room back to the full Assembly Meeting, while the rest of the participants watched and commented on the deliberation and the evidence presented.

For the final session of the Assembly Meeting, Board members summarised what they had heard during the afternoon and explained what actions they would take as a result. Four members of the Assembly Meeting sat on stage with the Board and commented on and challenged the Board on what they heard.

Given the time constraints of this first test of the NHS Citizen Assembly Meeting (the current draft design suggests two days would be needed for this format of event), not all groups were able to reach the stage of solutions, but all conversations helped clarify the problems and highlighted areas of agreement and disagreement on how these problems should be addressed.

The following sections offer a more detailed account of the conversations that developed within each issue group, highlighting key themes, questions and action points. Sections vary in format and length, as they reflect the variety of facilitation methods and people involved in each issue group. Some issue groups tended to focus on key themes and concerns shared by people experiencing similar situations. Other groups, given the wide scope of the issue they were discussing, split into a number of very different conversations and in such cases highlighting overarching themes proved more challenging.

In each instance, however, we have tried to capture as faithfully as possible the main concerns, questions and possible solutions that participants wanted to bring to the attention of NHS England.

Access to services
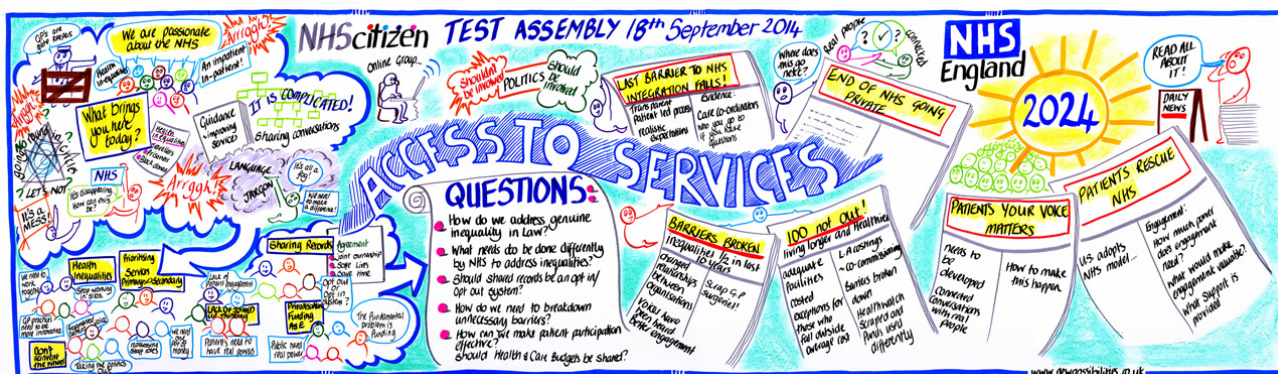
According to NHS England's Assembly Information Pack on Access to Services: "Access is an important part of primary care and has a significant influence on a number of outcomes. Participants in the Gather process had raised the following problems:

- The need for funding to be made available for new GP practices that are needed

- The level of funding for primary care

- Developing a primary care strategy

- Care for the elderly

- Withdrawal of practice Minimum Income Guarantee

- Transforming how men of working age can access primary care

- How will the shift from hospitals to primary care be sustainable

- Problems getting GP appointments leading to an increase in A&E attendance

- Developing a primary care strategy

Good access involves patients having a variety of means of accessing advice and support, in a timely and convenient way. Patients should expect 'the right access to the right care'."

The Access to Services mini-plenary conversation started with participants drawing a picture symbolising a significant life episode or an interaction with the NHS. This exercise gave people an opportunity to introduce themselves and explain what drove them to get involved in the process. People shared their experience of living with long-term illnesses or caring for a relative and their frustration with waiting times and a lack of empathetic response from professionals. There were citizens reacting to the closure of their local hospitals and demanding action against what they believe are arbitrary closures, which deeply affected their communities; and third sector representatives working on health rights for prisoners in Bristol.[2]

Stuart Wallace and Andy Matthews (two of the "issue flaggers" in Gather) offered information on two different dimensions of Access to Services. Stuart talked about transforming the way men of working age can access primary care services through increasing awareness among men and professionals. Andy talked about the need to funding new GP practices following property development.

This issue group also included a '**virtual**' table of five participants who took part in the day by watching the webcasts and using an online discussion forum for their conversations. It was difficult at times to keep the online discussion in step with the room discussions in London, and some of the participants felt a bit disconnected with the Assembly, but they reported that they valued the online discussions. Issues discussed included trust, transparency, ownership and accountability for both data and information.

Participants were asked to identify specific aspects they wanted to discuss in greater depth. People highlighted several important problems and then joined the conversation they were most interested in:

- Health inequality and literacy
- Keeping the NHS public
- Data sharing of medical records to improve access
- Linking primary and secondary care
- Making sure we know about solutions that already exist. Let's not reinvent the wheel!
- Joined up thinking and treating patients holistically
- IT systems and whether we should have integrated or diverse data systems (online group)

This first stage of the conversation served to understand the issue and raise key questions to address:

- If health inequalities are widening, what's the NHS going to do differently to address the needs of disadvantaged/ marginalised groups?
- As the NHS commissions services out to public/ private companies, is it still accountable to people? How?

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[2] Board members Ed Smith (Deputy Chairman), Victor Adebowale (Non-Executive Director), and Ian Dodge (National Director for Commissioning Strategy) joined this issue group in the afternoon session. Simon Stevens (Chief Executive) joined the group for part of the session.

- Should we be cautious about datasharing? Should we have an opt-in or opt-out system?
- Should GPs forgo independent contractor status? Would the NHS then improve?
- How can patient voice be listened to and acted on more effectively?

The facilitators asked participants to further elaborate on these questions, by imagining the news headline they would like to read in 2024 and reflecting on what steps should be taken to get there.

The headlines were a testament to people's creativity and sense of humour:

- "Last barrier to NHS integration falls"
- "Patients living longer and healthier because of personal health budgets"
- "Healthcare inequality halved in the last ten years"
- "US adopts NHS model"
- "NHS: 21st century health restorer using the latest technological scientific advancements"

Although articulating and discussing solutions was difficult given the time constraints, each group was able to identify at least some key actions that they thought should be considered by the NHS.

- Policy should cross two parliaments: policy change every 5 years is distracting and prevents any serious, long-term forward planning. Catching up with policy in a changing landscape means both patients and staff feel lost in the system. Should we remove politics from planning?
- Individual CCG pots of money are too small to make an impact.
- There's need for structural change so that NHS workforce can respond to modern needs.
- Sharing of records can improve access to the right services and faster. However, a public dialogue/ consultation should be opened on whether to have an opt-in or opt-out system.
- Minor ailment aspects of GP service could be devolved to the pharmacy sector. Using the appropriate level of competence could improve service access and make the NHS budget go further.
- Professionals have to be trained to listen to patients more and better rather than assume patients don't know.
- Service provision has to be simpler and clearer, making everyone in our community aware that they have a voice, which the NHS should listen to and respect.
- CCGs and GPs need to collaborate more and better with the voluntary sector, as well as with their patient involvement groups. There are not enough funds to encourage engagement.
- People with disabilities (e.g. the deaf community) should be empowered so that they are less reliant on others (e.g. interpreters) through greater targeted information and education on health.
- Direct extension numbers for minority languages should be available.

Most people felt the NHS needs to find ways to empower people and give them the tools to help themselves. For this to happen more rigorous evidence should be gathered to back investment in co-production and strengthen legal accountability and scrutiny mechanisms.

Overall, different groups highlighted a trust deficit and, while there was commitment from people to

be more involved, they asked for tangible results and feared that NHS Citizen might turn into another talking shop.

Mental health services

The NHS England's Assembly Information Pack on mental health states:

"Parity of Esteem is the principle by which mental health be given equal priority to physical health. The key facts show the scale of the challenge:

• Mental health problems account for 28% of morbidity (the incidence of disease)

• Outcomes for people with mental health problems are poorer, life expectancies are shorter (an average of 10 years less)

• Early identification and diagnosis rates are lower, referral to appropriate services takes longer (1 in 10 people wait over a year for access to psychological therapies including talking therapies)

The government's mandate for 2013-15 set NHS England the task of putting mental health on a par with physical health, and of closing the gap between people with mental health problems and the population.as a whole."

Approximately 30-40 people who joined the mental health discussion.[3] These sessions were facilitated by Rowan Conway, Director of Connected Communities, and Selina Ullah, a community activist and facilitator from the Yorkshire and Humber region. The session began with a presentation

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[3] Board members Bruce Keogh (National Medical Director), Moira Gibb (Non-Executive Director) and Paul Baumann (Chief Financial Director) joined this group in the afternoon session. Simon Stevens (Chief Executive) joined the group for part of the session.

by the two Shropshire Young Health Champions who described their experiences and the challenges facing young people with a wide range of problems. Following the presentations participants, introduced themselves and tried to answer the following questions in small groups:

- What can the NHS do to improve mental health services?
- What are the issues that are important to you?

Most people had lived experiences either as service users, carers, family members or as friends, and they were very knowledgeable about the subject area. Participants recounted personal stories about their experience in the mental health system and highlighted areas of mental health care that needed to be improved. These included:

- The need for real parity of esteem between physical and mental health care

- Integrating primary, secondary and social care to treat patients holistically to better address multiple conditions

- Improving public health and prevention, for example promoting activities that have been shown to improve mental health such as exercise and healthy eating

- Supporting and promoting approaches that involve co-design, co-production and empowering service users

- Addressing the inequalities in funding and services for young people

- Improving access to services for marginalised groups

- Improving access to talking therapies

- Improving access to timely services – addressing long waiting times

- Addressing the isolation that people with mental health conditions face

- Improving crisis care

- Taking action to reduce stigma and inequality associated with mental illness

- Improving education and training available to healthcare professionals and the public

- Ensuring there is sufficient funding for mental health services

- Focussing on wellbeing and mindfulness

- Supporting recovery/after care projects that support people back into work

There was general agreement about the key issues that needed to be tackled. However, because of the broad nature of the discussions, and the limited timescales, participants did not have time to develop shared solutions or identify who in the system needed to do what to make improvements in mental health care.

The need for real **parity of esteem** between physical and mental health was a key theme in all discussions and an issue that is now enshrined in the government's mandate for 2013-15. Participants highlighted the need to improve access to

Participants in the mental health Discussion.

the right services, provide better information and choice of services to patients, improve crisis care and ring fence funding for mental health.

Participants felt strongly about the need for an **integrated care** approach, which views patients in a holistic way. Quite often people with mental health issues also suffer from other physical illnesses and all small discussion groups identified the need to recognise the interconnectedness of mental and physical health. One participant with a degenerative neurological condition highlighted the lack of support for people who are diagnosed with severe or terminal conditions and how this can affect the mental health of patients and their family. Another young participant, who experienced gender dysphoria and had mental health problems, expressed frustration about the significant obstacles experienced in organising home care. One participant commented on the need for "a social prescription, not just a medical prescription".

Education and training kept emerging throughout the discussions. This included offering better training and awareness raising on mental health among primary health providers, such as GPs as well as the public. One group also suggested that mental health workers should be better trained to help people from minority groups and those experiencing gender dysphoria. Participants felt that a great deal of progress could be achieved if best practice was shared more effectively. More and better information about mental health is also needed to reduce stigma.

Young peoples' mental health was also highlighted as a key issue. Participants pointed out that many people with long term health conditions in childhood and adolescence. Participants felt that more funding should be spent on **early identification and diagnosis**. Participants also suggested that more of the health budget should be spent on providing more support in schools and colleges and training health care professionals to better enable them to help young people.

There was broad agreement in the group that people should be given more control over their care. This means **co-producing services** with service users and learning from good practice. Participants felt the NHS should use patients' vast knowledge as an asset. One participant who had spent 20 years in the mental health system shared his experience working for Florid, an organisation that employs service users to improve mental health care. He recounted his involvement in auditing and interviewing psychiatrists and other professionals as an empowering experience, in which he could use his knowledge to improve services through recruiting the right people.

The isolating nature of living with a mental health condition emerged as a key theme in many of the small group discussions. **Loneliness and isolation** have significant impacts on both mental and physical wellbeing. In-patients, the elderly and housebound people were highlighted as groups that were particularly at risk. Some suggestions were offered as ways to combat loneliness, such as encouraging peer support programmes. One participant noted that 'having someone to talk to feels important'.

Access to timely mental health services came up in many of the discussions. Participants were extremely concerned about crisis care and waiting times to access 'talking therapies'. Responses to people in crisis, for example arresting or holding people in cells, was highlighted as extremely damaging. This often occurs in the evenings and at weekends when there are no trained staff to respond to people in crisis.

Local services were often the focus of discussions but it was felt that national support was also important in driving improvements. One participant suggested using Asset Based Community Development and the need to encourage community health champions, such as a GP Mental Health Champion to facilitate information sharing, sign posting and co-production in the community.

Funding consistently emerged as a key issue. Participants recognised the need to do more in the NHS with less; however, there was a general feeling that funding for mental health services should

be ring-fenced. Prevention and timely responses should be an integral part of the NHS strategies in addressing financial cuts and growing demands. Participants emphasised how committing more to preventing ill-health makes strong economic sense.

Gender identity services

According to NHS England's Assembly Information Pack for Gender Identity Services: "The main influences on gender identity are developed in the brain during early development and it is therefore not a lifestyle choice.

• It is estimated that 20 people per 100,000 are transgender.

• The current growth rate in the number of transgender people is 15% per year. Better social, medical and legislative provision for transgender people, as well as greater awareness, may be leading towards this increase.

• Demand for services for transgender people is increasing each year with relatively few specialised services to cope with demand with a small number of specially trained staff.

• Few younger people present for treatment despite the fact that most gender dysphoric adults report experiencing gender variance from a very young age. Social pressure, in the family and at school often prevent children from revealing their gender variance.

• When transgender people reveal their gender variance they are exposed to a risk of bullying, hate crime, and discrimination."

Around 25-30 people joined the Gender Identity discussion[4], most of whom had lived experiences in this area as patients, carers, friends or relatives. They discussed several important aspects and raised many questions about care standards within gender identity services:

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[4] Board members Barbara Hakin (National Director: Commissioning Operations), John Burn (Non-Executive Director) and Margaret Casely-Hayford (Non-Executive Director) joined this issue group in the afternoon session. Malcolm Grant (Chair) joined for part of this session.

- Transparency around waiting times

- Availability of records to new healthcare professionals (so that a patient does not have to repeatedly explain their medical history)

- Inconsistency of protocols and procedures

- A lack of services for young people

- A lack of training and accreditation opportunities for medical professionals, both for specialists and GPs

- A lack of information available to patients about their treatment

> *"Gender dysphoria describes the discomfort felt by people whose innate gender identity, the sense of being a boy/man or girl/woman, conflicts with their visible sex characteristics."* (NHS England Assembly Information Pack for Gender Identity Services)

Two broad themes led people to want to get involved. Participants highlighted the **social stigma** faced by people with gender dysphoria, especially those who are transitioning or have transitioned. Many participants reported stories of verbal and physical abuse as well as being stigmatised by people within the healthcare system, being treated as if they were "strange" or "weird" by the some of very people they were seeking help from.

Participants also expressed frustration with the **lack of information and support** available from the NHS. There was a consensus that healthcare professionals often did not communicate effectively with patients. One participant said she was once asked to wait outside while clinicians discussed her case, which led to feelings of isolation, confusion and a lack of understanding about treatment.

Joan, an "issue flagger" from Gather, gave a presentation at the start of the session, describing her experience with the gender identity services as like being in a "black hole". She said that, after years of using these services, she still does not know what is happening with her own treatment and that this lack of communication has led to feelings of fear and frustration.

Young peoples' mental health was also highlighted as a key issue since many people with long term mental health conditions develop them before they are 18. Participants felt that more funding should be spent on early identification, diagnosis and a choice of timely accessible, acceptable treatment for those that need them in settings they are happy to visit. This needs to start at primary school and requires training teaching staff and school nurses to recognise symptoms and provide support and signposting to young people, as well as more services available to them including crisis services.

There is currently only one Gender Identity Service (Tavistock and Portman NHS Trust), located in London, that works with young people aged under 17 years. This means that, although the service operates some satellite clinics in the regions, many patients have to travel long distances to get the treatment they need, and that there is no opportunity for them to seek a second opinion.

One of the key issues that participants spent a long time discussing was GP services. GPs are at the frontline and usually the first port of call for people experiencing gender dysphoria. However, many GPs have a **lack of knowledge and understanding** of gender diversity and gender dysphoria, which at best leads to a situation where the patients are having to educate their GPs and, at worst, leads to further stigma, isolation and a lack of treatment progression. Participants felt that frontline healthcare workers needed better **training** and that the voluntary sector and the transgender community could play a role in this. The unwillingness of many GPs to collaborate with gender specialists by prescribing and monitoring the treatments recommended by specialists during transition, and subsequently to provide lifelong prescribing and trans-relevant healthcare was

discussed. The potential of GPs with a special interest in gender, working in collaboration with gender specialists, to act as local champions for trans health awareness was also discussed.

Participants felt that gender identity services needed to take a **patient/individual centred approach** to care. The system is geared toward a gender binary view, which assumes patients want to follow similar paths – for example, gender reassignment surgery – but this is not always the case.

Many of the discussions inevitably led to conversations about the **lack of funding** for services. Inadequate capacity to deliver surgery in a timely manner was discussed; it was acknowledged that this was partly due to historically-inadequate workforce planning for succession and service expansion, and the absence of an accreditation and training process for gender specialist, which resulted in few doctors electing to work in the discipline. There was a consensus that limited funds led to long waiting lists and selective commissioning (e.g. a perceived bias towards treatment for trans-women over other types of gender dysphoria). A number of attendees reported using private healthcare, believing that without doing this they would not have received the treatment they required.

Young people's healthcare

The NHS England's Assembly Information Pack on Young People's Health Care states:

"There are approximately 12.3 million children and young people in England, representing 22% of the population. All children engage with the NHS whether it be midwifery, neonatal, health visiting, primary, secondary or tertiary care.

Health problems that develop in childhood often continue into adulthood. Being an obese child roughly doubles the risk of being an obese adult. Two thirds of current smokers started smoking before they were 18 years old and 83% started before they were 20.

Bullying worsens childhood and adult mental health and is experienced by between a third and half of British school children and young people.

There has been an increase in average waiting times to 15 weeks for specialist child and adolescent mental health service (CAMHS) since 2011."

Young people's health and care is an extremely broad issue. Participants in the group focussed mainly on:

- Mental health services
- Sexual health services
- The transition between children's to adults' services
- Communicating with health professionals
- Involving young people in service improvement and policy making

Claire Wells, one of the "issue flaggers" from Gather, started the discussion by giving a short presentation on drugs and alcohol use among youth and improving health outcomes of children. Specifically she focussed on early intervention and prevention. [5]

The discussions that followed highlighted a demand for greater empowerment and involvement of young people in the decisions that concern them, which was reflected in the main questions raised by participants:

- Why aren't young people being given a voice?
- What stops young people having a say in the services and issues that affect them?
- What is stopping young people from being treated as individuals in healthcare?
- What prevents adults valuing and respecting young people?
- What makes transition from children's healthcare to young person's healthcare so difficult?
- What are the barriers that prevent young people from accessing healthcare?

Several crosscutting themes emerged from these conversations.

Transition to adult services

- Young people need the targeted care to help them make the transition to adulthood.

- The transition from children's to adults' services was often expressed as a concern, especially as it was felt that transition could come at a time when stable care was needed the most, for instance when a young person might also be experiencing change in education and housing.

- It was also a concern that, in the transition to adulthood, individuals might lose access to services that are only available to young people and that this does not take into account peoples' complex needs over time.

Youth voice

- Participants felt that young people need to be more involved in co-designing policies and implementing them, so that services can respond better to their needs and their families.

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[5] Board members Jane Cummings (Chief Nursing Officer) and Ciaran Devane (Non-Executive Director) joined this issue group for the afternoon discussion. Simon Stevens (Executive Director) joined for part of this session. Malcolm Grant (Chair) joined for part of this session.

- There needs to be a two-way conversation between young people and health professionals, with professionals really listening to young people. In order for this to happen, young people need support to develop their own voice, build their confidence and knowledge, and feel motivated.

- There was some discussion about why adults/professionals did not engage with young people, including the idea that adults/professionals were afraid of saying "no" or failing to meet young people's expectations.

- Participants stressed that they took part in the Assembly to have their voice heard. They want to be advocates for children and young people but expect to see their efforts at engaging translate into tangible change.

From left to right: Tom Yems, Simon Stevens, Kat Cormack and Jane Cummings.

Information and communication

- In addition to the importance of being heard, the need for information and improved communication was also highlighted. Participants felt that there was not adequate information, including about where to go to seek information or how to make a complaint.

- Poor communication was also a key issue, both between young people and health professionals and between services.

Access to services and individuality

- Young people want to be able to access services, but the system was not designed with them in mind.

- Participants also felt that the system did not take into account and respond to the individuality of those young people who don't "fit the tick boxes". Government services were described as silos, which makes it difficult to treat young people holistically.

As participants defined and unpicked the issue in greater depth, the conversation developed to identify the barriers that prevent young people from accessing healthcare. Participants used post-it notes to write their barriers and those in the group that felt they could do something about it would stand up and explain how. MJ Black from the Gender Identity Services group also joined the discussion to give participants some perspective from the youth trans community.

Through this process, a few potential solutions were explored:

New technologies

- Professionals need to use more technology in their work with young people. Eg: emails, texts rather than sending letters.

- Using Apps and other technology can improve the information flow between young people and the NHS.

- The NHS should have a more outreaching presence on social media, especially Facebook.

Engagement and communication

- Participants felt we should "create [a] culture of listening to what is possible, not explaining what is not possible".

- Adults need to be better educated. Their attitude really matters. They need to be more careful about how they approach conversations with young people and they should stop taking control (i.e. "adults know best" attitude). Young people should be engaged more constructively: they have a lot of potential and "are there to learn from" as well.

- We should foster joined up thinking, by improving communication and links between education and health, in terms of health education, school health services etc.

- It's not just about healthcare workers – we ALL need to do something differently to make change, by working together.

In a discussion focussed on 'who needs to do what to make a difference?' there was a clear consensus that adults need to listen more and better – and need to stop talking over young people and taking control of young people's health. It's a two-way conversation and young people also have to step forward and do everything in their power to encourage all youth to take control over their healthcare. In order to do so, young people need investment and support in improving their confidence and knowledge, for instance through mentoring.

Self-care and personalised services

NHS England's Assembly Information Pack on Self-care and Personalised Services states: "Self-care/management and personalisation are part of an overall approach to enable and empower individuals and communities to take an active role in their own health and care."

"Communities have practical skills, knowledge, capacity and passion and the NHS should access them to become equal partners to improve health and wellbeing and reduce health inequalities."

"A personalised NHS supports a person's right to determine the course of their own life; it joins-up care around people's holistic health and wellbeing needs, it recognises that there is more than medicine, and that one size does not fit all."

This issue group started with Andrew and Gareth from Gather offering a brief outline of the issue. One of the facilitators read an excerpt from David Gaskin's blog post on joined up thinking. David was also among "issue flaggers" from Gather, but could not attend the Assembly Meeting. [6]

Following an introductory session, where participants answered the question 'what brought you here today', the groups tried to define and unpick the issue.

Facilitators invited groups to raise key questions that would later inform topics of discussion. A number of key problems were identified:

- Complex needs and long term conditions need to be addressed in a more holistic way.

- There is still a problem with a patchy, postcode lottery system and a lack of coordination.

- Personalisation is still based around a bureaucratic, target driven and short-term approach.

- There exist service saturation issues.

- The NHS culture prevents "risk taking" and makes it difficult to admit things are not perfect.

As people were invited to split into six small groups to define the issue and related problems in greater depth and start outlining solutions, **more integrated care and joined-up thinking** as well as better, **more targeted GP training**, emerged as key crosscutting themes.

As groups started focusing on solutions to the problems and questions identified in the previous session, there was strong agreement on several points:

- More joined up thinking that includes local authorities and local agencies and better integrated commissioning

- Putting patients in control of re-designing primary care, but making sure the healthcare system is genuinely ready for patients to have control

- Enabling medical professionals to put patients first

- A care coordinator role to help join up care for patients

- Datasharing

- Investing in intermediate care resources

- More focus on prevention

- More effective use of Apps and technology as enablers

- Better local level coordination to include more effectively Healthwatch, Health & Wellbeing Boards, Local Authority departments, local voluntary / city groups.

A bigger role for minor care service professionals, paramedics, qualified first-aiders and pharmacists working in the local community was also identified as a possible solution to service saturation issues.

People reflected on whether roles within the NHS are already changing or whether citizens need to push more. It was emphasised how fantastic examples of good co-production processes already

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[6] Tim Kelsey (National Director for Patients and Information), Karen Wheeler (National Director: Transformation and Corporate Operations) and Noel Gordon (Non-Executive Director) joined this issue group in the afternoon session. Malcolm Grant (Chair) joined for part of this session.

exist everywhere in the NHS, but there should be more effort in rolling them out and enabling these processes in different contexts.

There was much discussion on issues about the role of active stakeholders and how they should "represent" others. Is having one representative within CCGs and other bodies effective? What training would they need? Can they ever be truly representative?

There was also discussion around how to facilitate engagement, highlighting the need for greater support for people to participate, especially when they have additional needs; such support should also include funding people who need to cover care and/or can't afford travel fares.

Several action points were identified as crucial in working towards effective and long-lasting solutions.

What needs to happen?

- There needs to be serious commitment to co-production.
- Funding training for patient champions at all levels of the NHS could help facilitate engagement.
- Personalisation funds should not be perceived as a way of offloading patients from the system leaving them by themselves.

Who needs to do what?
- Participants stressed how they need endorsement from national organisations such as [National Voices](#).
- NHS England's Board needs to demonstrate full commitment to co-production.
- Procedures to facilitate co-production should be put in place.
- The Board could commission NHS Citizen to design a national process for co-production.

Participants expected NHS England Board members to make a tangible effort in showing full understanding of what co-production entails and how it works.

Furthermore, there should be more research into the barriers of co-production and more support for co-production at a local level, as well as more enablers of co-production right across different levels of the NHS, from GPs to commissioners. In order to achieve this, more resources are needed for sharing, rewarding and incentivising best practice. Greater training for GPs is pivotal to make sure they commit to the process.

Board reflections

Following the issue group discussions, NHS Citizen Assembly participants from all issue groups and NHS England Board members reconvened for the final plenary. Two representatives of each issue group highlighted the key points that emerged from their discussion and shared their insights (see above). After this, one Board member from each group reflected on what they had heard in the afternoon session and four participants volunteered to respond to the Board members' comments to ensure the reflections were accurate.

Ian Dodge reflected on the **Access to Services** discussion. He recognised the

NHS Citizens and members of the NHS England Board at the NHS England AGM.

frustration felt by participants that the most marginalised in society have the most significant problems in accessing basic services. He recognised the need to work in a collaborative way to improve access to services and that NHS England needed to think about its role in this process. The short length of time between the last session of the full Assembly Meeting and this session with the Board meant that the NHS Citizen team were not able to ensure that a representative from the Access to Services discussion was represented on stage.

Bruce Keogh commented that the conversations he had heard were constructive but born out of immense frustration. He recognised the disjointed nature of mental health care provision and the need to achieve parity of esteem between mental and physical health. He acknowledged the complexity of this area of health and the challenges ahead as he asked how services should be designed to allow people to get physical and mental care at the same time. He was open with the fact that NHS England do not have all the answers, recognising the opportunities of co-production and peer support, particularly with regard to young people, as they increasingly experience mental health issues. Keogh reflected on the clear social and economic case for a renewed focus on improving **mental health care**, stating that the time has come to join up health and social care, improve crisis services, and capitalise on the opportunities opened up through peer support. He assured the Assembly participants that NHS England would be able to report back on improvement at next year's AGM. Emmerson Walgrove from the Mental Health issue group challenged Bruce Keogh for a lack of solid commitments, stating that more emphasis should be placed on mental health in the Five Year Forward View.

Reflecting on the **Gender Identity** group, Barbara Hakin highlighted the constructive nature of the discussion in the group, saying "…there could have been recriminations for services not being good targeted at me…If only treatment in the NHS was as nice and courteous [as participants were to me in the room]. It's about dignity and respect!" She was clear in her support for gender identity services and stressed that NHS England had to show strong commitment towards improving these services. This is particularly meaningful as Gender Identity Services fall under Specialised Services; these are commissioned by NHS England, which therefore has direct responsibility and accountability. Barbara Hakin recognised the need to improve frontline services, stating that NHS England should work with GP educators to ensure GPs are able to give helpful information and refer people to the right services, avoiding distress and long delays in treatment. She was clear that NHS England needs to make commitments to working with GPs and others at the local level to improve frontline services. She also highlighted discrepancies in care quality across the country and the need for specialised services to learn from best practice, although she did not make any commitments as to how this would be achieved. NHS England must also ensure training and information is widely available to improve services and challenge stigma.

In response to Barbara, Emma Roebuck from Gay Advice Darlington reflected that all the issues raised needed addressing by NHS England and that these issues require more than a day's discussion. However, she also said that today signified a "fantastic start" to initiating action to improve services for what is a very marginalised group of people.

Jane Cummings commented on the "incredibly powerful and brilliant session" on **Young People's Healthcare** she had joined in the afternoon. She noted that there was significant cross over with other issues such as the need for an integrated approach to care which treated patients as individuals. She also emphasised the need to improve links between health and education to ensure that support was available to young people in their transition to adulthood. In her response Kat Cormack, a participant from Hertfordshire, noted that Jane Cummings had clearly been very engaged and listened carefully to the Children and Young People discussions. Kat emphasised that young people were not apathetic, rather they were disillusioned and they need words to translate into real commitments and change.

In his reflections on the **Self Care and Personalisation** session, Tim Kelsey emphasised the fundamental importance of making sure patients and carers have real control over care. He added that this needs to be accompanied by greater transparency around how local care operates. Tim highlighted some specific areas that NHS England should focus on. They included developing the self-care agenda through a "communal endeavour" to "unleash the power of people"; providing more support to carers; and making the most of digital tools to give people more control over their care. He said that there was consensus among the Board on the importance of creating an ongoing conversation about the lessons from the day's conversations and to come back at some point in the future with ideas to move forward.

Fiona Carey, a Patient Representative from the East of England, reflected that Tim Kelsey's account of the afternoon discussion was a distilled and fair account. She noted that the Board members had clearly listened, but that clearer statements about what they were committing to, with time limits and delivery dates, were needed. Fiona did acknowledge that addressing these issues will be challenging and recognised that the involvement of the Board in NHS Citizen was a good start. She ended by saying, "We will be back and we will have questions".

Final reflections

A number of crosscutting themes emerged from the issue working groups:

- The NHS needs more funding to address the growing demand for services effectively.

- Care should be patient-centred and holistic. This requires more joined-up thinking and services working together beyond silos. In this respect, the role of care-coordinators could prove pivotal.

- Participants asked for greater and more targeted training of front-line staff and GPs, to raise awareness about, and improve response to, mental health issues and offer better support to young people and people suffering from gender dysphoria.

- The NHS needs to work better and more effectively with local community groups to address issues of inequality of access to services.

- The NHS has to empower patients, also by training staff to listen to patient needs and provide them with the required confidence and skills to take better care of themselves and be more in charge of the decisions that affect their lives.

- Greater investment in, and commitment to, co-production could really make the difference in terms of patient empowerment and effective use of the resource and assets of both service users and professionals.

- Forums such as NHS Citizen have to be more than just talking shops and start showing tangible results.

Although all conversations were rich and constructive, the limited time and wide scope of the issues meant that the groups struggled to work together towards defining clear solutions. As most participants were experienced stakeholders, they came with their own set of ideas and strategies and simply shared them with others.

As highlighted in the Board members' reflections above, there was a commitment on their part to respond to the concerns and the proposals they had listened to. However, most of the issues raised

were extremely complex and needed more time than half a day to discuss and make commitments on, as also stressed by Bruce Keogh in his final reflections.

As pointed out by many participants the hope is that this is only the beginning of a continuous and transparent process of co-design and co-production of healthcare, where patients are genuinely empowered.

Annex 2 – Improving Access to Services

1. At the NHS Citizen Assembly, we heard about the frustrations that people have with accessing general practice services.   These conversations illustrated and corroborated the data we collect through the GP Patient Survey, which conducts a survey twice a year, asking nearly a million people about their experience of general practice.

2. Three quarters of people report a positive experience of being able to access their general practice, and make an appointment. This is particularly true the older you are, and the more long-term conditions you have. But we know that patient satisfaction is declining. Patients are saying it is harder to get through on the telephone, with only 73% saying it is easy to get through on the telephone, compared to 79% just two years ago. Moreover, satisfaction with opening hours has declined from 80% to 77% over the past two years. We also know that there are big geographical variations, with some parts of the country having much higher levels of satisfaction than others.

3. We want to change this. In our five year forward view, we recognise that general practice is under pressure, with relative under-resourcing compared to hospital services in recent years.   Rising dissatisfaction with access is just one marker of this, as practices struggle to keep up with the rising demand. The conversations at the Assembly reinforced the evidence we have heard. That is why we have set out a series of actions to stabilise general practice for now, and describe some new models of care for primary care to increase the scale and scope of services on offer.

4. Secondly, we are investing £150 million, through the Prime Minister's Challenge Fund to improve access, in pilots across the country to look at ways in which practices can come together to offer patients a better service. We announced the first twenty pilots earlier this year, and already they are beginning to demonstrate some alternatives. For example, GPs in Slough have been offering extended hours on weekdays (8am to 8pm) since 14 July and on weekends since 9 August (9am-5pm Saturday and Sunday) for over 148,000 patients.   Patients with complex needs or unstable conditions are offered a direct line to the clinician with whom they work most closely. We are evaluating these pilots carefully to make sure we learn what is most effective in addressing patient needs.

5. Thirdly, we are exploring different ways in which patients can access services. On Children's Takeover Day last year, the board directly heard about some of the experiences of young people in accessing services.   People expressed an interest in being able to have email or telephone consultations rather than always having to have a face to face consultation. We are piloting

some of these as part of the access pilots, to identify which are likely to be of most benefit.

6. Finally, we will work with CCGs to take targeted action where we know there are particular problems, recognising that there are big geographical variations between areas in patient satisfaction. We would like to explore further through the NHS Citizen process how we might work together to understand more about specific problems and collaborate to develop potential new approaches to address them together.

ANNEX 3 - Self-care and Personalisation

As explained in the information pack provided by NHS England for this issue group, self-care and personalisation are part of an overall approach to enable and empower individuals and communities to take an active role in their own health and care. Self-care is about supporting people to develop the skills and confidence they need to look after themselves. A personalised NHS aims to support a person's rights to determine the course of their own life. The ambition is to join up care around people's holistic health and wellbeing needs. However, there are still many limits to how the system works in empowering patients and carers.

This paper provides a brief response to each of the key issues identified below:

1. **Developing the self-care agenda through a "communal endeavour" to "unleash the power of people"**
2. **Making the most of digital tools to give people more control over their care**
3. **Providing more support to carers**
4. **Training for staff to listen to patient needs and provide them with the required confidence and skills to manage and make decisions about their health and care**
5. **Training for patient champions at all levels of the NHS could help facilitate engagement**
6. **Commission NHS Citizen (that is patients and service users) to design a national process for co-production**
7. **Care should be patient-centred and holistic. This requires more joined-up thinking and services working together beyond silos. In this respect the role of care-coordinators could prove pivotal**

1. **Developing the self-care agenda through a "communal endeavour" to "unleash the power of people"**

NHS England will launch a new programme to effect this change through the commissioning system by:

- Demonstrating the value of individuals and communities in their own health and care and the impact of key approaches such as peer support and social prescribing;
- Developing key tools/resources on how to commission these approaches;
- Supporting partnership working between patients and professionals;
- Measuring and rewarding what matters (including patient and clinician activation); and
- Promoting adoption and spread of this agenda in partnership with local communities and/or communities of interest.

This programme will run initially for 2015-17, as per the scope of the proposed 'Realising the Value' project, but would need further funding to support adoption and spread, beyond 2017.

2. **Making the most of digital tools to give people more control over their care**

While linked to the above, NHS England will deliver an additional component, in collaboration with NESTA, to understand the impact of digital tools in the context of self-management support. This programme will aim to run concurrently in 2015-17.

Providing more support to carers

NHS England will aim to effect this change through its Commitment to Carers work programme, the key aims of which are:

- Raising the profile of carers;
- Education, training and support;
- Develop and deliver tools/resources on how to commission support for carers to develop knowledge, skills and confidence;
- Design and implement measures and incentives.

In November 2014, NHS England will launch commissioning support principles, which will aim to:

- Increase the identification and recognition of carers;
- Provide good practice evidence for benefits of long-term funding for carers' services;
- Reduce the number of carers who end up with poor health as a result of their caring responsibilities contributing to disability and frailty;
- Identify and share local examples of good practice.
- Develop case studies to exemplify the diversity of practice and communities.
- Produce commissioning support principles to inform commissioning process and decisions on services.

3. **Training for staff to listen to patient needs and provide them with the required confidence and skills to manage and make decisions about their health and care**

This is covered by item 1, bullet point 3 - supporting partnership working between patients and professionals.

Specifically, NHS England will work in partnership with key stakeholders to deliver a new programme to assess the current levels of health and care professional 'activation' (using the Patient Activation Measures survey) and support their training and development, in approaches to partnership working (2015-17).

4. **Training for patient champions at all levels of the NHS could help facilitate engagement**

The Participation Academy that NHS England is developing will be a vehicle for promoting training opportunities and learning networks, but won't be an organisation providing training. This would be provided through commissioned programmes such as the Expert Patient Programme and Patient Leadership training. NHS England will

build on existing work with patients and service users, working through NHS Citizen, to identify the most relevant training needs and how they can best be provided.

5. **Commission NHS Citizen (that is patients and service users!) to design a national process for co-production**

Here we propose that NHS England will support the development of a national model for co-production via the NHS Citizen approach, which will be taken forward by working through the co-production arrangements being set up for Coalition for Collaborative Care, of which NHS England is a partner (2015-17).

The model will be based on:

- research into the barriers of co-production;
- training for co-production right across different levels of the NHS, from GPs to commissioners and at national and local levels
- measurement and incentives.

6. **Care should be patient-centred and holistic. This requires more joined-up thinking and services working together beyond silos. In this respect the role of care-coordinators could prove pivotal**

NHS England will:

- provide renewed focus to support commissioners to embed personalised care and support planning (2015-17);
- support delivery of personal health budgets - for people with continuing health care needs - who from October 2014 will have the legal right to have one, giving them more control of the care they need;
- launch the Integrated Personalised Commissioning Programme, which will provide opportunity to develop and test approaches to pool funding across health and social care for people who need the most support, through personalised care and support planning and the option of the personal budget (2015-18); and
- explore how we can promote and embed new roles, such care coordinator roles in partnership with Health Education England (2015-17)

Annex 4 – Mental Health

The NHS Citizen Assembly highlighted a broad range of concerns and issues about mental health services. The discussions reinforced other feedback and insight we have heard from a range of groups. We are keen to involve people in the way we take specific actions forward to address the issues raised.

The need for real parity of esteem between physical and mental health care

It is now NHS England's responsibility, working with partners, to address parity of esteem in a systematic way. The government's mandate for 2013-15 set NHS England the task *of putting mental health on a par with physical health, and of closing the gap between people with mental health problems and the population as a whole.*

1. NHS England would like to work with the citizen assembly and other groups to agree a 'dashboard' of what real parity would look like to them.
2. NHS England will engage with the Citizens assembly to develop a 'roadmap; to parity between now and 2020.
3. NHS England will engage in the mental health intelligence network programme, which like cancer and cardiovascular conditions, means that citizens can be provided with the information across the pathways of in their local communities so that they can ensure that commissioners and providers of care have user voice and coproduction at the heart of plans and parity assurance processes.

Integrating primary, secondary and social care to treat patients holistically to better address multiple conditions

– NHS England seeks to work with Citizen voice to develop our approach to integrated care pathways on three priority areas: people with psychosis where we are now bringing in early access to treatment, including their physical as well as mental health care and where currently they are at risk of death 20 years earlier than the rest of the population
– People with chronic pain and those with cancer, stroke and liver disease where they have both physical and mental health conditions and for who at present we do not have an agreed integrated model of care
– People who are in a mental health crisis. As part of our NHSE England response to the Crisis Concordat, we will establish an expert reference and care pathways group including the Citizens assembly members

Improving public health and prevention, for example promoting activities that have been shown to improve mental health, such as exercise and healthy eating

– We are developing a programme of work around prevention and health

promotion across the lifespan, and would value the input of the young people and citizens assembly to this work
– We are exploring the ways in which we can use digital and peer support innovation to advance this work at pace.
– We would like to develop a programme of work for our own NHS England work force to role model what healthy physical and mentally healthy lives would look like. This advances our Time to Change commitment as an organization

We are working with Public Health England and partners across the system who have this as a high priority within their work programme.

Supporting and promoting approaches that involve co-design, co-production and empowering service users

We are now seeking to develop new ways in which we can advance NHS England's commitment to co-design, coproduction and empowerment. These will be worked through in the areas of:

Increasing access to psychological therapies

– The Children and Young People's Increasing Access to Psychological Therapies (CYPIAPT) programme has co-design and co-production at its core.
– The new NHS England access standards for early intervention psychosis and for psychological therapies will include user voice and coproduction right at the heart of the design of the pathways
– Our work with partners across the system will enable faster development of the skills that peer support workers and our current workforce require to embrace or new integrated care approach

Currency and care pathways approach

– As part of our new mental health care pathways and currency payment approach with our patter Monitor, we are establishing a new programme of work under the leadership of the national clinical director and user coproduction will be at the heart of that approach.
– We would value their leadership in developing our new measurable outcomes programme, patient experience measures, and their support in defining value

Improving access to services for marginalised groups

There are particular inequalities in relation to people from key communities. These citizens often have repeated presentations to our crisis services and would value the advice of the Citizens assembly members on the development of

our planned programmes of work including:

- The Crisis Concordat programme
- The work with the HSCIC Information Centre and other partners on how to help us identify those who present often and for whom a review of the care plan is essential
- We are building a Parity of Esteem dashboard, to set out progress we are making in achieving parity across a number of areas. Within this we will report on as many of the protected characteristics we can get data on, so that we can monitor and improve access to services for marginalised groups. All of our guidance to CCGs and best practice is set up to be inclusive of all service users. We are keen to share the dashboard and working with the NHS Citizen network and coproduce further versions with them.

Improving access to talking therapies and addressing the inequalities in funding and services for young people

Identifying and tackling poor mental health in children and young people appropriately is essential to help them recover, supports their families and helps them remain in education.

NHS England directly commissions specialist mental health services and primary care service and allocates money to CCGs to provide services to meet the mental and physical health needs of their populations, including children and young people. The following list provides some facts about the money spent:

- In 2011/12 £11.15 billion was spent on all age mental health disorders and in 2012/13 it had risen to £11.28 billion
- £400m will have been invested in Increasing Access to Psychological Therapy over the course of this Parliament.
- £54m will have been invested over the four year period from 2011-2015 in the children and young people's IAPT programme to transform child and adolescent mental health services (CAMHS).

Improving access to timely services – addressing long waiting times

Waiting times for people needing to use mental health services vary and there is currently no maximum waiting time limit as there is for physical health services. Once referred there is no expectation that they will be seen within an agreed timescale. For example, one in 10 people referred to psychological therapy services are waiting over 1 year to be seen. This includes people experiencing potentially life-threatening conditions[1].

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[1] We Still Need to Talk: Getting the Right Therapy at the Right Time Mind 2013

This is going to change during 2015/16 and NHS England is now working to introduce waiting time standards for different conditions. These are:

– Treatment within 6 weeks for 75% of people referred to IAPT services with 95% of people being treated within 18 weeks
– Treatment within 2 weeks for more than 50% of people who experience a first episode of psychosis
– Improved psychiatric liaison in urgent care settings.

This is a long term programme of work that will start in 2015/16 with the expectation that each year more waiting time standards will be set for more mental health conditions.

Addressing the isolation that people with mental health conditions face

We recognise that his is an important issue and one that many people experience. Given the societal nature of isolation and stigma for people with mental health conditions it is not an issue that NHS England can take forward on our own but we will raise this with our partners to see how we can best support them to address this issue. NHS Citizen would offer a valuable space for us to collaborate on what actions could be taken forward.

Improving crisis care

Mental health crisis care is inconsistent across England with people sometimes held in police custody because there is no other safe place for them to be assessed. Improving crisis care for children, young people and adults is a priority and NHS England is committed to delivering a range of actions set out in the Crisis Care Concordat. This includes: making the 111 single national telephone help line service responsive to people needing mental health services; supporting CCGs to ensure they have adequate places of safety, access to crisis home treatment services, street triage and joint training programmes, and expert mental health care provided by a liaison mental health team in accident and emergency departments.

In every part of England, NHS England's mental health strategic clinical networks have launched Crisis Concordat programmes with all their partner agencies including police, ambulance, transport services, A and E, social services, housing, and several areas are piloting new improved models. The northeast area has produced a guide to crisis standards and the Southwest has developed a step by step guide to best practice in commissioning and providing liaison mental health services. We are already seeing great progress with, for example, in London, the number of people being brought to police cells reducing from hundreds to single figures this year.

A range of additional information and resources are available at the crisis care concordat website - http://www.crisiscareconcordat.org.uk/resources/

Taking action to reduce stigma and inequality associated with mental illness

We are working with the Time to change campaign to combat this bot within the NHS and in wider society. Time to change is England's biggest programme to challenge mental health stigma and discrimination and is led by the charities Mind and Rethink Mental Illness.

Improving education and training available to healthcare professionals and the public

We will raise this with Health Education England to explore ways to take this forward as appropriate. We would be happy to discuss this issue further as part of a citizen panel with partners, involving HEE and LETB representatives to enable them to fully participate in the discussions. We have invested this year in a training programme in Mental Health Commissioning for every CCG and user voice is at the heart of this programme led by the NCD

Ensuring there is sufficient funding for mental health services

We have an injection of £40m this year and £80m next year to improve access to evidence based services and implement waiting time standards. We will work with partners, including service users to ensure that this additional funding has an impact on people's access to services and through NHS Citizen we would want to share progress and seek insight from citizens about how effective this is.

Focusing on wellbeing and mindfulness

This is an important focus and we are keen to look at how we can shift behaviours and culture to support a focus on wellbeing and mindfulness, especially in our role as an employer of some 6000 plus people. We will seek opportunities to consider this matter with partners, such as Public Health England, to see how we can best we can act to address this. Within NHS England we woud like to trail this for our own leadership as art of our Time to Change programme commitments

Supporting recovery/after care projects that support people back into work

One of the objectives of the Increasing Access to Psychological Therapies Programme (IAPT) is to support people to stay in employment or get back to work. As well as promoting this objective we will raise the issue with other organisations such as the Department of Work and Pensions to see how we can support them in their work to address this issue.

Annex 5 - Children and Young People Health and Care

NHS England recognises just how important meeting the health, care and wellbeing needs of Children and Young People is not just for their own health but for the future of our communities and society as a whole. Children and Young People make up over a fifth of our population, they will be the ones, as a new generation of healthcare users, who are able to make significant culture and behaviour changes around how we as citizens use health care. So, for example, as we are developing our primary care programmes now, we know we need to involve young people not just to get their views (which are important) but also because as the proposed changes become mainstream, over the next 5 years, these young people will be young adult service users and the drivers or leaders of new health and citizen behaviours. It is critical that NHS England routinely and creatively involves young people as active citizens, service users and as our future leaders.

The discussions at the NHS Citizen Assembly have helped us to consider how we can be more inclusive and focussed on how we can routinely involve young people and empower them to influence and co-produce services and support in partnership with us.

The actions we are committing to taking forward include:

1. NHS England will continue to support the NHS Youth Forum as an effective communication resource to engage with young people nationally.
2. NHS England will specifically support the NHS Youth Forum's three programmes of work; to improve communication between health care professionals and young people, reduce stigma when accessing sexual health services and continue to focus on young people's mental health.
3. NHS England will continue to support the Children's Commissioner Takeover day to contribute to youth engagement.
4. The Department of Health and NHS England Mental Health Taskforce will engage, listen and respond to the experiences of children, young people and their families using mental health services.
5. Further work is required to ensure services are aware, sensitive and responsive to the needs of young people with gender identity concerns.
6. NHS England will continue to focus on improving transition experience by collaborating with colleagues in adult care, sharing frameworks that assist local organisations to ensure the process of transition is consistent and sustained.
7. Ongoing work with education and schools will be pursued to ensure information about the NHS is available outside the NHS; innovative programmes such as the creation of 'digital badges' will be tested.
8. NHS England will work with Department of Health to ensure capacity within the workforce exists to support health and wellbeing in schools.

1. NHS England will continue to support the NHS Youth Forum.

The Youth forum continues to provide an excellent way to reach out to young people and to hear their voices both through face to face meetings and the connections via social media. NHS England is committed to role modelling the importance of youth voice. We will role model to the system the importance of

engaging, listening and responding to young people, to meet our commitment to the Children and Young People's Pledge and Article 12 of the UNCRC. Next stages of this work is to further develop the interconnectivity of other youth groups relating to health across the country, including groups linked to health service providers. Getting strong alignment across voices in prevention, commissioning and service provision is essential for whole system improvement.

2. The NHS Youth forum is also actively delivering on **three core objectives around communicating with health professionals, young people's mental health and young people's sexual health.** We will support the work of NHS Youth forum in reducing stigma of accessing sexual health services, improving communication about key issues including confidentiality and raising concerns with information that is written by young people for young people and ensure a focus on young people's mental health is sustained. Each of these three priorities has a programme of action attached. We will work to ensure that these programmes of work are appropriately linked up with NHS England activity and policy to ensure that the work can gain greater reach and traction. Delivering on programmes of work that have been developed by young people for young people will help NHS England to improve our services and build credibility with young citizens and service users.

3. NHS England is delivering a programme of activities as part of the **Children's Commissioner's national Takeover Day**. This has now become a national programme of action for NHS England, where we bring very diverse young people (including those who are seldom heard) together with the Board to explore improvements and commitments that can be taken forward together. As part of Takeover day 2013, the board pledged to ensure that models of youth engagement (youth forum or similar) were developed regionally, bringing a greater focus on local youth voice. While action on this has started, we can re-double our efforts to make sure that this is progressed and well supported.

4. The Department of Health and NHS England **Mental Health Taskforce will engage, listen and respond to the experiences of children, young people and their families using mental health services** so that they are partners in improvement of services.

5. Further **work is required to ensure services are aware, sensitive and responsive to the needs of young people with gender identity concerns**, collaboration with Voluntary Sector organisations will be critical. We will discuss with the Trans Gender Network and consider as part of the current gender identity services review how we can most effectively take this forward.

6. Dr Jaqueline Cornish as National Clinical Director for Children, Young People and Transition, is focusing on **improving transition experience by collaborating with colleagues in adult care**, sharing frameworks that assist local organisations to ensure the process of transition is supported and consistent. Commissioning specifications will highlight the need for organisations to focus on transition and

ensure ongoing monitoring is in place so that young people no longer experience 'falling off the cliff' when moving into adult care.

7. Ongoing **work with education and schools is required to ensure information about the NHS is available outside the NHS**, innovative programmes such as the creation of 'digital badges' will assist in engaging children and young people in new and meaningful ways with the NHS. Work to improve communication between health care professionals and young people will receive ongoing focus by collaborating with Health Education England and Great Ormond Street NHS Foundation Trust with the development of evidence based co-produced resources.

8. A regular theme of feedback that has come through not just from the AGM workshop, but also from a range of other forums is **the limited school nurse resource**. While this programme sits with Department of Health, rather than NHS England, as system leaders, we have a responsibility to ensure insight gathered and young people's experience is shared, and also to work with the Department of Health to explore solutions.

Annex 6 – Gender Identity

This paper provides a brief response to each of the key issues identified during the NHS Citizens Assembly transgender discussion. The issues identified were:

- Equity of access
- Communication and Information
- Issues with access and capacity
- Resources and Capacity
- Workforce and skill

Inequity of access to the gender dysphoria care pathway

From the outset of NHS England taking on its responsibilities in April 2013, we have worked hard to develop a greater understanding of the needs and experiences of the transgender population, so that we are in a better position to offer a fairer, more caring and comprehensive approach to support and treatment. Historical inequalities, rooted in the spontaneous and unplanned manner in which service providers have emerged and evolved, have led to variations in service user experience and ability to make treatment choices at all stages of the care pathway, from its beginning with GPs and throughout its course with specialised service providers and others. This variation has, to some extent, been exacerbated by poor communication and, all too frequently, has resulted in poor experience of services.

Communication and information

We have started to address the issues raised by trans and other gender-diverse people, and, in doing so, we have developed a dialogue with these communities to support and inform us in the development of a draft specification and policy that has been submitted into the NHS England prioritisation process. We intend to develop a continuous process to improve our understanding of their needs, as we further improve the commissioning and provision of these services.

We want to continue this productive and influential engagement with trans and other gender-diverse people and, in doing so, improve participation and access to information through successful engagement events and on-line information, and enable people to access accurate and up-to-date information on the full range of services available to them.

We are committed to continuing to facilitate and grow the trans gender network which will host its third national workshop in November. The digital and online aspect of the network will offer additional ways for people to participate and contribute, ensuring trans peoples voice and experiences can influence all health and care policy and development.

Issues with access and capacity

We have established a Taskforce that has already started working to bring together all the issues identified by service users, commissioners and service providers, into a

coherent and comprehensive action plan, to address problems with accessing help with gender incongruence-related healthcare needs and develop the necessary service provider capacity to deliver this in a timely and effective manner. The task force, led by Ann Sutton, Director of Commissioning Operations, includes participants with key responsibilities for service planning and delivery, including those responsible for commissioning GP and primary care services, as well as those who commission specialised services at national and area team level.

Resources and capacity

The Taskforce will identify and evaluate resources currently available, make recommendations both on how existing service might change to increase their effectiveness and what service developments will be needed to match capacity with need. A focus on equitable access and delivery of services will be at the heart of this process.

Workforce and skills

We are working with NHS England commissioners of primary care and GP services to agree the roles and responsibilities of their providers (including GPs) in the delivery of the gender dysphoria care pathway and lifelong healthcare for trans and other gender-diverse people. We have begun a collaboration with medical Royal Colleges and Health Education England on career development and accreditation necessary to underpin workforce planning, so that we will have properly-trained and appropriately-skilled health professionals that understand and respect this community, and who are able to provide for their healthcare needs.

Annex 7 – NHS Citizen Assembly Digital Engagement

This is a brief summary of the digital engagement achieved through a multi channel approach. Further analysis will be available at a later date as part of the wider review of the approach to digital engagement.

Webcasting

This table shows the raw webcasting figures. It is worth noting the high viewing figures from the Gender Identity discussion.

Assembly webcasts	Total viewers	Archive viewers	Live viewers
Self-Care and Personalisation Discussion Webcast	38	23	16
Mental Health Discussion Webcast	51	36	19
Young People's Health Discussion Webcast	38	25	15
Access To Services Discussion Webcast	54	33	26
Gender Identity Discussion Webcast	153	117	45
NHS Citizen Assembly	248	162	102

(NB: the total views don't line up with the live and archive numbers because this figure is from IP addresses. If the same IP address watched both live and archive this only adds one to the total views)

Twitter
We're awaiting a far more detailed breakdown from Radian6 but we get a taste of what happened by looking briefly at the Symplur results:-

http://www.symplur.com/healthcare-hashtags/NHSCitizen/analytics/?hashtag=NHSCitizen&fdate=09%2F17%2F2014&shour=15&smin=00&tdate=09%2F18%2F2014&thour=15&tmin=00

Headlines:
More than 3,700 tweets with (for the 24 hour period) an average of 155 tweets an hour. There were 678 people using the Twitter hashtag #nhscitizen

Here's the top10 tweeters by mention:-

- NHScitizen @nhscitizen 521

- @nhsengland 321

- @livibf 263

- @kathevans2 172

- @kittycormack 124

- @nhsyouthforum 115

- @thinesg 99

- @tkelsey1 95

- @joemccrea1966 84

- @gileswilmore 80

A few other interesting things to note:
There were large spikes in viewers to the NHS citizen website both on the 1st and 2nd of September (Agenda Setting) and on the 17th and 18th for the Assembly. Figures of in excess of 200 unique visitors in both cases, which contrasts with a background of highs that are around 100 a day.

There are approx. 30 videos from the day on the YouTube account. While most have gained single-figure viewers, one video of Alfie Nikitis has been watched more than 360 times. https://www.youtube.com/watch?v=JO1pmFY34pM

It is among the videos that have been shared here - in a really interesting way: http://uktrans.info/medical/73-nhs-draft-policies-consultations-reviews-etc/268-nhs-citizen-assembly-gender-identity-information-pack