NHScitizen

Learning Report

4 May 2016

Contents Page

Contents: **Page No**

Forward

The many people involved with NHS Citizen have been busy over the last year. Together, we have been undertaking a series of activities to shape further and build a vehicle which provides a number of different opportunities for deep conversations between citizens and NHS England about issues relating to our health.

This Learning Report represents the combined effort of the team and citizens working to make sense of our individual and collective experiences of NHS Citizen over the last year. While it is not a full and comprehensive evaluation, we have worked hard to look at a wide-ranging set of relevant questions, hoping that the discussion and answers will help to illuminate what has happened this year and support the way forward for NHS Citizen.

As we indicate in the report, the information came from many sources. While not always successful, we have worked to co-produce NHS Citizen and this report.

We would like to thank all the citizens who contributed to all NHS Citizen activities over this year and who expressed their thoughts and opinions in the many ways available to them. This is the Learning Report, so in particular, we would like to thank those who specifically gave up their time to contribute to these activities. These are the people we interviewed on the telephone and who participated in focus groups, providing lots of really important material. Two citizens also worked with the team to shape the learning questions and the report itself and we would like to thank them for their unstinting challenge. The work is, of course, richer for having such a broad range of views.

We would also like to express our sorrow that our friend, critical friend and supporter, Kate Ansell, who many of the NHS public voice community knew, died earlier this month. Without her challenge, NHS Citizen would have been very much the poorer and we will miss her.

We are looking forward to a next phase,

The NHS Citizen Team

Executive summary

This is a report of lessons learned from NHS Citizen activities between April to December 2015. During this time, principles and structures developed during the co-design phase (2014-2015) were tested through one round of activities, followed by a short period of review and reflection.

During this period of review, data collected as part of a 'learning programme' was used to address a number of questions. These included: what lessons had been learned in the course of putting into place - and potentially changing – these principles and structures, how NHS Citizen relates to the wider healthcare system and other Public and Patient Involvement initiatives, what has been learned from the programme about public involvement, co-production, and culture change, and how NHS Citizen provides value to NHS England and citizens.

Learning about the NHS Citizen process

The implementation of NHS Citizen has taken place against a background of considerable change within the NHS. Partly as a consequence of this, there was delay in starting, and a reduction in resources available for, this phase of work. Never the less, this time period has seen over 3000 people participating in one or more of the following NHS Citizen activities:

- The identification of 126 issues of concern in on and off line 'Gather' activities.

- A selection phase in which these were reduced to a smaller set for discussion with the NHS England board (via a selection panel, Citizen's Jury and online voting process).

- Discussions of five these of issues at the Citizens' Assembly bringing together Citizens and members of the NHS England Board and senior management.

This report combines data taken from a variety of sources, including information gathered as a part of programme activities, an online survey, phone interviews and two focus groups with participants in NHS Citizen activities. Collation of this data was also supported by a number of discussions with NHS England staff and Board members, undertaking case studies of the way in which a small sample of seldom heard groups have engaged in programme activities, and ongoing conversations on the Gather website.

The feedback has been quite mixed. Many have seen NHS Citizen as a welcome development, and have been enthusiastic about what it has, and might be able to, achieve. Others have felt frustration at the limitations, which arise in part from its relatively early stage of development and the restrictions imposed by the tight time scale and resources available during this phase of the work. Many useful comments were made about how it could be further developed and improved in the future.

Feedback on the Assembly was particularly positive, with some seeing it as an 'exemplar' of good practice in public and patient involvement and particularly welcoming the wide range of participants who participated. Feedback on the Gather process was more reserved. Although overall over 300 people participated in this process, with over 100 issues identified, some had found the online process difficult to navigate (resources were not available to implement planned improvements of this element of the programme). There was concern that discussions had sometimes become dominated by a few strong voices and about the low level of engagement by NHS and NHS England staff.

Two overall concerns expressed about the work during this period related to the lack of feedback from NHS England – and opportunities for continuing involvement – in issues raised at the Assembly meeting, and the limited opportunities provided for more active citizen involvement ('co-production'). On the other hand, the existence of NHS Citizen was also seen to be an important indication of NHS England's commitment to the concept of public and patient involvement, and many supported its continuation and further development.

How NHS Citizen relates to the wider healthcare system

NHS Citizen is one of a large number of avenues for patient and public involvement in NHS activities. A central aim has therefore always been that it should complement, rather than duplicate other activities, acting as a 'network of networks', collating issues and concerns from across the country, and bringing those with particular relevance to the work of NHS England and its Board. Specific activities to explore how links could be established between local activities and NHS Citizen were undertaken in six 'development sites and in 'offline' Gather activities.

The networking aspect could only partly be achieved during this phase without a major change to the software, and the time scale was such that only a limited number of local activities could be undertaken. In spite of this, there was evidence that some individuals and groups had been able to use on and offline opportunities to create new links and share information. Some saw NHS Citizen as having potential for use at a local level, as a route for taking local issues to a national level, as an exemplar of a different way of working, or as a source of resources for local involvement activities. For others, the link

between local activities and a national development of this kind remained unclear, with some continuing ambivalence about how far it represents an opportunity – or a threat – to local activities.

Learning about citizenship and co-production

In creating a new route for supporting dialogue between NHS England and the public, NHS Citizen provided a valuable opportunity to learn more about on and offline processes for public and patient involvement, how the idea of 'co-production' can be made a reality, and what being a 'Citizen' of the NHS could mean.

Exploring how NHS Citizen could be made accessible to a wide range of different groups, including those whose voices are 'seldom heard' was a key part of the work during this phase. Considerable resources were given to 'outreach' activities (building links with relevant organisations and groups), and to making activities accessible, for example, through provision of both on and offline activities (and webcasting key activities), and creating 'easy read' communications, ensuring that those attending activities had suitable support in place. A case study highlighted in the main report illustrate these activities, and their results, with a small number of 'lesser heard' groups including Gypsies, Travellers and young people.

The idea of co-production – mobilising the resources of citizens – is being widely discussed currently and is one of the principles underpinning work in NHS Citizen. There have been a number of different ways in which citizens have been able to get involved during this phase of the work (via on and offline Gather activities, in the Citizen's Jury and Assembly and in the development sites). However, more active involvement, in terms of joint work in the planning and delivery of activities has been limited. Some effort was made to remedy this during the learning programme (through involvement of citizens in planning and analysing feedback, and overseeing learning activity). The value of this and feedback from the survey indicates the potential for taking this element further, through creating more opportunities for citizens with relevant experience (with and without additional training) to take a more active part in research activities, or take up roles in the facilitation of on and offline group discussions and through disseminating information via social or other media (citizen reporters).

Learning about culture change

A key working hypothesis for NHS Citizen is that its full potential can only be achieved if all the relevant parties feel confident in being able to work with each other. Considerable work went into exploring, with both citizens and NHS England staff what might be required for the development of a more open and collaborative culture. Regular

conversations with Board members, Executive team members and departmental staff have taken place. NHS Citizen has been a standing item on the Organisational Development Director's calls, and some exploration undertaken into the opportunities for embedding programmes of related work into performance plans.

A key learning from this has been the slow (and time consuming) nature of change work of this kind, particularly in an organisation as large and diverse as the NHS. Some successes can be reported: particularly the quality of discussions that took place at the Assembly which were valued by several of the NHS England staff and senior management who attended. There was also learning about how challenging this kind of engagement can be, for managers and staff, as well as patients and public volunteering their time to be part of such activities who find themselves in the 'middle ground' between NHS England's commitment to public and patient involvement, and the demands of delivering NHS services in a highly (resource and time) pressured and politically sensitive environment. One way in which NHS Citizen could contribute is through providing relatively small scale demonstrations of successful work of this kind, which could contribute to creating a 'ripple effect' rather than being seen as a 'top-down' imposition.

The value of NHS Citizen

How to assess the value of a programme like NHS Citizen is a challenging question. For some, the value was seen in its ability to demonstrate a different way of involving people. However, others saw the key value as lying in its ability to contribute to the development of effective policy and practice. However, the lack of feedback or opportunity to continue involvement in the issues raised was a source of frustration for many participants in the learning activities. Nevertheless, many people did feel that NHS Citizen has demonstrated 'value' during this period, with just under half of survey respondents reporting a positive experience of programme activities, and that it had addressed issues of concern to them. A similar number reported that the programme had increased their understanding of NHS England, the Board, and how decisions are made, and that it had provided them with new contacts or networks and/or changed their views and behaviour. A key 'value' for some was the opportunity the Assembly had provided for citizens to meet with board members, and the 'symbolic' value of activities of this kind in demonstrating a positive commitment to citizen involvement. Participants in various activities, including NHS England staff, remained optimistic – and enthusiastic, about the continuing potential of the programme, particularly if further opportunities are created for citizens to contribute to the programme activities.

NHS Citizen going forward

The future of NHS Citizen is currently under discussion, with a key question being how it might fit in with other developments, such as the setting up of Sustainability and Transformation Boards, and within Vanguards and Pioneer sites. Feedback provided through the learning activities indicates a number of points that can support these discussions:

- The value of building on the potential identified for involving citizens more actively, through creating new roles such as citizen researchers.

- The importance of having clear communications concerning both activities of public and patient involvement activities of this kind, and any changes arising from programme activities, with ongoing opportunities for involvement after issues have been identified.

- The possibility of smaller scale 'demonstrations' of how NHS Citizen could work in particular policy areas.

- The value of tying activities directly into NHS England strategic priorities – but also having an eye to issues which cut across these priorities, or represent future policy developments.

- The importance of providing both staff and citizens with both the skills and support that can enable them to engage in collaborative discussions: this could include resources and skill development activities, demonstrations of good practice, or supporting champions of co-production and connectors between local and national activities.

- The importance of having an easy to navigate online presence, which is easy to engage with, but also well moderated to ensure a range of voices are heard.

- The value of tying any developments in with other involvement activities such as the Youth Forum, or organisations representing particularly groups of service users.

Section 1: Introduction to NHS Citizen and NHS Citizen learning activity

1.1 NHS Citizen

The principal aim of NHS Citizen has been to develop a process through which health issues can be raised by citizens or NHS England, enabling citizens, NHS England staff and Board members to 'develop their voice in public spaces', and create opportunities for citizens to be more involved in NHS England decision making[1]. A full account of the methods and processes used through the programme so far can be found on its website http://www.nhscitizen.org.uk. Activity was divided into two phases – Design and Build.

An evaluation was published in June 2015 covering the Design phase from NHS Citizen's inception in early 2013 to April 2015. Following the Design phase, which involved many activities and events that engaged citizens in creating and planning NHS Citizen, the Build phase began. The present learning report follows on from the Design phase evaluation report and reflects on the first nine months of the Build phase from April 2015 to December 2015.

An overview of the key stages in the Build phase of NHS Citizen:

- April 2015 – NHS Citizen Design published at www.nhscitizen.org/design

- 7th July - 11 September 2015- Online Gather process took place with citizens suggesting issues to go to the Citizens' Assembly

- 21st June – 5th September 2015 – Offline Gather process took place in different areas of the country

- 22nd September 2015 – 32 issues proposed by Gather users were reduced to 19 by a 'Gather Panel', and prioritised for voting.

- 29th September – 5th October 2015 – Voting took place to select 10 issues to go forward to the Citizens' Jury

- 27 & 28 October 2015 – Citizens' Jury took place, selecting five issues to go to the Assembly

- 25th November 2015 – Citizens' Assembly took place

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[1] NHS England (2013) Transforming Participation in Health and Social Care: The NHS belongs to all of us, Leeds: NHS England; NHS England (2015) Patient and Public Participation Policy (ref. 04414), Leeds: NHS England.

1.2 NHS Citizen Learning Activity

In order to reflect on learning during the Build phase, a programme of learning activities was designed to capture the diverse forms of input and deliberative discussions, characteristic of NHS Citizen[2]. These activities ran between January 2016 and March 2016. A working group, made up of citizens and individuals from the NHS Citizen team was set up to develop, oversee and reflect on Learning Activity. It met at the end of October 2015 to begin planning learning aims and objectives and continued to meet monthly whilst activity took place.

Learning activity included:

1. A review of previous learning reports and feedback gathered.

2. A review of the Theory of Change Map undertaken during the Design process.

3. An online survey and quick feedback form (Appendices 1 and 2 respectively).

4. A series of telephone interviews – see Appendix 4 for more detail.

5. Three case studies with a sample of citizens, representative of seldom heard groups.

6. Two focus groups (one with citizens and one with the NHS Youth Forum).

7. Deliberative debate and other feedback provided on the Gather website.

8. Bringing the learning together into this report, due for publication in April 2016.

Learning activity focused on capturing learning from the Build phase of NHS Citizen, in order to inform the future planning of NHS Citizen and related involvement activities by the NHS and others. The key themes that were addressed and which form the following section headings of this report were:

- Learning about the NHS Citizen Process: e.g. the mechanics of Gather, the Citizens' Jury and Citizens' Assembly.
- How NHS Citizen relates to the wider healthcare system.
- Learning about patient and public involvement, co-production & citizenship – the challenges and opportunities.
- What we have learned about culture change and building relationships for change.
- The value of NHS Citizen for NHS England and citizens.

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[2] Following initial planning and development for a one-day event, it was decided that a programme of learning activity would better capture the broadest range of feedback.

The first two themes relate directly to NHS Citizen itself and provide the learning that can contribute to taking the work forward in the future. They include case studies about the involvement process of some groups and individuals and their response to their NHS Citizen experience.

The final three themes are concerned with using the experience of developing and delivering NHS Citizen activities to address a broader question of citizen involvement, a question central to a number of recent policy developments. For example, the Five Year Forward View 2014 set out an aim for the NHS to:

'…*engage with communities and citizens…, involving them directly in decisions about the future of health and care services'* (Five-year Forward View, 2014, p.13)

The remainder of this section briefly sets the scene for the rest of the report, by outlining the policy arena and context in which NHS Citizen has been developed, with reference to prior and more recent research in this area. This establishes the context for the thinking and ambitions behind NHS Citizen.

1.3 The background and context of NHS Citizen

NHS Citizen was developed and designed based on many established principles relating to involvement and deliberative democracy. As noted in the Design phase's evaluation report, a number of reviews took place of relevant literature on culture change, citizenship and the development and use of communication technologies. It was also developed using knowledge of previous programmes that combined a number of consultative and deliberative methods, such as the Cabinet Office "Peoples' Panel" between 1998 and 2002[3]; the "GM Nation" consultation in 2003 on genetically modified food; and the "Your Health, Your Care, Your Say" consultation in 2005 on a planned White Paper on Health and Social Care. In particular, NHS Citizen was designed to be flexible and capable of changing in response to the information it gathered, using an action research approach.

Action research combines research and intervention. A goal orientated action is undertaken and its effects generate information about the system to which it is applied. This information is used both to make immediate, ad hoc changes to the intervention and to refine the underlying theory of change. In so doing, action research moves iteratively towards more effective interventions. This sidesteps the need to first develop a complete view of the system, which would present a significant challenge with a complex organisation such as NHS England.

> *"Action research provides the opportunity to look at a phenomenon while it is evolving... and to fiddle with it as you test out hypotheses 'on*

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[3] Manwaring, R. (2014) "The Search for Democratic Renewal: The politics of consultation in Britain and Australia." Oxford University Press.

the run'. It's a chance to look at the potentially myriad variables that might be coming into play as they occur."4

Written into action research is the expectation that the intervention will change to a lesser or greater degree over time, along with the expectation that the first intervention will be imperfect. However, defining and therefore gauging change in relation to co-production and citizenship is necessarily influenced and limited by the contested nature of these ideas (e.g. Fotaki, 2014)[5]. When, where and how staff, service users and the wider public see themselves as citizens, and what form associated ideas of "co-production" might take, is therefore not straightforward.

Changes in the programme as it developed were taken in response both to ongoing feedback and collection of data within the programme, as well as in response to changes in the wider context in which it was taking place. Some key developments in the wider context during the early development of NHS Citizen included:

- The launch of the Five Year Forward View in October 2014 setting out a shared vision of the future of the NHS, developed by the partner organisations that deliver and oversee health and care services including Care Quality Commission, Public Health England and NHS Improvement (previously Monitor and National Trust Development Authority).
- NHS England's Business Plan, associated with the Five Year Forward View, launched in March 2015, forming the focus for NHS England delivery.
- The evolution of new joint health and social care arrangements that were developing and beginning to work across the country.
- A change in Government, followed shortly after by a major review of public spending.
- Personnel changes within the NHS Citizen team and NHS England.

The Learning Report begins with a presentation of data collected related to specific NHS Citizen activities, to answer the question: what has been learned during the 'Build' phase of the work, particularly in terms of putting into place, and potentially changing, the design that was developed during the co-design phase. The third section considers the broader question of how NHS Citizen relates to healthcare systems, with the fourth section concentrating particularly on its relationship to other Public and Patient Involvement initiatives. It highlights what has been learnt about the challenges and opportunities of co-production and the concept of citizenship.

To complement this, the fifth section explores what has been learnt about culture change and about building relationships for change, both within the current culture of

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[4] Hase, S. (n.d.) "Mixing Methodologies in Research"
[5] Fotaki, M. (2011) "Towards developing new partnerships in public services: users as consumers, citizens and/or co-producers in health and social care in England and Sweden". Public Administration, 89(3): 933-955.

the NHS, and of NHS England. The sixth section looks at both the current and potential value of NHS Citizen for both citizens and NHS England. The penultimate section asks what is next for NHS Citizen, and more broadly, for public and patient involvement activities in the NHS. The report ends with a set of recommendations that are based on what has been learnt so far from NHS Citizen.

Whilst this report is not a formal evaluation report, it has sought to bring together a range of perspectives from staff and citizens who have had varied depths of involvement in NHS Citizen. It attempts to reflect the wide range of views and good ideas presented, whether they are from a majority or minority of those engaged in the process. It is hoped that as a result it captures the very different experiences of NHS Citizen and indicates how the future of NHS Citizen and other public involvement activities can benefit from this diversity of perspectives and resultant learning.

Section 2: The NHS Citizen process

2.1 Introduction

The co-design process through which NHS Citizen emerged during the development phase involved nine large public consultation events and a number of smaller events, which took place between April 2013 and March 2015. The findings from this phase were written up in a series of documents, collectively called the "NHS Citizen Design and next phase", posted on the NHS Citizen website. The overall design was agreed by the NHS England Patient and Public Voice Team (who commissioned the programme) and formed the basis of the work plan for the Build phase of the work, which this report considers.

Building upon the ideas of action research, it was acknowledged from the start that such a large initiative working in such a complex organisational environment could not be built all at once. As set out in the NHS Citizen Design, the intention of this initial build year was to focus on creating the basic elements of NHS Citizen, in a simple form that could be extended over time, and developed in response to learning captured. In process terms, that meant that this year's work covered three parts of the NHS Citizen machinery.

- Identifying issues (via on and offline Gather activities).
- A selection phase in which these issues were reduced, through a selection panel, vote, and Citizens' Jury, to a smaller set for discussion with the NHS England Board.

- Discussions between citizens and the NHS England Board (at the Citizens' Assembly).

The initial plans for the Build phase were for two rounds of each of the above processes, but the unavailability of full funding to support the digital and network-building elements of the work meant that other activities were scaled back to free up resources for a stopgap digital development. Some key digital elements such as developing a more sophisticated 'Gather' site, bringing in voices and networks from elsewhere, and creating a "participation passport" or NHS Citizen identity were therefore not able to be developed during this phase.

2.2 Identifying issues

Public Involvement activities often begin with an issue that the organisation wishes to consult the public about. NHS Citizen sought to take a different approach, to move towards a co-productive process through which the public could identify the issues that were important to them. These issues could then be discussed and deliberated, informed by supporting evidence. The issues that had good discussions and reached conclusions could be passed on to the right part of the NHS, or the NHS England Board. Identifying of issues took place between July and September 2015.

The process itself was named 'Gather'. This incorporated some of the network-building elements of the 'Discover' processes that had been proposed during earlier parts of the design phase. At its core, Gather consisted of a process, largely but not exclusively through a website (referred to as the 'Gather site'), in which citizens could 'post' issues that they wished to see discussed. Others could contribute their thoughts and observations about this issue.

Although the full list of issues was held on the website, not all of them were initially raised there, with offline discussions also taking place. A key aim of NHS Citizen is to include 'seldom heard voices' and the voices of those members of the wider public not actively engaged with the NHS. Therefore, a range of other activities took place, including:

- Offline 'Gather' activities.
- A programme of communication and outreach activities which included establishing personal contact with a number of groups and use of social media.
- Direct communication with representatives of groups known to be seldom heard in public involvement work, and who were found to be underrepresented in NHS Citizen activities to date, to encourage their participation where appropriate.
- Work in six 'development sites' which in some areas included visits to local community groups. Issues from one of the development sites were posted on Gather.

Online Gather activities included:

- Gather website open for two months.
- People signing up to the website, generating and contributing to discussions.
- Twitter chats.
- 129 issues raised on the website, of which 32 were proposed for discussion at the Assembly.

Offline Gather activities included:

- Attendance at and/or creation of six public events around the country by an NHS Citizen staff member. This included interactive presentations about NHS Citizen at the NHS 'Expo' conference in Manchester in September 2015.
- Production of a guide to support citizens to set up their own Gather events.

Additional networking took place through outreach activity and development sites work to raise awareness of the Gather process and NHS Citizen. However, attendance at events was limited by the reduced funds and subsequent project delays that reduced the lead in time for organising events in collaboration with partners. This meant it was difficult to get the connections needed for a more diverse and wide ranging set of offline events. For instance, a number of other events pencilled in were postponed, including with Friends and Family of Travellers and events in Bradford and Haringey.

2.3 Feedback on the identification of issues

- *"..The level of participation [in identifying issues on Gather]… was very good…"* Citizen.

- *"Best aspect: a good idea, poorly executed. Worst aspect: it seems as though computer-savvy lobbyists who have endless time to post took over the show"* Citizen.

- *"Could there be topics nominated from NHS England? That would be really beneficial."* NHS Staff Member.

- *"My concern is that this highly technical approach - Gather etc – risks… taking energy out of the process and separates engagement from mainstream NHS business".* Citizen.

- *"There is a clear demarcation in involvement on and off line. The co-ordination of the narrative is not co-produced."* Citizen

- *"I like that you can create your own topic – raise an issue – but people might feel*

less comfortable with actually doing it – they might feel isolated especially if their viewpoint is in the minority." Citizen.

- *"Online – it's difficult – you get trouble as you get people stuck on a problem of their concern – and if they have a problem also they can be unpleasant or behave rudely or differently to how they would in person."* Citizen.

- *"It's important to make sure things aren't being selected just because they have most people 'vote' for them or discuss them… how are you making sure minority views get through?"* Citizen.

2.3.1. Feedback on the online Gather Process

- Feedback activities at the Citizens' Assembly 2015 and during the learning activity phase indicated that there were many people involved in NHS Citizen who did not visit the Gather site.
- Less than a quarter (46) of the 200 respondents in the survey carried out as part of the learning programme reported that they had posted on the Gather site, with the majority of these (67.4%) posting once or twice.
- The main reason given for not participating online was a lack of time.
- Several people also reported that they had difficulty in navigating the site. Other factors reported as being 'off putting' were the predominance of a few people posting with specific agendas not necessarily related to NHS Citizen, and the perception by some that it didn't lead to action, and so therefore was an ineffective use of time.
- However, there was also feedback from those who have used the site that it had been found useful by some, as a good way to discuss issues and connect with others.
- Several people noted that they found the behaviour of some Gather posters off-putting and unhelpful in progressing productive conversations between NHS England and citizens.   Several NHS staff indicated that they did not feel authorised to participate online and were worried that they might go 'off message'. They were unaware that they could post their own questions for discussion and were unsure about how to respond to the type of questions being asked. In contrast, some posters on Gather expressed a wish for a stronger presence from NHS staff on the site. This highlights the difference in language and cultures between different posters and NHS England. A briefing document for policy makers was produced, to help provide some support for engagement. However, this didn't act to allay concerns effectively.

- Some focus group members and telephone interviewees suggested that a stronger moderation of the website, for example, implementation of a 'one strike and you're out' policy might have helped. However others raised the importance of considering accessibility and democratic issues before banning people.
- A lack of clarity and/or understanding of NHS England's role led to a number of issues being suggested by some citizens which didn't fit within its remit.
- A number of people felt that the site was potentially valuable, but needed to be further developed to improve its functionality.
- Suggestions for improvements (many of which were in the original plans) included:
  - Creation of opportunities for people to contact each other directly so as to share contact details and communicate more privately with each other.
  - The ability to 'like' and 'dislike' other's views and suggestions, and highlighting of the 'most read' posts, so that it is easier to see the popularity of different perspectives and issues.
  - An embedded voting platform, so that it is easy for people to vote online in support of different issues.
  - A summary on the website's front page of the most active discussions.

2.3.2 Feedback on offline Gather activities

- Feedback from the offline Gather activities came from reports completed by the facilitators of these, based upon their own perceptions and discussions with participants, as well as written comments received directly from citizens at live Gather events, such at the NHS Expo in September 2015.
- There was no evidence that any events were run by citizens themselves, although a Guide for running events was produced and is available on the NHS Citizen website.
- Many issues that came from offline events didn't get developed in online conversations that took place and so were not proposed to go forward.
- Feedback from seldom heard groups stresses a preference for face-to-face interactions, which can better enable a minority viewpoint to be listened to respectfully and understood. Conversely, topics raised through the online Gather process were seen as less likely to be a priority for seldom heard groups who may not share the same concerns as the dominant population.
- Suggestions for improvement included:
  - The need for a clearer process for providing online updates about offline Gather activities.
  - Better linking between offline and online conversations so that those involved offline could be connected to online engagement.
  - Provision of more on and offline support to help people set up and run their own NHS Citizen events.

- A greater diversity of events being held or attended, in order to involve a wider range of people in the process.

One citizen suggested that wider, cross-cutting and systemic issues could have been addressed, such as mental health and wellbeing, the integration of health and social care systems, transparency across the health system, activating patients and the public, and identifying priorities for the next NHS England five-year forward view. There has also been the suggestion that online and offline activities be more closely aligned so that ideas for discussion are generated through live 'hack' events, supplemented by parallel online events.

2.4 The Selection Phase

Gather activities provided the opportunity for a very wide range of issues to be identified. Everything that was raised was handed over to NHS England as a citizen-raised issue. However, only a small number (up to five) could actually be discussed at any one time with the NHS Citizen Board. The selection phase took place between September and October 2015. Reduction of the many issues to a few involved:

- Inviting those on the Gather site to propose issues that could go through to discussion at the Assembly. This required at least one person on the Gather site requesting an issue to go forward to the Gather process (not necessarily the discussion originator). This narrowed the 129 originally posted issues down to 32.
- A 'Gather Panel', consisting of two people: Dr Soo Nevision, a partner on the NHS Citizen development site in Calderdale, and Pat, Chief Executive of National Voices, facilitated by a member of the NHS Citizen team. This panel was created given the difficulty in testing for published criteria for issues to be taken to the Citizen's Assembly (e.g. that the issue was nationally significant and within the remit of NHS England). It was felt there needed to be a filtering stage before public selection stages to ensure issues available for voting upon were eligible. Furthermore, there was a desire to balance the needs for specialist knowledge with the ability for external challenge. This Gather Panel used the published criteria and a balanced scorecard, produced as part of the design process, to reduce the 32 issues down to 23 and ranked them for the vote – although the panel did suggest that some of these issues be merged, and one be split, before proceeding. Participants on the Gather website rejected some of these mergers and accepted others: negotiation of these changes took place over a week and resulted in 19 issues. This added a further delay to the process.

- These 19 issues were then put to a vote, open to anyone who had signed up to the Gather website prior to 11ᵗʰ September, the cut off date for issues to be considered for this NHS Citizen's Assembly. 168 people voted out of 1,458 who were eligible to vote which represents 11.5% turnout.
- The 10 most voted for issues were taken to a Citizens' Jury, which then chose the five issues for presentation at the Assembly.

2.5 Feedback on the Selection phase

- *"Personal issues got higher scorings…people can equate to personal matters…[need to]…get wider issues….need an experienced group [of citizens]"* Citizen

- *"While issues do need to be of relevance to NHS England to go to the Assembly meeting, and this requires specialist knowledge, the process by which this test is applied needs to be open and fair."* NHS Citizen team member

More detailed learning on the Citizens' Jury can be found in the Citizens' Jury Learning Report. Feedback on the overall selection phase through learning activity includes:

- Time was limited, due to delays in funding confirmation and narrowing the choice of issues from those suggested down to the ten issues brought to the Citizens' Jury, who then voted for five of these to go to the Assembly.
- Both citizens and the NHS Citizen team needed a longer time between the different phases of issue selection, to enable:
  - o greater input from citizens in the discussion of, and selection of issues for the Jury;
  - o more detailed briefings for and greater attendance by citizen presenters and relevant NHS Staff at the Jury and Assembly;
  - o information on the final five issues to be gathered and shared in good time before citizens and the NHS England Board meet at the Assembly.
- Although prior testing had been done, technological issues with presentations made remotely (via skype) to the Citizens' Jury and webcasting of the Jury made remote access to the event challenging.
- However, one issue presenter who did engage remotely was pleased to have had this opportunity and praised the team's efforts in providing this facility, despite technological issues.
- A Gather contributor suggested that citizen observers should be invited to citizen jury meetings. This had been considered before the Jury and rejected for

different reasons, including jurors potentially feeling under pressure by such observation.

- Some concerns were raised about the presence of some expert witnesses during jury sessions and the potential additional influence they could have brought to the selection of the issues they supported.
- NHS Citizen team members have reflected that some issues presented didn't align to NHS England Five Year Forward priorities, making it a challenge to gather information from NHS England teams as part of the selection process. This highlights a tension between enabling citizens to decide on what issues should be discussed, the focus of NHS England on its priorities, and the way in which citizens experience NHS priorities as being representative of 'silo' ways of thinking. Perhaps in future, NHS England could decide which ideas it wishes to sponsor, with alignment acting as one factor (but not the only factor) in deciding which ideas go through to discussions with the Board. This would mean issues that don't align could still be chosen.
- It has also been argued that when voting takes place to decide issues, scores should be weighted demographically, so that those groups (for instance young people) who may vote in smaller numbers have an equal opportunity for their voices and votes to be heard.

2.6 The Citizens' Assembly

Discussion of the five selected issues took place between citizens, the Board and senior managers from NHS England during a one day 'Citizens' Assembly' on 25th November 2015. Planning for this activity was extensive, with a significant amount of resources, both personnel and financial, spent. Work included:

- Preparation of material for the event, including information packs on each of the five issues selected.
- Communication and outreach activities, particularly aimed at people from groups typically excluded from involvement activities, and who are therefore 'seldom heard'. Additional targeting of those most effected by the issues to be discussed was also undertaken.
- Inviting citizens to take part in the Assembly through tailored emails and personal follow up phone calls. Contacts from 'seldom heard' groups were gained from NHS Citizen team members' existing networks and through NHS England's strategic partner organisations.
- Inviting people from seldom heard groups only if they felt comfortable to do so, and encouraging people to bring additional support where appropriate (e.g. a staff member from a trusted representative organisation).

- Mobilisation of participants from NHS England, including departmental staff, senior managers and the Board
- Planning and delivery of the event itself
- Webcasting and online engagement on the day widened access for those not attending.

2.7 Feedback on the Citizens' Assembly 2015

- *"NHS Citizen's Assembly – it's not a tick box! It's exemplary"* Citizen attendee

- *"What was achieved from it? If NHS England has something as a priority, then we're too late…. We need to be involved in deciding the priorities…"* Citizen

- *"I didn't take anything away from it….It was a [too] broad discussion"* NHS Staff Member

- *"[W]e get to mix with [health] service users at the same time as service providers, in the same discussion. This 'inside look' is not happening in the other things I go to. It's new, it's useful and it's valuable."* Citizen.

- *"There was not a facilitator present and one man just kept taking the floor again and again!"* Citizen

- *"It was a good event… as a policy maker, I don't have that much contact with people…"* NHS Staff member

- *"…people spoke about the social aspects of health care, about their experiences. The conversations weren't always about the topic in hand."* NHS Staff member

- *"I felt the input from participants was highly managed to resist change"* Citizen

- *"I have learnt more about what is going on at a national level"* Citizen

- *"It's valuable because it demonstrates public interest in people and in their health"* Citizen

- *"It was a friendly environment at the Assembly – it's the environment we want to have at the doctor – to feel welcome as young people… we don't always feel so welcomed."* Citizen

- *"I now use it [the Easy Read version of the Assembly Information Pack] as a model for mental health information in our work [with a seldom heard group]"* Citizen.

- *"Getting the [Assembly] information packs the night before allowed me to prepare [the group] so we were ready to engage… we knew what was coming, and who we wanted to talk to, and what about…You have to prepare people. Without this preparation there's no communication"* Citizen

- *"For my topic, the issue was structured appropriately and did reflect our strategy and was relevant to us. We know the areas for improvement so we could learn from the session which started to address these. It would be even more beneficial if we could focus on what we need and could shape it. But it was highly relevant."* NHS England Staff Member

More detailed learning from the day of the Citizens' Assembly can be found in the [Citizens' Assembly Learning Report.](#)

- Overall, feedback on the Assembly has been highly positive with 82% of feedback on the Assembly by attendees rating it as either good or very good. Four people rated it as poor, and no one rated it as very poor (Total responding to this question: 96 respondents, 48% of the 200 attendees).
- The most popular words used to describe the Assembly experience were 'thought provoking', 'productive' and 'interesting'.
- Many people valued the unique opportunity to meet and talk with members of the NHS England Board about the five issues identified.
- Whilst many people found the information packs useful, some found them to be too detailed, using unnecessary jargon.
- Whilst information packs were created, including easy-read versions, for attendees at the Assembly, team members reported that more time is needed to prepare and distribute these in advance. Significant work is required in translating NHS England policy and background evidence into language that is accessible for non-healthcare professionals.
- A young peoples' health organisation, supported by an experienced public engagement staff member, prepared for the Assembly by reading the information packs the night before and researching the topics and relevant NHS England Board members online. They were thus fully engaged in both formal discussions and their own informal discussions and interviews.
- Many people found the event to be inclusive, with a diverse range of people attending and the provision of appropriate accessibility support, including BSL interpretation, graphic illustration and access support staff.
- Some concerns were raised regarding accessibility – particularly in terms of the venue's location, ease of booking in advance, and the size of the venue, which

was difficult for those with mobility issues to navigate. However, others commented on the thoughtfulness shown in the use of the venue, in particular the 'break out space' which was described as being vital (i.e. when one member of a group needed to take a break, this space was available, without which everyone in the group would have had to leave).

- A few people raised concerns about how discussions on the day related to the discussions that had previously taken place on Gather.
- Many Assembly attendees fed back problems with the lack of individual facilitation and structuring of individual table discussions. It was reported that one or two people sometimes dominated discussions, or conversations drifted into areas unrelated to the discussion topics or became repetitive. Several people (in the survey and the focus group) reported difficulty in getting their voice heard, resulting in the feeling that their views had not been fed back into the wider discussions. Other respondents (telephone interviewees) described how they incorporated the views of both the health service users and providers seated at the table onto 'maps'. These were then fed back to the main table and eventually to the final plenary.
- Suggestions for improvement include:
  - Providing a named contact for accessibility at the announcement of an event;
  - Running a parallel online event to enable greater connection between physical attendees and those engaging online;
  - Having experienced facilitators on every table, in order to enable conversations to be better focused on the topics, ensure that all voices around a table are heard and to enable feedback from the table to be representative of different viewpoints expressed. This particularly helps conversations be as inclusive as possible, because without it conversations are likely to revert to prevailing social inequalities.
  - It has been suggested that a number of engaged citizens bring facilitation skills from their paid and voluntary work experience and that these skills could be better harnessed in future.

2.8 Follow up after the Assembly

> - *"…I think I could demonstrate how the feedback from the meeting would input into the strategy document."* NHS England staff member
>
> - "*Let us know where there is change – so we don't feel we spoke for no reason*" Citizen
>
> - *"My main concern is, where does it go next?"* Citizen
>
> - *"I improved my confidence at the Assembly – that things can be done and that I can pursue this."* Citizen
>
> - *"There is optimism and hope – and you could feel that at the Assembly – but did anything change? Well… what can be realistically expected? These processes are very slow and small."* Citizen
>
> - *"I find it depressing…that there is no tangible outcome of such large events. It sets up a negative cycle of thwarted hope: from hope to depressed, from hope to depressed… because the event gives hope, but then nothing comes of it."* Citizen

- Whilst most people attending seem to have valued the Citizens' Assembly experience, a key issue identified consistently was the lack of feedback or reporting from NHS England in the period since the Assembly.
- Several NHS England Board members and staff who have been contacted during the learning programme have reported that they valued the opportunity to get closer to issues and have contact with individuals they would not otherwise have heard from, through the Assembly. However, it was also noted that it could be difficult to respond when their work is focused on specific business plan priorities, which may not relate to conversations through NHS Citizen.
- Many citizens, through the survey, focus group, Gather, and telephone interviews questioned the value of the Assembly if what happens as a result of it is not made public.
- Since the Assembly, NHS England has been putting into place and undertaking planning activity around the future of NHS Citizen. Some citizens have voiced their interest in being engaged in this process, and the need for planning activity to be co-produced.
- It is also recommended that NHS England, through NHS Citizen, continues involvement of citizens so that the results of people's input and conversations

with citizens can be visible through citizens being empowered to continue activity in some form.

To better understand the value of broadening inclusivity at the NHS Citizen's Assembly so that participants adequately reflect the diversity of the population at large, we undertook three case study interviews by telephone with members and representatives of 'seldom heard' groups, who were identified as previously underrepresented in NHS Citizen. These qualitative case studies are helpful for pinpointing not just what is working in public engagement, but how it is working, providing insights which can then be taken up in the design of future involvement work.

What follows is a case study of one particular group, Future Pulse. However more general learning points taken from each of the three case study interviewees are given throughout this report under the relevant section topic.

Learning on widening inclusivity: a conversation with Future Pulse

[Future Pulse](#) is a three year programme run by Bright Ideas Nottingham and the Carers Federation, which seeks to improve access to health services for young people in Nottingham. Members of Future Pulse (all young people under 25 with media skills training), and their group facilitator decided to attend the Assembly as a result of engagement with groups previously underrepresented in NHS Citizen. In fact, as group members explain, this provided an important avenue for their own work on health issues: *"We'd had a month of media training and so the Assembly was our 'now moment' when we could put our skills into practice". "It's what we were wanting to do but had no avenue for".*

One member of the group elaborated on their motivations to attend: *"It felt important to us to represent young people in this forum…with a clear objective: to make the NHS into a better service for young people. To be there in the room with the heads of the NHS… to hear it from their mouths that young people's views and ideas are essential"*. Another interviewee added that, "*we got so many different points of view it increased our knowledge – the chief executive, the many different staff, the young people in care – and so we learned from it."* The group facilitator concurred with the young people's observations: "*The Assembly gave them a whole new level of experience to their work… they came back… more confident, felt more included and were more inclusive themselves as their empathy had increased. They were pushed to a new level and now trust more in their ability to do this work*".

The work the facilitator is referring to is the investigative activities Future Pulse undertake around Nottingham, on young people's health and policy. As one interviewee summarised, *"We do a series on the radio called 'Once Upon a Question'. We go*

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around the city and interview young people and health services, and we explore an issue. Then we vox pop it and discuss it. Then we script it for the Radio. Health is our topic… and we explore difficult subjects like alcohol abuse". One young person explained, *"Young people will suffer in silence if it is not safe or comfortable for them to come forward and ask for advice, especially in 'taboo' areas" like alcohol, or sex or mental health"*, another interviewee added that *"Radio is good for reaching young people".*

The radio programme referred to is Kemet FM, a Nottingham-based radio programme that appeals to young people and also to a local African Caribbean audience. Future Pulse Assembly participants explain, *"We used the interviews and vox pops we made at the Assembly for Kemet FM",* adding that, *"Now we're working this material up for a media event of our own".* Future Pulse is presenting their Assembly experience to the local CCG and other health services and citizens in the early summer. This outcome illustrates how NHS Citizen can build on and support the important work of groups who are striving to equalise and improve their healthcare services.

Following the Assembly, the Gather site has remained active, with new discussion topics being raised and learning activity being discussed and carried out. Although some Gather users have continued to engage with the website, online activity has significantly reduced without the immediate prospect of another Assembly, and given the inability of moderators to provide answers to questions about the future of the programme. Several people have commented on the resulting reduction in quality of conversations on the website and the apparent dominance by a small number of people. This shows the importance of demonstrating continuing commitment, thus keeping the power in the space, and not letting the energy level drop after set-piece events. If ideas can be kept alive through ongoing discussions, people will keep involved.

2.9 Conclusions regarding the development of NHS Citizen during the Build phase

Since the Design phase, NHS Citizen has had both successes and challenges, and attracted a very wide range of views. Overall most people that have given feedback have been positive about the programme and its potential to influence change and improve services for the future. At the same time, there is still much to be learned. Whilst some voices are highly critical of the programme, others recognise that a hugely

ambitious culture change, which NHS Citizen represents, will take significant time and ongoing learning along the way to truly enable improvements to be made.

Delays in starting this phase of the work meant that the time scale was incredibly tight for action throughout the Build phase. This mirrored the tight timescales with which NHS England generally works, and put limits on the ability of the programme to continue and enhance the level of active citizen involvement, started in the Design phase. More active support to enable citizens to organise and run 'Gather' events as well as a longer lead-in time to plan outreach activity may have increased this ability. There is currently a tension between the good intentions of NHS England to involve people and the tight deadlines by which staff are held to account. However, one area of successful work was the recruitment of Assembly attendees from seldom heard groups.

Specific outreach activity in this area demonstrated that with allocated staff and resources, a wider range of people can be engaged in programmes such as NHS Citizen. It was a good example also of cross-organisational working between different NHS Citizen team members and NHS England's Public Voice team. More active facilitation at events would better ensure that a diversity of voices to be heard, as the environment and more experienced, confident citizens can be intimidating for those new to engaging in this type of work. For some members of society, social and health inequalities are so great that they remain excluded from debate and their concerns become invisible. NHS Citizen has an important advocacy role to play here, seeking to connect with and give weight to the opinions of the most isolated. The involvement of members of seldom heard groups through this phase and the inclusion of their perspectives in NHS Citizen discussions represents a significant development.

The online Gather process drew mixed feedback. In part, the lack of available funding for further development meant that it fell into the very trap that the NHS Citizen Design had tried to avoid – creating a single forum rather than a connected discussion taking place in multiple locations. As the NHS Citizen Design itself predicted, this created the conditions where some groups or individuals would colonise the single space while others would not. This points to the need for further reflection on design, particularly on how to deliver a multi-channel conversation without the resources for large-scale network or technology building. It also points to a regionalised or localised "inkblot" strategy, where different approaches are tested and spread in smaller-scale environments, working with existing involvement networks. There is a need for clarity with regard to the type of outcomes desired and clearer and more tightly enforced rules on the conduct expected of participants. Safeguarding issues will need to be considered when exploring the potential for users to connect behind the public-facing side of any websites.   Additionally, finding ways for staff and citizens to move away from 'You ask – we respond' binary forms of participation is needed to increase online participation.

The earlier NHS Citizen can be engaged in any NHS England programme development, the better able it will be to work with both staff and citizens to influence change through parallel online and offline activities. Adequate time and resources need to be allocated to ensure that the process represents a wide range of views and voices and can fully utilise the assets brought by citizens and staff. Bearing in mind resource constraints, it may be worth identifying smaller-scale opportunities for change in the future, which could provide the basis for longer-term, sustainable involvement of citizens to the work of NHS England. Alternatively, engaging people on NHS England-only identified issues may seem more feasible. However, this could result in missing out on valuable citizen involvement, reinforcing potential silo ways of working and the expert/patient dynamic. Additionally it would miss the opportunity for highlighting issues previously unrecognised. Improving how issues that do not align with NHS England priorities are dealt with needs some further consideration.

Holding and attending the Assembly represents a brave move by NHS England Board and staff. Although themes were set in advance, there would have been a large degree of uncertainty about what was in store, from all perspectives. Therefore, the fact that it happened, that people did come together and that as an experience, it was assessed positively by most that attended, is a credit to everyone who engaged in the event, and to the team that ran it. Whilst frustration and disappointment has been expressed at the lack of action afterwards, it is suggested that if this is addressed through continued involvement, then the Assembly provides a high-profile demonstration of the value of constructive discussions between the NHS England Board and citizens.

A few people have emphasised the importance of continuing with the principles and practices of NHS Citizen, stating that there is a danger if it is discontinued, that this will be highly damaging to public involvement within healthcare in general. Developing a transparent process for NHS England to continue to work with citizens following public involvement activities, demonstrating what might have changed as a result of the conversations is paramount. NHS Citizen was established to improve two way understanding and decision making and cannot necessarily be concerned with responses to specific questions asked. However, if a response is promised, then this should be followed through. Notwithstanding criticisms received, most people have found the Build phase to be productive, although without continued public engagement by NHS England since the Assembly, there has been understandable cynicism expressed by some citizens, who question whether their involvement can actually influence positive change.

Section 3: NHS Citizen and the wider healthcare system

3.1 Introduction

Many involvement and research activities take place across the country, designed to involve public and patients in the work of the NHS. A range of bodies, within and outside of the healthcare sector, engage with members of the public, around a variety of healthcare issues. These include:

- NICE
- National and Local Healthwatch organisations
- Local CCGs
- Voluntary sector organisations such as Age UK and Patient Voice

Local authority scrutiny committees for health vary in their prominence, accessibility and responsiveness to issues raised by local people and voluntary organisations. Inspections by the Care Quality Commission of health and social care providers often involve discussions with service users, local patient organisations and, sometimes, local residents. Monitor and the Trust Development Authority (merged in 2016 to create NHS Improvement) tend to deal directly with NHS hospitals but their remit encompasses scrutinising and managing performance with regard to service quality, the patient experience and patient engagement.

NHS Citizen intends to work at a much deeper level – trying to work with and understand the healthcare system, in all its complexity. An aspect of this is trying to understand and create a process that understands and connects local and national systems, in the knowledge that most people's health experiences are locally based, but sometimes their issues take on national importance.

NHS Citizen was designed not to duplicate activities taking place elsewhere, but acting as a 'network of networks', collating issues and concerns from across the country, bringing those with particular relevance to the work of NHS England and its board, to a regular participatory event. Part of the early aim was therefore to provide the opportunities for different organisations already involved in raising and debating public views about the NHS, to identify others with similar concerns, and form new local and/or national networks. A prototype community or networking platform was designed during the design phase, but there were a number of flaws (in terms of protecting the confidentiality of participants) in this. With the limited funding for technology in the current phase, it was not possible to remedy these.

Some opportunities for networking were provided by NHS Citizen activities. The Gather site allowed individuals, or groups, to hear from others with similar concerns, although it did not easily enable people to contact each other, unless they were willing to give

contact details out on a public platform or find means of finding each other on other social network sites. Many of those posting information on the site were able to name other organisations, initiatives or research activities that were also looking at the issues posted.

A more concerted effort was made to facilitate networking at a local level, in five local areas across the country (Darlington, Birmingham, South Staffordshire, Telford and Liverpool), named 'Development Sites'.   There was also work carried out alongside local Healthwatch organisations, including Healthwatch Devon, which helped to explore how local issues and national trends could emerge from single conversations with citizens.

Nevertheless, the lack of significant activity dedicated to developing a 'network of networks' left some 'on the ground' wondering what NHS Citizen contributed to public and patient activities already taking place. This caused particular concern for Healthwatch England and some local Healthwatches who felt that NHS England was duplicating the work for which they had been established. Some local Healthwatches did see the opportunities provided by NHS Citizen, for example posting issues on the Gather site, hosting local events, or taking part in Development Site activities.

3.2 Activity undertaken with other bodies within the Healthcare system

Development Sites were identified as 'test areas' for a local NHS Citizen system. The commencement dates varied in the sites, with some beginning in October 2014 and others much later, during summer 2015. In all cases, activity included the following:

- Conversations with organisations, including CCGs, local health trusts, a local citizen research project and the local Healthwatch, as well as citizens, to understand and map local involvement activities.
- Identification of a local issue where the NHS Citizen approach might be useful to develop conversations around the agreed theme.
- Support for events that enabled conversations to take place.

Because of the experimental and strictly timed nature of NHS Citizen, areas were chosen on the basis of a request from the local area or through existing contacts. However, as with other aspects of NHS Citizen, if a local staff member that had been keen changed jobs, the main contact, and enthusiasm for engagement with NHS Citizen could be lost.

Additionally, funding for the current phase of NHS Citizen delivery stopped in December 2015, and so work in development sites also stopped. Therefore, learning from this area of work needs to take account of the very short timeframe for development sites,

but also take advantage of the pause as an opportunity to review whether this is the best way for NHS Citizen to work locally.

3.3 Feedback on NHS Citizen's relationship to the wider healthcare system

- *"NHS Citizen can take a role in supporting transparency and accountability at a local level. It needs to be transplanted to the local level"* Citizen

- *"My organisation said "Why engage in NHS Citizen? What's it got to do with us?" I argued because in our own projects we can replicate it – and now we know it's true. [Our group] gained new contacts; built new relationships; experienced equal partnerships (we interviewed and were interviewed); and now the young people are doing their own event. They're more engaged, enthusiastic and proud – of the work they've done and of showcasing it to the [local CCG and other] guests that are coming. Well, 'You're never a prophet in your own backyard!' applies here"* Citizen

- "*I would like NHS Citizen to be more representative of grass roots patient and carer networks at local and regional level… I think it needs to establish a connecting framework with existing involvement networks and allow more say to their agenda"* Citizen

There have been very different opinions given, from those working within healthcare, and from citizens, about NHS Citizen's relationship to the wider healthcare system. Although many citizens have expressed the desire for NHS Citizen to help connect local healthcare systems with each other and with the national system, feedback from staff have questioned the viability of this, partly due to there being an ever-changing field of healthcare focused organisations, and regular changes to the healthcare programmes within the voluntary sector, for example.

Learning about the relationship to local healthcare systems includes:

- A central feature of NHS Citizen is that it takes a 'bottom up' approach to the identification of issues, through creating the opportunity for citizens to nominate issues they would like to see addressed. This approach was at times 'at odds' with the approach taken locally, which often focuses on the achievement of legal obligations in relation to public and patient involvement, mainly delivered through consultation exercises. NHS Citizen's open approach to discussions not

specifically on the local 'consultation' agenda was perceived as challenging for some local healthcare organisations.

- Depending on how far a local health service has progressed in redesigning local provision can effect how helpful they perceive an NHS Citizen approach to be to their involvement work.

- Some citizens, when engaged with the NHS Citizen process at a local level, have spoken highly of their engagement with NHS Citizen. They have felt listened to and have been enabled to mobilise themselves about local issues of importance to them.

- Information was received from a number of different sources that bodies such as Healthwatch (which operate independently within local areas and who therefore differ considerably from one area to another) have responded to NHS Citizen very differently. Some were reported to have perceived NHS Citizen as attempting to duplicate their work, or that NHS Citizen is direct competition and a challenge, while others were reported to have welcomed the opportunity to connect the local with the national framework.

- A number of citizens engaged in NHS Citizen indicated a significant lack of satisfaction with involvement activities at a local level. Some respondents to NHS Citizen learning activity reported that they sat on Patient Reference Groups or acted as a 'lay' representative on their local CCG. Others noted that they had not taken up such roles because of the constraints imposed on them: "*Local transparency is still an issue….the one 'lay' person on the board has to toe the line…I feel more change can be achieved from outside*".

- Whilst many citizens reported wanting to see NHS Citizen engage more with local healthcare systems and their involvement activities, others felt that NHS Citizen should be focused on the national issues only, and not become involved at a local level.

- For a national programme, like NHS Citizen, to lead on connecting the local with the national, takes:
  - o time to build relationships;
  - o resources as local areas are more likely to engage if there is tangible benefit to them in the form of support;
  - o commitment, both from NHS England and local healthcare bodies, to connect their work and enable citizens to influence national issues. This cannot be achieved by NHS Citizen alone.

- Suggestions for future development include:
  - o NHS Citizen to work locally through supporting citizens to build skills in engaging with the system ('activating the patient') which can then be used at a local level, rather than NHS Citizen directly working on local issues.
  - o NHS England to place a stronger requirement on local NHS bodies to engage with the national programme of NHS Citizen rather than the national programme reaching out locally.

- o NHS Citizen to act as an exemplar of engagement, co-production in particular, to local areas, which could support local healthcare organisations in developing and sharing what works well. It has been suggested that NHS Citizen could become a branded 'mark', which local areas can gain as they deliver on NHS Citizen principles and practices.
- o NHS Citizen to identify examples of good practice locally which can be shared at a national level.
- o NHS Citizen to be embedded as an approach within local Sustainability and Transformation Plans, which could support local health economies to work with local people to plan and manage the re-ordering of local budgets and programmes in sustainable ways.

3.4 Conclusions on NHS Citizen's relationship to local healthcare systems

The way in which NHS Citizen connects with local healthcare systems has been one of the main areas of feedback from citizens. An important aim from the start has been to work with and complement local work. Given the different ways in which local healthcare systems operate in their local area, it would have been difficult and costly for NHS Citizen to connect with all of these systems effectively given its current stage of development.

The fear, by some local public and patient engagement activities, that NHS Citizen might be a competitor, rather than a potential partner, has also lead to variance in how well these connections have worked so far and might work in the future. However, although there are challenges, there is also the opportunity for different activities and organisations to work together with citizens to find appropriate solutions.

NHS Citizen can perhaps help address this issue through supporting the capacity building of citizens who are then better equipped and knowledgeable about ways of working with and across these systems, and linking them together. Engaging citizens in developing citizen research, and connecting up with citizens who are already doing research on health policy issues (for example, Future Pulse young people), could also help in identifying examples of good practice around the country with regards to citizen involvement and co-production (inside and outside of the NHS). This could then be celebrated and potentially extended to other geographies through the NHS Citizen process.

It may also point to the need to explore ways of engaging more fully with the various local public and patient involvement activities to address the competitor or collaborator dynamic directly.

Section 4: Public and patient involvement (PPI), co-production and citizenship

4.1 Introduction

NHS Citizen was conceived as being a 'culture change' programme. The Five Year Forward View, when it was published, picked up on NHS Citizen, which became a way of exploring one of its key themes: the need to establish a new relationship between the NHS, and its patients and the communities it serves.

> "*We need to engage with communities and citizens in new ways, involving them directly in decisions about the future of health and care services. Programmes like NHS Citizen point the way…*" (NHS England Five Year Forward View, p. 13)

"*One of the great strengths of this country is that we have an NHS that - at its best - is 'of the people, by the people and for the people'.*

Yet sometimes the health service has been prone to operating a 'factory' model of care and repair, with limited engagement with the wider community, a short-sighted approach to partnerships, and underdeveloped advocacy and action on the broader influencers of health and wellbeing.

As a result we have not fully harnessed the renewable energy represented by patients and communities, or the potential positive health impacts of employers and national and local governments." NHS Five Year Forward View, 2014

On the one hand NHS Citizen was concerned with providing new ways for public, patients and indeed, NHS staff, to develop their role in engagement with NHS England. On the other hand, it was learning more about what would be required to enable key decision makers to engage in meaningful dialogue with public and patients (rather than just consultation), in ways that were facilitative of mutually agreed change, rather than simply confrontational.

There are a number of ideas that have been important in relation to this aspect of the programme. The first was that undertaking 'culture change' activity would form useful action research, e.g. that you can learn a great deal about a system by trying to change it and can use these learnings in a continued cycle of action. Another element was attempting to bring co-production into the development and delivery of NHS Citizen

activities. The concept of co-production, which has been defined as mobilising community resources to enhance the development and delivery of public services, has come into increasing prominence in recent documents (Osborne, Radnor & Strokosch, 2016[6]). This concept was central in the design of NHS Citizen, which was conceived as a process of 'co-design': designing the process of NHS citizen 'in public' through a series of engagement exercises. However, limited timescales and resources effected the achievement of co-production. Plans for greater involvement during the Build phase, for example citizens as moderators, or contributors in the production of evidence packs, had to be dropped because of this.

Opportunities for citizen involvement instead included the following activities: posting issues on the Gather site; participating in online discussions via the main website and social media; involvement in the Citizen's Jury and Assembly; and activities in the development sites. Learning activity (which this report summarises) has been one way in which citizen and staff views have been captured and fed into planning future activity. A working group, including two citizen representatives, has overseen this. Although it had been hoped that learning activities would be a form of action learning, through the training and involvement of citizen researchers and equal representation of citizens on the working group, there was no additional funding to support the costs of this.

Finally, there was the introduction of the concept of 'citizenship'. This builds on the idea that people could, for a short time at least, step out of their existing roles (a patient, carer, health professional, manager or commissioner) and meet together as individuals with a common interest in improving the NHS. Another, related, idea is that for real change to take place, there would need to be a 'social movement' of citizens spearheading this change, through their active involvement in the programme. How far these two ideas support, or potentially contradict, one another is subject to debate.

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[6] Osborne, S., Radnor, Z., Strokosch, K. (2016) "Co-production and the co-creation of value in public services: a suitable case for treatment?" Public Management Review, 18(5) 639-653.

4.2 Feedback on PPI, co-production and citizenship

"*NHS Citizen is another attempt to show that NHS England is prepared to listen to patients. However even if this happens, it has no influence at decision making by commissioners and providers*" Citizen

"*An obligation to respond is needed*" Citizen

"*Use an ask mode approach rather than a tell mode and facilitate the network*" Citizen

"*[NHS Citizen] cannot work locally…it needs to focus on the national…*" Citizen

"*Citizen engagement… if it doesn't link into [healthcare] practice it makes it theatre… you need to co-create from a group at a local level.*" Citizen.

"*Young people are the future – if you have policies for what needs to get done – young people are the way to do this, we are shaping the future*" Citizen

'*[As a citizen, you are] either outside throwing grenades in, or co-opted and so seen as like a staff member. You need to hold a line between these, you don't have to be aggressive to be heard, but you can be critical…*' Citizen

"*I think that the really big issue is selling NHS Citizen to the broader English public*" Citizen

"*There are so many initiatives for public involvement it is hard to keep track of them*" Citizen

"*I think NHS Citizen is a clever, interesting and thoughtful attempt to establish a dynamic and co-produced relationship with the public*" Citizen

"*A bigger idea was needed, and is still needed around elevating Involvement. Citizenship has this potential*" Citizen

Whilst some citizens spoke of positive ways in which they have been engaged with PPI activities, including within and outside of healthcare, many raised concerns that PPI activities, particularly within local healthcare settings, can be inadequate. 'Usual suspects' were seen as acting like 'co-opted staff supporting the system'. The issue of payment for involvement has additionally generated mixed views; with a few people saying this would help more people get involved. Many others though have said this can compromise a person's voice. One suggestion is that NHS Citizen could be a route through which good practice in involvement can be demonstrated, offering a challenge to local healthcare organisations to follow the lead.

Other learning has included:

- Most citizens, staff and board members engaged in learning activity have found NHS Citizen to be a worthwhile experience but it has a long way to go before embedding co-production as a model within NHS England's Involvement activities.
- Some people have questioned whether NHS England can truly achieve co-production, or even whether this is desirable, particularly at a time of considerable financial challenge for NHS England.
- Others have argued that bad decisions, based on assumptions of citizens' needs, are expensive and that co-production can enable a better spend of reduced funds.
- The incredibly quick timescales within which NHS England works can be a barrier to co-production. It has been argued that without clear corporate objectives, NHS Citizen is a peripheral programme to the business of NHS England. If, in its next phase, it can be embedded within the metrics by which each department is monitored, this may enable it to become part of everyday business.
- There is the potential for a better functioning website / online forum, as originally envisaged, which could provide a space for different PPI activities to connect. It would also help in identifying key gaps across the country that a national approach may help address.
- The model of involvement that NHS Citizen has enabled has inspired citizens, staff and Board members. However, concern has also been raised about the sustainability of NHS Citizen, particularly in moments of relative quiet, such as the post-Assembly period, and the lack of a clear plan for the future.
- NHS England may be able to provide leadership and/or direction to local PPI in CCGs and NHS trusts etc., to encourage involvement both at a local level and nationally, to support the joining up of conversations. This will be reliant on locally engaged citizens helping to drive this and for local PPI mechanisms to engage with this.
- Where engagement with seldom heard groups has been most evidently productive, an important preparatory step was taken by someone accompanying people to events. These 'supporters' took a leadership role, both by bringing people to the event, and helping build the 'seldom heard' individuals' capacity to get involved.
- Many people involved in NHS Citizen demonstrated understanding of the purpose of NHS Citizen to enable the public to influence NHS England decision-making whilst developing the quality and equality of conversations between NHS England and the public. Some however seemed to have misinterpreted it as an alternative mechanism to progress individual issues or a route for complaining about local issues.

- Some individuals within NHS England have experienced citizens as adversarial in their communications, and this has made these individuals less likely to engage with NHS Citizen as a result. Perceptions within and outside of NHS England are that they have not coped well with the challenges citizens have provided to NHS England.

- Some citizens have asked for greater clarity on types of PPI, alongside some form of advice about navigating PPI, depending on what people want to achieve. This may help people understand better the role of NHS Citizen in relation to local PPI.

- Overall people were supportive of the concept of NHS Citizen and cited this as the main opportunity for members of the public to engage directly with NHS England. This demonstrates the potential for NHS Citizen to take involvement activities to a new level.

- A number of people have registered interest in taking more of an active role in the future, particularly in relation to citizen researcher roles, and facilitation at events.

- Some have identified a gap in the knowledge and skills of citizens in being able to engage effectively and on a more equal footing with NHS England. Likewise, it has been suggested that NHS England staff lack the confidence and skills to engage with citizens. For instance, language used by professionals is often full of 'jargon' and lacking understanding of citizens' needs when providing information. NHS Citizen could potentially play a role in supporting this, through perhaps running a development programme to support citizen 'champions' or 'leaders' and a programme for staff 'champions' or 'leaders', who could then take this learning to larger numbers of citizens and staff, thereby generating the social movement that NHS Citizen could become.

- NHS Citizen made a commitment that all issues raised through the Gather process would be taken on within NHS England. However, this commitment was not fulfilled because it required all departments within NHS England to engage with this process. Having NHS Citizen embedded within the PPI team but not elsewhere in the organisation meant it could not guarantee that citizens became engaged with NHS England in all issues.

- There is a perception within NHS England that NHS Citizen has been used as a lobbying route by a minority of people. This perception prevents effective partnerships between staff and citizens. For effective co-production, both citizens and staff need to be confident about it, with better understanding of each other's perspectives, and therefore able to approach conversations with an open mind and a commitment to collaborative working.

Finally, staff and citizens have called for a deeper embedding of NHS Citizen principles and practice throughout NHS England departments and in the leadership of NHS England (e.g. citizens engaged as part of the Board and/or the setting up of a citizen

reference group for executive staff to work with). Strong interest in continuing conversations that have started through NHS Citizen has been shown. On the whole there was strong support amongst many staff and citizens that everyone has something to contribute towards healthcare improvements and that greater collaboration, both within NHS England and with citizens is highly desirable.

4.3 Conclusions about NHS Citizen, PPI, Citizenship and Co-production

Measuring degrees of public involvement cannot be taken as a literal and direct measure of the success of NHS Citizen. Engagement with seldom heard groups in particular is not something that can be measured in any simple linear fashion, because different groups, and different people within those groups, do not begin from the same starting point in terms of resources and capabilities. Levels of involvement can only be gauged in terms of where one started from. The question to ask then is not 'how successfully did a group engage', but whether or not we are adequately supporting the capacity for even the most invisible of groups to become more involved at a level that suits them. The follow up interviews conducted with members of seldom heard groups inform our learning on this point, which are summarised as follows:

For some seldom heard group members participating in the Assembly, the stigma created by discrimination and the denial of their existence is felt to be lifting slightly, and the symbolic importance of being present (i.e. of being visible as well as being heard) at an event of national scale and executive board level status is part of this. Participating in the Assembly made a positive difference to interviewees from seldom heard groups in terms of esteem and confidence to engage. At the same time the event's national scope broadened their existing networks, with useful organisational and informational contacts being taken up and continuing to be drawn upon. Engaging in face-to-face conversations and interactions was preferred by all interviewees to online discussion, because the directness of communication allowed for different backgrounds and perspectives to be explained and respectfully understood. For discussions to be a safe and welcoming space for groups whose experiences and understandings may differ from the mainstream, sound facilitation is required. Without this, members of seldom heard groups are at risk of being 'seldom heard' all over again – of being excluded even when they are physically present at the table.

Each group or individual came with support – a staff member, colleague or friend who did more than just advocating for the needs of a specific group, but who could be seen instead to be operating as a "boundary spanner"[7]. This person may be a member of a seldom heard group, or a trusted representative. Such boundary spanners can be of enormous potential value to NHS England, because they help facilitate an authentic

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[7] Williams, P. (2002) 'The Competent Boundary Spanner', *Public Administration* 80 (1): 103-124

recognition and understanding of different perspectives, enabling policy directives to shape themselves around complex realities, crafting policy solutions that are negotiated between different groups and domains.[8]

NHS Citizen can play an important role in facilitating the work of such boundary spanners and the different experiences they articulate, by raising their profile from a local to national scope. In the terms of NEF's co-production assessment tool[9], they are "assets" – to their representative communities, to the health service and to NHS England. As the case study of Future Pulse demonstrates, NHS Citizen can be the avenue citizens have been waiting for, to take their work to the next level. To move along this avenue required a vehicle, in this case the support of Bright Ideas Nottingham and the Carer's Federation, with the whole process being led or driven by the group's adept facilitator, a boundary spanner, who is at the same time bringing this boundary spanning skill and capacity to the young people being supported, so that in future they can do the same.

Co-production presents a challenge to staff who have clear work objectives, which do not include specific requirements to involve patients and the public, and which they are held responsible for achieving. It also presents a challenge to citizens who have to negotiate a balance between being supportive and collaborative whilst also retaining the ability to be critical and challenging. Both parties can feel vulnerable as a result; this restricts the ability to engage in open, honest and productive working relationships. NHS Citizen could play a role in supporting the development of co-production by using the programme itself as action research. This could explore what contributes to making co-production a success, working with staff and citizens to identify and showcase exemplars of co-production activity, and supporting innovative methods of developing this at a national level. NHS Citizen has a basis from which to develop and learning activity itself has continued to enable the programme to engage further with citizens through the working group and with staff and citizens through, for instance, interviews and focus groups.

Whilst this does not constitute co-production, it could quickly become this, overseeing and supporting the transition of NHS Citizen into its next iteration.   It is recommended that NHS England continues the harnessing of citizen input into future development of NHS Citizen and/or other NHS England involvement activities, building ever closer to a model of co-production. There is the potential for NHS Citizen to support both NHS

[8] Cooper, A. (2015) page 159 in 'Containing Tensions: Psychoanalysis and modern policymaking', *Juncture* 22 (2): 157-163

[9] Stephens, L., Slay, J., Penny, J. (n.d.) *Co-production Self-assessment Framework: A working reflection tool for young people and practitioners.* London: New Economics Foundation. Accessed via: http://api.ning.com/files/GDVu6mbJRocHRh6aAmlOFRduczdAhcyjZaZ06TIZz*AdVweucmrfkgqvqpvDYGciQiO-vMKrkW8qclFPPRZ94EKZuUvHbjsb/CoproductionreflectionYP.pdf

England and citizens to work meaningfully together instead of communicating in the form of consultation exercises. An NHS Citizen 'Brand' of citizenship, that signifies true meaningful involvement, could help enthuse citizens and staff to get engaged. If co-production can be realised, then perhaps a social movement will grow accordingly. Whilst investment is necessary to achieve this, the potential economic, social and wellbeing dividends[10] make this a potentially wise spend of limited resources, and an opportunity to build on the evidence base for co-production.

Finally, NHS Citizen could support a development programme for citizens and staff. This could focus on building greater confidence, knowledge and capacity for collaborative working, so that individually and collectively, meaningful involvement is increased, leadership is developed and ultimately health outcomes are improved.

Section 5: Culture change

> "…*change in the English NHS requires a three-cornered debate or conversation between English citizens who play three roles: (1) Patients (2) Voting Citizens, including politicians and (3) Health and Social Care Professionals, including managers and civil servants. If any one of these three groups feels put down, ignored, or marginalised, resistance, anger, or resentment occur, which then obstruct constructive change…*"
> Citizen

5.1 Introduction

An early working hypothesis for NHS Citizen was that it would fully achieve its potential if all the relevant parties were confident in being able to work with each other. Given that the NHS was built on traditional expert/patient relationships and that indications were that these tend to form the basis of working practices, we wanted to be able to work with the NHS England's senior leadership on exploring this. The NHS Citizen team was interested to explore what it would take to develop transformative open and collaborative working across the organisations. This became known as the culture change strand. It was the final, and perhaps most fundamental, theme, explored during the NHS Citizen learning activity, as it posed the greatest challenge to the status quo. The NHS Citizen team needed access to work within and across the organisation, particularly to embed its work within the workplans of those responsible for the culture change/organisational development interventions and processes.

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[10] Parsfield et al. (2015) *Community Capital: The value of connected communities*. London: RSA Action and Research Centre. Accessed via: https://www.thersa.org/discover/publications-and-articles/reports/community-capital-the-value-of-connected-communities/

NHScitizen

5.2 Activities undertaken in relation to culture change

Members of the NHS Citizen team worked within NHS England at a senior leadership level, alongside the more public-facing side of the programme. This included regular conversations with board members and executive team members, as well as with departmental staff. Two workshops were also held with the senior leadership. These explored the challenges of working openly with citizens and also presented the developing model of NHS Citizen. These workshops took place at a time when the organisation was establishing itself and adjusting to the arrival of a new CEO. The Leadership Forum (the top 120 leaders in NHS England) was engaged. However, it took some six months to gain another round of access to these leaders, due to a number of internal barriers. However, the Chairman and other key Non-Executive and Executive Directors were in regular contact with the team. The strategy for engaging with the organisation changed, and interventions were supported by a number of National Directors. NHS Citizen was a standing item on the OD Director's calls, and opportunities to develop programmes of work that embedded into performance plans were explored.

Conversations were held with key personnel at NHS Trust Development Agency (TDA) and Monitor as they thought about their collaboration and the possible role they may have with citizens and patients on the dynamics of change and co-production. This is an ongoing, open door opportunity for NHS Citizen, as well as the other Five Year Forward View signatories.

A key issue was one of timing. The loss of a number of key Executive Directors and their reports opened up new lines of enquiry and a chance to re-think from a wider perspective how NHS Citizen sits within the corporate framework of NHS England. The pioneer phase of the work was successfully concluded, the idea had been resourced, incubated and protected, and it seems that now NHS England is ready to look at spread and scale.

5.3 Feedback on culture change

"If anything is actually going to change for the long term, we need to encourage citizens to demand differently. Otherwise we will just go from initiative to initiative and not systematically change anything - this year's initiative, next year's pain" Board Member

"OD Directors are keen to support this way of working and how best to shift the culture and ways of working (behaviours) will be a very exciting programme of work" Executive Director

"We need a co-ordinated programme of embedding this metrics into the organisations systems and processes, 2-3 years time horizon" Executive Director

"NHS Citizen…could go further if seen as part of the macro level change in the culture of NHS England around dealing with people as co-producers – but we are a way off getting there." Board Member

Learning from NHS Citizen around culture change includes:

- Culture change within a large, complex and hierarchical structure such as NHS England requires time, resources and authorisation. Although NHS Citizen was working with Board members and executive directors, it was led by the Public Voice team and so struggled with gaining buy-in from across the organisation. Many within the organisation saw it as another initiative that would be replaced in the future.
- Traditional ways of engaging between professionals and non-professionals have been challenged through NHS Citizen. However, the programme is at very early stages in enabling NHS England and citizens to move away from a consultation mode and move nearer towards co-production. Many have said that this needs to continue.
- A programme such as NHS Citizen needs a commitment of at least five years. This would support staff and citizens to see this as a programme worth engaging with.
- Some citizens have suggested that a regular route of communication between board members and citizens, such as a standing agenda item and representation of NHS Citizen at board meetings would help fill gaps in feeding back and reporting on actions.
- Citizens engaged (and not yet engaged) with NHS Citizen hold a variety of skills and experience. Many will have been involved in culture change activities in other industries, as well as within the NHS (e.g. current and ex-members of staff). Ways of utilising this wealth of experience and skills could be useful for NHS England in addressing the culture change necessary to truly embed NHS Citizen and its principles for the future.
- Opportunities for citizens and staff to engage at all levels of NHS England (through working groups; with citizens acting as 'critical friends' providing advice and support) could help quicken the change needed. Such opportunities would need to be carefully curated, to ensure that appropriate skills and experience are maximised and both staff and citizens feel supported to be honest, and able to make mistakes without fear of becoming 'scapegoats'.

- Whilst culture change may seem to be focused more on the workings of NHS England, culture change needs the engagement of both NHS England and citizens. For instance, most staff and citizens have found some of the online conversations and posts to be destructive and unhelpful, and have said that such activity prevents others from getting involved. However, a few posters believe their activities are supportive of the programme and that it is the system's problem that more people do not engage. This perception relates to the perhaps entrenched position amongst some members of the public that they are recipients of services from medical professionals who are tasked with solving the individual's problems, without any responsibility or engagement in such problem-solving by the individual themselves. It also relates to the perhaps entrenched position amongst some healthcare professionals that they are the experts holding all of the knowledge, seeing the individual as ignorant and passive. In transactional analysis terms[11], this child (citizen) - adult (professional) relationship requires engagement of both parties to shift to an adult-adult relationship. Although this is a significant change that will take time, commitment on both sides, and resources to support this, ultimately a shift of this kind could be transformational leading to improved healthcare services and cost savings long-term.
- Suggestions for improvements include:
    - NHS England could encourage collaborative working between staff and citizens by actively supporting staff to celebrate good ideas that come from citizens. This would also make it easier for citizens to see how their ideas influence policy and practice.
    - There is perhaps a role for NHS Citizen in exploring innovative models that seek to shift relationships, empowering staff and patients, such as Health coaching, health as a social movement, and NHS Citizen as an action research programme. Links with the Behavioural insights team could support the dissemination and promotion of models that work well and are scalable, to NHS bodies and citizens across the country. This could significantly support the embedding of 'adult-adult' relationships between healthcare professionals and non-professionals, with a parity of esteem between the two.
    - Embedding of NHS Citizen into NHS England's future business planning and corporate objectives will make it easier for staff to engage.

5.4 Conclusions around culture change

Culture change is a huge challenge for any organisation and community, let alone an organisation such as NHS England that has approximately 5,000 staff (with 1.3 million

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[11] Berne, E (1964). *Games people play: The psychology of human relationships*. New York, USA: Penguin Books.

staff employed throughout the NHS), manages a budget of over £100 billion and serves over 50 million people. It is clear that a Build phase lasting only eight months cannot achieve change on such a scale as is required within such a large institution. Additionally, NHS Citizen spanned a time of governmental change. For an organisation that is a key campaigning interest for political parties and citizens, the time period seems significant and is likely to have had an impact on the ability of NHS England to make bold changes within the organisation at this time.

The NHS Citizen team have experienced, that being in the middle between NHS England and citizens has been a sometimes uncomfortable and politically charged place to be. This can provide useful insights into how it feels for NHS England, as they are in the middle between changing governments and the general public. The necessity to meet targets that demonstrate tough cost savings and continuous improvements in a rapid timescale can lead to a focus on reporting 'upwards', rather than open communication with those on the receiving end of such changes. Both NHS England and citizens seem keen for this to change. It will take a long-term commitment from both to enable this to happen as well as a greater understanding of each other's perspectives and awareness that this can be a long term, slow moving process.

Whilst wholesale, sustainable change may take time, identifying areas within NHS England that can act as 'test beds' for such change, may help demonstrate tangible impacts. It could be argued that it is in the interest of both NHS England and citizens to identify small-scale exemplars of co-production that could be translated into other areas, rather than attempting to instil it across the organisation at once. This would not only make it easier to support such work, it perhaps would enable NHS Citizen to work through a 'ripple effect' rather than being seen as a 'top-down' imposition. However, this needs to be done within the context of wider culture change activities, working across the infrastructure of NHS England and Public and Patient Involvement, to prevent exemplars being isolated within silos of action.

Section 6: The value of NHS Citizen

During the learning activity, both citizens and staff were asked to give their opinions on the value of NHS Citizen to NHS England and citizens, what it has been and what it could be.

6.1 Feedback on the value of NHS Citizen so far

"It makes giving your opinion more accessible" Citizen

"At the moment, the jury is out on NHS Citizen because too few people use it." Citizen

"[You] do stuff you've never done before" Citizen

"NHS Citizen is an excellent initiative. It shows the good intent and walking the talk…. People like myself have been asking and waiting for something like this for a long time" Citizen

Whilst follow-up activity since the Assembly is still pending and the programme is in its early stages, it is difficult to draw definitive conclusions about the usefulness and value of NHS Citizen to NHS England and citizens. For citizens, it seems, that feedback and responses within good time from NHS England on what has happened as a result of citizen input, is key to whether people consider it to be of value or not. However, the value of NHS Citizen so far to those who responded to the survey[12] can be shown through:

- Just under half of survey respondents (48%) rated their experience as somewhere between somewhat positive to excellent, around a quarter (24%) rated it from somewhat negative through to awful, while 28% rated their experience as neither good nor bad.
- 50.5% of survey respondents said that NHS Citizen addresses issues of importance to either some or a great extent. 36.5% said it did to a very limited extent or not at all, with 13% saying they didn't know.
- 19 survey respondents said that NHS Citizen has either not added anything of benefit or that being involved had decreased their faith in PPI activities
- However, 94 people agreed that NHS Citizen had achieved one or more of the following:
  - Increased my understanding of the work of NHS England (51)
  - Provided me with new contacts or networks (44)
  - Encouraged me to get more involved with the NHS nationally (42)
  - Increased my understanding of the NHS England Board (40)
  - Increased my understanding of how decisions are made within NHS England (35)
  - Encouraged me to get involved with the NHS locally (34)
  - Changed the way I look out for or welcome people whose voices aren't usually heard (34)
  - Changed the way in which I listen to others (28)

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[12] 204 respondents, with an average of 125 responses for each qualitative question (e.g. questions about people's experience of NHS Citizen).

- o Changed the way I express my views and ideas (22)
- o Increased my confidence in the NHS (21)
- Another value of NHS Citizen was seen in its attempt to involve the wider public in programme activities, and not just those currently accessing NHS services.
- A key value for some citizens was the opportunity to meet NHS England Board members and engage in a direct dialogue, sharing their experiences of the issues being discussed. Likewise Board members and staff appreciated dialogue with people they wouldn't otherwise have met.
- Another key value for some citizens was the 'symbolic' nature of NHS Citizen – a few citizens have reported that they have spoken about their experience of NHS Citizen within local healthcare settings and it has been helpful in demonstrating what can be possible.

6.2 Feedback on the future value of NHS Citizen

"[NHS Citizen] *is the most important thing in NHS today which can ensure the transformation of NHS.*" Citizen

"*More rapid response to the issues raised could reduce the overall expense of service and lead to shorter time to treatment.*" Citizen

"*Can NHS Citizen help with…how to transform citizen participation into legitimate data?... could there be a discussion about how to have an effect on specific areas in relation to all the evidence that is out there?*" NHS England staff member

"Help the NHS do more research..." Citizen

 "Listen and take account, as we may have the answers. We can recommend tweaks, which could save money." Citizen

"I had hoped for its advocacy potential… Gypsy life is associated with dirt and disease, that's the dominant ethos. Drugs, alcohol and violence all add to the problem. So resilience becomes important – to be proud of Gypsy life and to build that pride – it isn't there yet but there's potential to grow this…" Citizen.

"Young people can be a platform to communicate… we can get information and discuss it and create a forum… If you give us something to put our minds to, we will use it, and this is valuable to you" Citizen.

Whilst many engaged in learning activity recognised that perhaps NHS Citizen had not yet achieved all that was possible, feedback on the future potential value of the programme included it enabling:

- Citizens to be utilised as a source of intelligence, evidence and public opinion;
- Citizens to support and provide ideas for solutions to NHS England;
- NHS England to listen to what citizens (including patients) are saying;
- Citizens to contribute to the work of NHS England;
- a strong, public, two-way connection between citizens and NHS England;
- a transparent route for citizens' voices to reach the right place in the NHS England structure, in a useful and effective way.

The involvement of NHS England staff in NHS Citizen was seen by some as key to its future value whilst others saw NHS Citizen as instrumental in keeping patient and public voices high on national and local agendas, acting as a symbol of effective involvement and ultimately co-production. If NHS Citizen can maintain involvement and keep conversations going, then citizens and staff will be better able to identify its value.

109 respondents to the survey indicated an interest in future involvement with NHS Citizen, whether attending events or getting more directly involved through working groups (61 people), becoming a citizen researcher (41 people) and/or facilitating discussions at NHS Citizen events (37).

Some board members, staff and citizens expressed excitement about the potential of NHS Citizen to enable real change in the relationship between NHS England and citizens, which could lead to significant improvements in healthcare and cost savings. Some others were sceptical about whether this could be really achieved. However, whilst four out of 204 people have said NHS Citizen should be scrapped, many felt it was broadly on the right track and should continue. Some felt more strongly, that to discontinue NHS Citizen at this point would damage the goodwill of people to commit to future involvement.

6.3 Conclusions about the value of NHS Citizen

Assessing the value of NHS Citizen to the work of NHS England and citizens depends on the way that value is defined and measured. Value measurement was not a specific output required as part of NHS Citizen and nor should it be, as this could result in reducing the programme to a set of metrics, unhelpful to action research and deliberative conversations. However, learning activity revealed a widespread recognition of the potential for NHS Citizen to add value, helping mobilise both professionals and non-professionals to collaborate in a non-binary way, using all the assets available within communities and individuals. All involved require support and facilitation to make potentially difficult conversations and collaborations informative and

productive. These can then help improve healthcare outcomes, using available resources more effectively, in a way that better meets communities' needs and generates greater understanding of and collaborative responsibility for decision making.

A key value of NHS Citizen, its powerful potential, is that by generating a diverse range of citizen input into policy discussion, it enables NHS England to hold the circumstances of different groups in society in mind. As one citizen put it, *"If I were a member of the Board I would make sure to have the input of young people on our circumstances and our preferences (for example on sexuality, sexual health and mental health), and to refer back to them asking, 'would this service design work for you? Is it comfortable for you? Is it safe for you?' These sorts of conversations avoid mistakes, save money and most of all save lives".* This citizen refers to one community, that of young people, and yet we are never just in one community. As another citizen observed, *"communities are always in flux and transition and we move into and out of different ones all the time, like a waltz spinning around on a great big filled dance floor".* NHS Citizen has the potential to enable NHS England to continually flex and adjust to this complexity, becoming more responsive and thus more effective and efficient as a result.

Although a minority of voices disputed the potential for NHS Citizen to deliver benefits, many expressed the belief that there is a place for NHS Citizen within NHS England's infrastructure, and that it provides one of the only ways for citizens to get meaningfully involved with healthcare at a national level. There was a clear message from diverse groups that NHS Citizen needs to continue, with improvements embedded along the way. Whilst it will be difficult to evidence the total value of NHS Citizen in the short-term, continuing conversations and agreeing milestones towards its demonstration, will be helpful in building a shared language for articulating value. This requires a long-term commitment by NHS England to the future of NHS Citizen, which empowers citizens, staff and Board members to work together to embed the programme principles within delivery, demonstrating to citizens that involvement can have instrumental impact.

Section 7: What's next for NHS Citizen?

NHS Citizen is caught in multiple tensions between:

- the desire for co-production and the need to save money;
- idealism about and the reality of the pace of change;
- the different ideas of what is and who can be an "NHS Citizen";
- an intermittent political emphasis upon localism and significant government interest in the devolution of some aspects of healthcare and its governance; and

- the different agendas and aims of everyone involved in the NHS, from patients through to politicians.

Whilst co-production is identified as a way of mobilising additional resources from the community, NHS Citizen learning is that mobilising these resources can be an expensive activity. It takes staff and citizen time, particularly in the set up phases, with tangible benefits difficult to demonstrate in the short-term.

NHS organisations across England are facing considerable financial challenges, with some in crisis, needing to save money in the short-term, creating a context that appears less conducive to co-production. This perspective is echoed by many citizens engaged in learning activity who have voiced their concern at the reduction of meaningful opportunities for involvement and a decreasing space for the voice of citizens within local healthcare structures such as CCGs and Vanguards. However, constraints and increasing pressure on public funding of the NHS, means that innovative and/or tried and trusted solutions that support delivery of healthcare in a more sustainable way, and that costs less in the long-term, is essential. There is growing evidence for the benefits of co-production to the delivery of more effective services that produce improved health outcomes and financial efficiencies. This indicates that investing in the mobilisation of citizen resources through programmes such as NHS Citizen is critical and is something that NHS England cannot afford not to do. It could be argued that not investing in these resources now could prove counter-productive in the long-term.

Since NHS Citizen began, the relationship between NHS England and the programme has gone through changes. Not only contextual changes, as identified earlier, but also changes in NHS England staffing and Board membership involved in the programme. These have brought different perspectives to the concept of co-production, citizenship and NHS Citizen. Additionally, as activity has been relatively quiet since the Assembly 2015, NHS England has been able to reflect organisationally on NHS Citizen. Learning activity and the input of both staff and citizens to this report, has aimed to support future planning.

However, the recent period has created uncertainty about the future funding of NHS Citizen, coinciding with changes from a learning event to learning activity, no information about future NHS Citizen activities since the Assembly, and knowledge of ongoing funding pressures for the NHS. NHS England and a reduced NHS Citizen team have continued to work together on the future of NHS Citizen, but this has not been in the public domain. Therefore, citizens who have been waiting for action following the assembly and announcements of plans for the next Citizens' Assembly, have been subject to what seem like sudden, unexplained changes to the programme's direction.

This lack of certainty about the programme's continuity has been evident in opinions expressed by citizens during learning activity and in discussions on the Gather website.

Clearly there is cynicism about whether NHS Citizen will deliver against the variety of expectations invested in it. Having periods of time when communication and action is non-existent enables these cynical perspectives to grow and this can create a vacuum for productive conversations. NHS England is committed to the future of NHS Citizen, although this is likely to be within the reality of fewer resources for delivery and in the context of NHS England staff having increased pressure on their time because of resource constraints. However, relationships have been formed and groundwork achieved that can be built on. NHS Citizen is still in relatively early stages for such an ambitious, culture change programme and there is still a long way to go. A foundation has been built for achievement of the programme's aims.

Although it is likely that delivery of NHS Citizen is likely to change, NHS England's commitment to navigating this highly complex area of work in partnership with citizens is to be celebrated. The appetite expressed by citizens, small VCS groups, larger organisations and NHS England staff for progressing NHS Citizen to a deeper level of involvement is equally so. Most people have demonstrated through their contributions to learning activity that they could be committed to helping make NHS Citizen work. If more people knew about and could get involved in NHS Citizen, they would value the opportunity it provides and would want to understand and support the work of NHS England.

The potential for NHS Citizen to be involved in the development and delivery of local Sustainability and Transformation Plans offers a way for the work of NHS Citizen to positively influence the local health landscape. There is space for further conversations with organisations such as Healthwatch England about greater collaboration in supporting citizens to effectively input into national and local issues. Likewise, there is recognition that NHS Citizen needs to be able to work across and support joint working between NHS England departments, as well as relationships between NHS England and citizens, to continue conversations that move beyond binary approaches.

Whichever way NHS England choose to procure the next phase of NHS Citizen, the value of engaging external organisations to deliver the programme outweigh the challenges of being on the boundaries of the system. Staff within NHS England have to work within departmental hierarchies which can act as a barrier to influencing change. Being outside of the organisational structure means that NHS Citizen team members can connect the different departments through delivering its activities. Involving citizens, particularly those less involved in Public and Patient Involvement activities, is also arguably easier for external organisations, as they are one step removed from NHS England, but with access into the organisation. At the same time, it will be important for NHS Citizen principles and practices to be embedded within NHS England, supporting delivery of NHS England's Patient and Public Participation Policy. NHS Citizen can help support the development of NHS Citizen 'leaders', 'champions' and/or 'connectors' to enable embedding to take place. This will require engagement from all departments

and management levels, and NHS Citizen will need freedom to work beyond the Public Voice team.

Section 8: Key recommendations arising from Learning Activity

Following learning activity, and having taken into account the diversity of comments and suggestions made by citizens, partners, NHS England staff and Board members, and the experience of the NHS Citizen team, the following form the key recommendations for future development of NHS Citizen and deeper involvement with citizens across NHS England:

1. Continue development of NHS Citizen, with ongoing research and learning, to enable ongoing improvements as the programme progresses.

2. Focus on building and supporting the mobilisation of assets within citizens, NHS England staff and Board members through programmes of development. These can support teams of 'champions' or 'leaders' for co-production and 'connectors' between local and national issues, relevant communities of interest and NHS England and citizens.

3. Develop closer links with NHS Youth Forum to engage with the wider younger population, running a parallel programme for 'young champions' or 'connectors', utilising existing online and other platforms, such as radio, that engage well with young people.

4. Find small-scale, but longer-term opportunities, with freedom to experiment, to model co-production in areas of service improvement, both live projects within NHS England, as well as identification and dissemination of co-production that is producing results at a more local level.

5. Use NHS Citizen to engage citizens in co-production of the 2017-18 business plan. Activity could enable citizens, NHS England staff and Board members to work together and develop a model of co-creation that could be developed ready for citizens' involvement in setting the next Five Year Forward View.

6. Build on and connect with research generated through programmes such as Connected Communities, Realising the Value, localnets.org and Health as a Social Movement.

7. Develop a citizen researcher programme, which can capture data from involvement activities that work well in different contexts. This could lead to involvement approaches and identification of local healthcare issues that are relevant to the national arena and within the remit of NHS England, that are potentially scalable.

8. Develop a new online presence, and/or develop the use of existing social media, for NHS Citizen, that is easier to use and can support the development of a social movement which engages both staff and citizens to collaborate in addressing issues and designing better healthcare and involvement solutions. Online activity should be focused on supporting 'live' activity, rather than replacing it.

9. Connect with and potentially support NHS England activities such as the CCG Patient & Public Involvement Lay Members Network, the Collaborative Commissioning Programme Oversight Group and local Sustainability and Transformation Plans. Additionally, links can be made with other programmes such as the King's Fund's Leading collaboratively with patients and communities programme, and good practice found elsewhere, such as the 4pi National Involvement Standards, developed by the National Survivor User Network and National Involvement Partnership.

10. Continue to build involvement of and co-production with specific groups who are heard least in Patient and Public Involvement activities, such as those from culturally marginalised groups and those with particular expertise through lived experience. Alongside efforts to widen inclusivity and improve the accessibility of NHS Citizen to all, as NHS Citizen builds, it can be more ambitious in reaching out to the wider population as a whole. This could be done, for example, by attending and possibly running weekend and family events, that could be produced with or led by citizens, which can allow for and encourage involvement of those who aren't able to or don't otherwise wish to take a more co-productive role in NHS Citizen. As citizens have suggested, attending health events or fairs in different cities with posters and leaflets, as well as offering some kind of award

or incentive, can engage more people and in particular young people who might find a website discussing majority opinions alienating, less than welcoming or simply a bit boring. Greater presence at the places or events where a wide range of people gather is one way that could help build a stronger groundswell of general support for the more in-depth co-produced activities that are likely to involve smaller numbers of people.

Appendix One: Glossary of terms

Co-Design: The process of designing a service or product with people that will use or deliver it. Source: http://www.designcouncil.org.uk/

Co-Production: The design and delivery of services by citizens and professionals in equal partnership. Source: Co-production Practitioners Network (NESTA)

Engagement: The process of asking patients and the public (including specific groups) about how services are planned and provided with a view to informing decisions.

Involvement: A term that encompasses a range of ways in which citizens may input into, participate in and influence policy-making and practice

CCG: Clinical Commissioning Groups are groups of General Practices that work together to plan and design local health services in England. They do this by 'commissioning' or buying health and care services.

Healthwatch: Healthwatch England and local Healthwatches are 'consumer champions in health and social care' with a set of statutory powers that support consumer voices to be heard. Source: http://www.healthwatch.co.uk/about-us

Appendix Two: Survey

Welcome to the NHS Citizen Feedback survey

We would like to learn more about your experience of being involved with NHS Citizen, and how we can make improvements.

This short survey is one of a number of ways in which you can contribute to our learning process. Other ways include completing a feedback form (which you can access here), commenting by email to hello@nhscitizen.org.uk, through telephone interviews (if you want to do this then please provide your contact details at the end of this survey), and contributing to discussions on the Gather website.

The Survey deadline is midnight, **Sunday 7 February 2016.** Please note that you can leave any of the questions blank.

Thank you for telling us what you think. Your views will contribute to the shaping of the future of NHS Citizen.

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1. How did you first hear about NHS citizen? (please tick next to your answer)

__ From a family member, friend or colleague
__ Through a group or organisation I'm involved in
__ Online
__ I was contacted by someone working on NHS Citizen
__ Other (please explain)
……………………………………………………………………………………………..

2. If you heard about NHS Citizen through a group or organisation you are involved in, please tell us the name of this organisation:

……………………………………………………………………………………………..

3. Have you participated in discussions on the NHS Citizen Gather website?

__ I have participated in discussions on the Gather website
__ I have not participated in discussions, but I have signed up for an account on the Gather website
__ I have not signed up for an account on the Gather website, but I have looked at the site
__ I have not looked at the Gather website

- If you have looked at Gather, signed up for an account and/or participated in discussions, please go to **Question 4.**

- If you have not looked at the Gather website, please go straight to **Question 11.**

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NHS Citizen Gather website

4. How many individual posts have you added to the Gather website? A rough estimate will do (multiple posts on the same issue, or discussion thread, should be counted individually)

___ 1 or 2

___ 3 - 5

___ 6 - 10
___ 11 or more

5. In how many different 'issue' (i.e. discussion) threads have you posted?

___ 1 or 2

___ 3 - 5

___ 6 - 10

___ 11 or more

6. How do you usually access the website? (i.e. on what sort of device - such as a mobile phone or personal computer; and in what location - such as at home or on the move)

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7. Are there specific reasons why you have not participated more than you have in the discussions on the Gather site?

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8. Is there anything that prevents you from accessing the site? (This might include the site being incompatible with technology you are using such as particular browser or assistive technology; or perhaps problems with understanding the layout)

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9. What are the best and worst aspects of the Gather website?

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10. Do you have any worries about sharing your opinions and profile in a public online environment? If so, what are these?

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- Please now go to **Question 13**

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11.   Are there any specific reasons that you have not participated in discussions on the Gather website? What are these?

……………………………………………………………………………………………..

……………………………………………………………………………………………..

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12.   Do you have any particular worries about sharing your opinions and profile in a public online environment? If so, what are these?

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Your feedback
13.   Which of these other parts of NHS Citizen have you engaged with? Please tick all that apply.

__ Receiving the NHS Citizen email newsletter
__ Following NHS Citizen on Twitter or Facebook
__ Taking part in an NHS Citizen conversation on Twitter
__ Visiting the NHS Citizen
__ Attending the Citizen's Jury meeting on 27-28th October
__ Attending the Citizen's Assembly meeting on 25th November 2015
__ Attending other national or regional events as part of NHS Citizen- such as national design events during 2014 in London, Manchester, Leeds, and Birmingham
__ Watching NHS Citizen events via a webcast
__ Participating in NHS Citizen work at a local level (e.g. with Clinical Commissioning Groups (CCGs) or NHS Trust)
__ Other (please explain)

……………………………………………………………………………………………..

14.   To what extent is NHS Citizen addressing views, ideas or issues that are important to you? (Please choose one response)

| To a great | To some | To a very | Not at all | I don't know |

extent   extent   limited extent

__   __   __   __   __

15.   Do you have any comments about the accessibility of NHS Citizen activities? Accessibility includes things like how easy it is to register and attend events, to get involved in online conversations, and to get information from our communications.

…………………………………………………………………………………………..

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16.   Please tick any of the following statements that you agree with. Being involved in NHS Citizen has...

__ Increased my understanding of the work of NHS England
__ Increased my understanding of the NHS England Board
__ Increased my understanding of how decisions are made within NHS England
__ Provided me with new contacts or networks
__ Changed the way in which I listen to the views and ideas of others (for example other patients, staff, managers, NHS England Board)
__ Changed the way I express my views and ideas
__ Changed the way in which I look out for or welcome people whose voices aren't usually heard
__ Encouraged me to get more involved with the NHS nationally
__ Encouraged me to get more involved with the NHS locally
__ Increased my confidence in the NHS
__ Other (please explain)

…………………………………………………………………………………………..

…………………………………………………………………………………………..

…………………………………………………………………………………………..

17.   Overall, how would you rate your experience of NHS Citizen? (please tick one)

Excellent   Good   Somewhat   Neither   Somewhat   Bad   Awful

Positive   good nor   Negative
bad

—   —   —   —   —   —   —

18.   **This is the most important question:** Do you have any comments about how you have found NHS Citizen, and suggestions for how it could be improved?

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Moving forward

19. Please tick any of these statements that you agree with. In the future NHS Citizen will...

__ Enable NHS England to listen to what citizens (including patients) are saying

__ Create a strong, public, two-way connection between citizens and NHS England

__ Give citizens a transparent route for their voice to reach the right place in the NHS England structure, in a useful and effective way

__ Give an open and robust accountability mechanism for the decisions made by NHS England

__ Give citizens better opportunities to contribute to the work of NHS England

__ Give the Board of NHS England a new source of evidence and public opinion

20. Would you like to be involved in the future of NHS Citizen in any of the following ways? Please tick all that interest you.

__ Identifying issues and discussing these via the NHS citizen website

__ Facilitating online discussions on the NHS citizen website

__ Attending local NHS citizen events

__ Organising or facilitating local NHS citizen events

__ Attending national NHS citizen events

__ Facilitating discussions at national NHS Citizen events

__ Being involved in working groups to develop different aspects of NHS Citizen

__ Becoming a 'Citizen Researcher' (for example, by identifying and researching topics or issues and putting information about these on the NHS Citizen website, or in other published formats)

__ Becoming a 'Citizen Reporter' (for example, by communicating about NHS citizen activities via social media and other channels)

__ Establishing connections (creating a network) via NHS Citizen, with others with similar concerns and interests to you

Diversity monitoring

The following information will help us understand how NHS citizen is working for different sections of the community. You do not need to complete this section of the survey, but if you do, your responses will help us to understand who we are engaging with, and help us to ensure we hear from lots of different people.

21. How old are you?

__ Under 20   __ 40-49   __ 70+

__ 20-29   __ 50-59

__ 30-39   __ 60-69

22. I identify my gender as:

__ Male

__ Female

__ Trans

__ Other

………………………………………………………………………………………………..

23. Which of the following best describe your ethnicity?

__ White- British   __ Asian/ Asian British- Indian

__ White- Irish   __ Asian/ Asian British- Pakistani

__ White- Gypsy or Irish Traveller   __ Asian/ Asian British- Bangladeshi

__ Any other white background   __ Asian/ Asian British- Chinese

__ Mixed/Multiple- White and   __ Any other Asian background
Black Caribbean

__ Mixed/Multiple- White and   __ Black/African/Caribbean/Black
Black African   British- African

__ Mixed/Multiple- White and   __ Black/African/Caribbean/Black
Asian   British- Caribbean

__ Any other Mixed/Multiple   __ Any other

ethnic background   Black/African/Caribbean/Black British

__ Arab   __ Any other ethnic group

24.   What is the highest level of education that you completed?

__ Primary school

__ Secondary school

__ Trade or business certificate

__ Apprenticeship

__ Higher or further education diploma or degree

25.   Which one of the following best describes your current employment situation?

__ Full time paid work

__ Part time paid work

__ Casual time paid work

__ Home duties (not looking for paid outside employment)

__ Unemployed

__ Retired

__ Permanently unable to work

__ Other (please specify)

…………………………………………………………………………………………..

26.   Do you currently work in the health sector?

__ As an employee

__ As a volunteer

__ In another capacity

27.   Have you taken part in or organised NHS patient or public involvement activities (apart from NHS citizen events)?

__ Frequently

__ Occasionally

__ Rarely

__ Never

28.   Do you have a long term condition or disability?

__ Yes

__ No

29.   How involved do you feel in NHS decision-making?

__ Very involved

__ Quite involved

__ A little involved

__ Not at all

Further information

It may be useful for us to get in touch with people who raise interesting suggestions to talk through improvements. If you would be happy for us to do this, and do not mind giving this feedback without anonymity then please provide an email address or contact telephone number. We will only use this information for this purpose.

30.   I would be happy to talk further about my views on NHS Citizen and my phone number or email address is:

……………………………………………………………………………………………..

……………………………………………………………………………………………..

Thank you very much for filling in our survey. Please email this survey back to hello@nhscitizen.org.uk or post to NHS Citizen Survey, NHS Citizen Team, Tavistock Institute, 30 Tabernacle Street, London, EC2 A4UE.

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Appendix Three: Quick Feedback form

NHS Citizen is a national programme to involve the public in NHS England decision making. More information about NHS Citizen can be found on the website.

This feedback form is for anyone who has been involved in NHS Citizen. Please feel free to share this form. There is also a more detailed online survey, which you may want to complete as well. The feedback deadline is **7 February 2016**.

How did you get involved in NHS Citizen? For example, through the online Gather forum, by coming to the Citizens Assembly or being part of another meeting.

……………………………………………………………………………………………………

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……………………………………………………………………………………………………

What was good about being involved in NHS Citizen?

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……………………………………………………………………………………………………

What could be improved about NHS Citizen?

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……………………………………………………………………………………………………

Do you have any other comments about NHS Citizen?

……………………………………………………………………………………………………

……………………………………………………………………………………………………

Please return your completed form by email to hello@nhscitizen.org with the title 'Feedback' or post it to NHS Citizen Team, Tavistock Institute, 30 Tabernacle Street, London, EC2 A4UE.

Please make sure we receive your form by 7th February.
                                    Thank you for your help!

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Appendix Four: Topic guide

Prior to interview, you will need to check you have the following information:

1. How the person has registered an interest in a telephone interview – was it through the survey, a partner, direct email etc.
2. Any qualitative feedback the person has already given through, for instance, the survey, so that you can ask follow up questions on their feedback

Starting off the interview:

1. Introduce yourself and your role as part of NHS Citizen and inform the person that their views will help contribute to the learning from NHS Citizen so far. A report will be written which will be shared with NHS England, and publically (due in April 2016).
2. Check that the person is happy to continue and inform them that their views will not be directly attributed to them, feedback is captured anonymously but may be used in the form of quotes within the report.
3. Ask the person how they first got involved in NHS Citizen and when they were last involved in NHS Citizen, ask them to talk generally about their experience of NHS Citizen e.g. was it good, bad, indifferent and why? (This is an ice breaker to get the person talking)
4. Agree the length of time for the interview with the person in advance (try not to take longer than an hour)

Questions for the interview
Note: Please use some or all of the below topics for interviews with the citizen, as appropriate. Feel free to adapt or add questions, as needed, and depending on what the person may say, do ask follow up questions that may come to mind. However, please try and keep conversation focused on the below topic areas and in particular in relation to the person's experience of NHS Citizen.

1. **Mechanics of NHS Citizen – ask the following questions, in relation to the person's involvement in NHS Citizen**

- What aspect of NHS citizen were you mainly involved in.
- Which elements of this do you feel worked particularly well or were particularly useful?
- Are there elements you would like to see changed going forward?
- What needs to be put in place for future improvement?

2. **How NHS Citizen fits into the wider system of citizen participation activities within the health sector, mainly those at a local level**

- What is your experience of other citizen participation activities (health service or otherwise) (you will be able to get a sense of this from their survey response)
- How do you see NHS citizen as being either similar to, or different from these? (eg what advantages does NHS citizen provide over other activities? Are there disadvantages to the approach it takes)
- How do you see NHS citizen as being able to contribute (support, complement or add value) to other citizen participation activities?
- Would anything need to change in order to maximise this contribution?

3. **Understanding the value of NHS Citizen to both NHS England and citizens so far, and its potential future value**
    - What do you see as being the main way in which NHS Citizen has been able to help the work and aims of NHS England so far?
        o Can you give examples of this from your experience?
    - What have you seen as being the as the main value or contribution that NHS Citizen can make to the 'citizen's' who take part in its activities?
        o Can you give examples of this?
    - Is there further potential for developing this further, and if so, does anything need to change going forward to enhance this value?

4. **Citizenship and coproduction – the challenges and opportunities – and what it takes to produce different kinds of outcomes**
    - What do you think we have learned so far about the concept of NHS 'citizenship'?
    - What have been the main challenges – and what have we learned or would be required, to address these?
    - How far do you feel the programme has gone toward the concept of 'co-production'?
    - What have been the main challenges here? What have we learned – or would be required – to address these?

5. **What we have learned about culture change and building relationships for change?**
    - What have you learned from this, about the key factors that contribute toward successful relationships (i.e. that contribute to the success of NHS citizen?) – can you give examples of your experience of work with professionals? Can you give examples of your experience in relation to other citizens? E.g. what have you experienced – good and/or bad – from those within the system and from citizens that have either helped or hindered positive working relationships with each other?

- What are the key areas where you feel a major culture change needs to take place in order for something like NHS citizen to be successful? What would help contribute to this culture change?

Feedback given already
If the person hasn't already talked through their feedback previously, ask any follow up questions there may be to get a greater understanding of their feedback, clarify any points or ask recommendations as a result

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Appendix Five: Interview, focus group and case study details

Interviews and focus group activity held as part of Learning Activity

Telephone interviews took place with:

- 7 citizens (12 people were contacted, 6 did not respond): Randomly selected from survey respondents
- 9 citizens: Assembly attendees recruited as part of outreach activities, interviewed for development of case studies
- 4 NHS England Board members
- 4 Executive Directors
- 3 Advisers
- 5 NHS England staff members

Focus group activity took place with:

- 17 citizens (3 were unable to attend on the day): 55 citizens were invited including survey respondents, Citizen Jury members, Issue presenters at the Citizens' Jury and Citizens' Assembly and other assembly attendees.
- Approximately 15 members of the NHS Youth Forum (at the Forum's residential weekend)
- 6 NHS Citizen team members

Additionally meetings were held with:

- 1 Healthwatch representative
- 1 NHS England Staff manager, involved in planning the future of NHS Citizen
- 1 of the original leads in the NHS Citizen team (now moved to another job)

Five Learning Activity working group meetings took place between October 2015 and March 2016, with an average attendance of eight people. This group included:

- Representatives from each of the NHS Citizen partner organisations
- Two citizen representatives