Involvement Launch Evaluation Report

This evaluation report briefly outlines a summary of the feedback received and main points raised during the group discussions and workshops.

Launch

The **Involvement Launch** took place on Tuesday 10 June 2014, at Curve, Leicester, LE1 1SB, from 10am to 1pm and was attended by over 110 delegates. Facilitator for the event was Stephen Williams, while Stephanie Belgeonne, Midlands and Lancashire CSU senior communications and engagement partner welcomed delegates, giving a brief overview of how Involvement is growing and the importance of effectively engaging with colleagues and patients.

Mary Simpson, NHS England Midlands and East head of patient and public voice, also thanked everyone for attending and reiterated the importance of effective engagement and learning from each other to avoid duplication.

Keynote speaker Centre for Patient Leadership co-director David Gilbert talked about his 25 years' experience in engagement and his work with the NHS to transform the engagement process through the Engagement Cycle. David spoke about how engagement practices are evolving through current trends, such as social media and technology, as well as changing attitudes, and added that various approaches should be adopted at a strategic level to benefit from engagement. He also talked about the importance of engaging with local communities and the public to gather true representative views that effectively influence the commissioning process.

A question and answer session with panel members Stephanie Belgeonne, Mary Simpson, David Gilbert and Midlands and Lancashire CSU senior communications and engagement manager Christine De Souza, answered valuable questions and comments from the audience. *(See Appendix 1)*

Christine De Souza and Midlands and Lancashire CSU communications and engagement officer Amy Egan demonstrated the functionality and usability of the new Involvement website (www.nhsinvolvement.co.uk).

Delegates attended two of the below 25-minute workshops:

Workshop	Theme	Lead
Twitter Tutorial	Social Media	Michael Seres, NHS Social Media
Partnership working to create change	Partnership Working	Jayne Quantrill, One East Midlands
Consultations: what you need to know	Consultations	Rebecca Addis, Consultation Institute

Workshop	Theme	Lead
Supporting Patient Leaders	Patient Engagement	Mohammed Mir, Patient Leader

For specific feedback and comments from these workshops see Appendix 2.

Stephanie Belgeonne and Mary Simpson drew the event to a close, summarising key themes and actions which emerged throughout:

- 'You said, we did' is no longer applicable, it's about everyone, together, and rather than defining people in categories as patients and professionals, seeing everyone as 'people'
- Attendees as an example of Involvement in practice – all sectors represented and participating
- Thank you to all those who attended, as well as speakers for giving so much thought-provoking content to take home
- Calling upon everyone to register and contribute to make Involvement really successful

Delegate feedback

Below is a summary of completed feedback forms from over 50 per cent of delegates who attended. This feedback will be taken into consideration for future events.

Please rate the following aspects of the venue (1 = poor; 5 = excellent)
Average score out of 5:

Please rate the following aspects of the day (1 = poor; 5 = excellent)
Average scores out of 5:

For further tables see Appendix 3.

Key themes from comments received from delegates:

- Separate breakout rooms for workshops
- Extended break to refresh
- Activities to complete within workshops
- David Gilbert's speech was received very well
- Workshop materials and tasks should reflect the advertised title
- Generally the venue location was adequate, however layout was not very practical
- Overall the event was organised very well

Appendices

1. Questions and comments to the panel
2. Workshop feedback and comments
3. Delegate views (filled out on luggage tags) on: How can we help you grow Involvement?

Appendix 1

Questions and comments to the panel

Panel: Stephanie Belgeonne, Mary Simpson, David Gilbert and Christine De Souza

Comment:	**There is a split between patients and professionals, but engagement is about 'people'.**
Answer	We call upon patients patient leaders due to the insight they bring to the table. There's something very different about working with people who have had change and a need for the quality relationships in healthcare. We are all patients, but there's something unique about people who use services everyday – they have a unique skillset. Involvement will look to de-split the language, calling people 'colleagues', or simply 'people'.
Response:	David Gilbert and Stephanie Belgeonne

Comment:	**Engagement is not about 'us' as NHS staff or 'you' as a as patients and public, it's about 'them'. Engagement is about the people on the edge who don't or aren't asked to get involved.**
Answer	Involving 'everyone' is the core ambition for Involvement and we should all be using the tools available to ensure this happens.
Response:	Stephanie Belgeonne

Comment:	**Reports, such as the Francis Report, do not reflect the anger that exists around failures. Sometimes we need more than this and the whistle to blow harder.**
Answer	The Francis Report highlighted that people did harness anger through the outcomes and it emphasised that anger is OK; however, it must be harnessed to create solutions.
Response:	David Gilbert

Question:	**How do you get through your experience as a patient?**
Answer	You have to manage your energy to turn it into something useful and we envisage that NHS Involvement will be a part of this solution. By using personal experiences, it is an opportunity to influence and change the system. It is also very important to always assuming a positive intent to engagement and experiences.
Response:	David Gilbert and Stephanie Belgeonne

Question:	**Why is there this categorisation in Involvement between patients and public and professionals?**
Answer	At present, we are working with you as professionals to get elements right and help to share best practice. As the project develops, the involvement website will become open to make it as accessible as possible to all.
Response:	Stephanie Belgeonne

Question:	**Where older people are concerned, there's the impression that everything is online, but not everyone has this access.**
Answer	The project is about establishing connections online in order to make a difference offline. Through these links and connections, we will be reaching people in whatever way they prefer.
Response:	Christine De Souza

Appendix 2

Workshop feedback and comments

Workshop	Theme	Lead
Twitter tutorial	Social Media	Michael Seres, NHS Social Media
Partnership working to create change	Partnership Working	Jayne Quantrill, One East Midlands
Consultations: what you need to know	Consultations	Rebecca Addis, Consultation Institute
Supporting patient leaders	Patient Engagement	Mohammed Mir, patient leader

Twitter tutorial

- Michael Seres started his blog about his very rare condition simply to keep family and friends abreast of his health
- The blog grew, and other people started to share it - it helped raise awareness about IBD
- Twitter is another way to communicate, and builds a voice for individuals or organisations. It's a way to interact with people who have the same interest, condition, or way of thinking
- US social media stats show that 80% of people go online to have conversations about health
- Social media is a new way of consuming healthcare and engage with others
- A blogs is an online journal – time tabling your journey, difficulties and experiences faced
- Blogs become an online depository of information for other people
- Online etiquette – we must try not to react in a rude or disrespectful way. Things we post online stays there for a very long time, if not forever. It can get shared widely too and becomes a reflection of who we are, so must be mindful of that
- Power of online media – example shared of Michael's doctor sharing his blood results to everyone on his follower list. Four surgeons from around the world responded and this began a discussion about his healthcare
- Another example – GPs texting all patients to ask how they were on a Monday morning. Ten per cent response with issues, providing great opportunity to signpost them to appropriate care provider
- Closing remarks – the world has evolved; social media is one of the evolutions of communications. But it will and must not replace face-to-face

Q1. What are the benefits to your organisation and/or you as an individual?

Public Sector:	Third Sector:
• Shared knowledge and resources • Shared workload/costs • Extra experience/knowledge/assistance • Avoiding duplication/less duplication • Easier for public • Co-producing services patients have prioritised • Wider overview • More voices • Better representation • Insider knowledge • Understanding the requirements of other organisations • Learning from the true experts – service users • Learning from each other / what other do • Align work • Feeling supported • Social capital of pointing other to a useful resource • Less of a lone voice in a large organisation • Shared learning • Making connections • Access to groups who I could not normally reach • Working together = better quality feedback • Widening stakeholder group • Supporting our customers in better – informed procurement of services • Better understanding of local issues • Better, wider engagement • Better data in – better data out • Support for colleagues • Stitching Frankenstein's NHS back together	• Opportunities to bring innovative services to the market • Ability to advocate on behalf of communities who don't traditionally have a voice • Opportunity to more citizens from being • passive beneficiaries of services to being providers designers • Networking and making new contacts • The chance to use the full range of skills that all members posses • The chance to develop understanding with people from different backgrounds • Use GP surgeries and their PPGs to connect • Beneficial for health to use VCS sector – maybe not equal • Common goals / common barriers • Opportunity to share "innovative solutions" • Ways must be found to include patients /public who are not online – they are excluded – their voices are not heard
Commissioners:	**Other Health (Private Sector and individuals)**
• Commissioning based on peoples desires/needs • Shared knowledge and resources • Opportunities and learn together • Cross over of services – health to social care • Experts as people – people as experts • Sharing and developing intelligence • Relationships • Bringing people with you • Partnerships provide patient experience info that can be used to hold contracted providers to account and improve service provision	• Strength in numbers • Wider networks / knowledge base • Cross fertilisation of knowledge

Q2. What are the challenges you face and what would help you overcome them?

Public Sector:	Third Sector:
• Time and money • Commitment to a shared goal and outcomes • Difficult to access people and to give everyone the fair chance to engage • Different NHS staff work in silos – territorial • Need culture change to overcome this mind set. • Need help for facilitating shared learning • Access and knowing who you need to speak to • Trying to break down barriers – silo working • Engagement – where to start/making a start • Higher up the chain not listening • Trust • Money • Not knowing where to start • Uncertainty over workload • Cost split • Failure to fully share • Communication delays • Time – deadlines are near it's not easy to drop everything • Not knowing who to approach • Not knowing where to start • Groups not knowing my organisation • Transport to enable people to become engaged • No internet/no mobile connections	• Ways must be found to include patients / public who are not online – they are excluded – their voices are not heard • Help to understand new commission structure - who is who in the CCG / CSU • Finding potential partners • Understanding NHS 'speak' • Who are the relevant commissioners? • Different organisational cultures and languages • Understanding the commissioning process • Capacity of VCS to engage as equal partners • Resources to enable effective participation and engagement • Accountability – positive engagement • Limited resources • Short term focus for some long term issues • Working together to share ideas/joint solutions • Many people not online • People with axes to grind and their own priorities • Public cynicism about the process and the reason for it
Commissioners:	**Other Health (Private Sector and individuals)**
• Finding out who people are – networking can be challenging • Protocols + policies, bureaucracy stopping innovation • Influencing role only • No budget for engagement involvement • Remote way of working removed from the reality • Breaking down the health service culture of working in functional silos	• Listening and hearing each others' voices – needs organised forum and strict agenda • Conflicting interests for resolutions • Many issues for resolution within the group – needs good facilitation and decision making lead • Unless you fall into specific remits there are no current benefits

Q3. Are there any key messages coming from your stakeholders?

Public Sector:	Third Sector:
• Don't give us a noose we can make our own • Listen (underlined several times) • Need to be on the ground – listening by way of outreach • We want the opportunity to be involved – being involved aides our recovery • Involve us more at an earlier stage • Recognise the need, Better Care Fund acting as a driver but need support to do it better • Lets involve everyone • Want more cross authority cooperation • Want to say things just once Want a one stop shop • Want taxpayers cash well spent • Key messages to NHSE • Not everyone wants to be involved • If NHS staff get paid to do this why can't the patients/public? • Sustainability – no point re-inventing the wheel if it vanishes over night	• Long term not short term interventions • Stop changing the systems! • Don't expect it for free • Nobody listens to them • How does a charity work with One East Midlands to deliver health messages? • Need to cross function - collaborative agenda across all stakeholder organisations in different roles • Listen to the 'grassroots' connect into the communities • The third sector is an effective & efficient mechanism for developing innovative services/solutions
	Other Health (including Private Sector and individuals)
• We have no money help us to be creative!	• Why are private providers – private healthcare continuously excluded & referred to as "others" • Why is the voluntary sector seen differently to the NHS/private sector? • We need to have our voices heard • We know what we want • We want a workable forum to support us

Consultations – what you need to know

The Consultation Institute offers various training courses on engagement and consultations, briefing papers and publications, as well as Quality Assured Consultation services offering advice and evaluation of potentially challenging and high-profile consultations.

Briefly, the key challenges people are facing in terms of consultation and engagement can be attributed to a number of things: a period of unprecedented change in the health sector; the integration of health and social care; political pressures; constraints on resources/money; the increased use of social media in engagement; and the fact that there is a proliferation of organisations that have a duty to consult (example CCGs, Monitor, Foundation Trusts and HealthWatch, amongst others).

Where there are any significant proposed changes to a service, there is a legal duty to consult. This legal duty is found in the 2006 NHS Act, which was amended in the 2011 Health and Social Care Act[1].

If it does 'go wrong', objectors can seek a judicial review, which has happened with increasing regularity in recent years (for example, the cases involving Lewisham Hospital, a Derbyshire PCT, Birmingham City Council, Royal Brompton/Leeds Infirmary and Kent & Canterbury Hospital). The Consultation Institute recommends that managers are fully aware of these cases and their wider implications.

The Gunning Principles

Rebecca covered the Gunning Principles - a set of legal rules which apply once it has been agreed that a consultation has to happen. These are:

1. **Consultation must take place when the proposal is still at a formative stage**
   The decision-maker cannot consult on a decision already made, otherwise the consultation is not only unfair – the outcome has been pre-determined and is pointless. Consultation needs to happen early enough. The Independent Reconfiguration Panel (**IRP**) conducted a review in 2010[2] identifying some patterns why consultations fail. It identified inadequate community and stakeholder engagement as one of its seven critical deficiencies.
2. **Sufficient reasons must be put forward for the proposal to allow for intelligent consideration and response**
   The IRP review found important content was often missing from reconfiguration plans.
3. **Adequate time must be given for consideration and response**
   Cabinet Office Guidance published in 2013 no longer necessarily recommends a 12 week period.
4. **The product of consultation must be conscientiously taken into account**
   People's views must be taken into account and the consultation must be transparent. The IRP in their review also saw this as an issue.

[1] This is now S1472 but is almost word for word what was known as Section 242 of the Act
[2] Independent Reconfiguration Panel, Learning from Reviews - An Overview December 2010

Lansley's Four Tests

The former Secretary of State for Health Rt. Hon Andrew Lansley outlined four tests when he took office in 2010. These tests are important and have provided new yardsticks by which proposals can now be tested. These are as follows:

1. Enhanced public and patient engagement
2. Clarity about clinical evidence
3. Support from Clinical Commissioners
4. Consistency with current and future patient choice

You may also like to refer to the NHS England Guidance December 2013[3] checklist for the four tests.

Critical Success Factors

The Consultation Institute has identified six critical success factors it sees as the key to a best practice approach. These are:

1. Strong Clinical leadership
2. Tell people the problem
3. Create a climate of involvement
4. Segment the audience in terms of how to engage and impact assessments
5. Promote an independent element in the process
6. Develop sustainable engagement models

Further details will be provided in the Consultation Institute's forthcoming Briefing Paper on "*The role of consultation in NHS & Social Care Reconfigurations in England", which will be available to Consultation Institute members.*

Questions/comments

The following points were made during discussions:

Many have experienced consultations where engagement has started late in the day and it has been a tick-box exercise with the strong belief that decisions have already been made. This has affected trust in the engagement and consultation process generally and willingness to get involved.

1. Linked to this, some felt the pre-consultation stage was crucial as it offers scope to ask fairly open questions about the issues
2. Some have had good experiences of engaging seldom-heard communities through intermediary organisations and good partnership working
3. Engaging with the third sector can be challenging - a lack of response can be because they are too busy or do not have sufficient resources to respond, rather than a lack of interest. There was some discussion about whether it was legitimate to give resources to third sector to help with engagement

[3] Strategy Unit of NHS England - 'Planning and delivering service changes for patients: a good practice guide for commissioners on the development of proposals for major service changes and reconfigurations' Dec 2013

4. The importance of engaging with opposition candidates as well as the incumbent MP was mentioned
5. Sometimes, in spite of having clinical evidence for change communities do not agree with the proposals put forward for consultation. This can be a very challenging issue.
6. Sometimes you can do everything right and consult with all your stakeholders to the best of your ability, but objections coalesce into opposition groups later in the day and MPs still challenge your consultation
7. Some asked for case studies on where good engagement and consultation has made a difference to demonstrate the impact that it can have

Access:

- Engagement is not just about patients and/or public – it's about everyone
- More detailed information is needed about how the NHS systems and processes work, in order to align practice needs to wider NHS needs
- Be inclusive – engage with everyone especially the seldom-heard groups, not just the 'usual suspects' to gain wider representation and perspective of needs
- Social and digital media is not the only medium to engage – CCGs and NHS should go out and reach communities and VCSs group in-person. Don't wait for people to come to you
- Cover travel for volunteers, public and patients so they can get involved - volunteers are not free, however they are freely available
- Do not assume views of hard to reach groups i.e. young people

Resources

- Keep hearing there is a lack of resources to engage properly, however people are committing
- Learn from others who have successfully engaged and use other resources which are already available and in existence i.e. charities, corporate companies, community groups, organisations
- Work with the third sector and other organisations who are already engaging and good at it, so we are doing engagement once and meaningfully – quality rather than quantity
- Use modern technology to engage via video, Skype and so on, in order to reduce travel time for a short meeting
- 'Keep it real' and ensure patient leaders are used as resource to contribute to CCG strategies and plans, so input is part of deliverable processes
- Volunteers are not free, however they are freely available

Information

- Communicate and educate everyone so they are empowered to be heard – 360-degree view
- Engage more on a local level so patients and public know where to go for information or help
- Patients do not necessarily know about CCGs and what they do – local level publicity required in 'patient-friendly' language
- Need to encourage information which uses less NHS jargon and language, so it is easy for patients and public
- Provide CCG KPIs, trends, figures so patient leaders can understand where the CCG requires assistance to make improvements and/or engage

Listen

- CCGs need to listen to their patient leaders and population and involve them in procurement
- Patient leaders are available to help review and monitor the frameworks they help to create
- Many feel that the NHS at various levels is not listening

There is a need to reach across these circles and ensure we engage patients with the support of engagement leads.

Support and Training required to:

- Communicate more effectively with CCGs, patients, public and other PPG groups
- Build relationships within CCGs (patient leaders) and in communities
- Negotiate with key people in non-hostile techniques to help improve services and make changes at practice level and wider
- Train other patient leaders so they are able to reflect needs and gaps in their localities
- Gain insight on how systems work i.e. procurements and contracts

Appendix 3

Delegate feedback on luggage tags: How can we help you grow Involvement?

How can I convince the senior managers to make engagement meaningful? More co-design, less surveys. They're panicked by it.	Doing well with transitions (paed and adult care) but need to not be afraid of engaging in sensitive issues (e.g. palliative care in children)	Effective in getting on the ground by talking to all the different people / communities who are in the seldom-heard categories
Funding for charities to get their service users involved in empowering others	Adult to adult conversations… help us to develop patient leaders	More localised patient forums including numerous groups and authorities
Raising the awareness for people with hearing loss currently an invisible disability - not taken very seriously but is and will be a huge drain on the public purse!	We need support for senior managers / directors to understand this concept. Without them on board we cannot deliver this. They should be here!	Compassion in practice indicates a desired local action would be to use patient story at every board meeting. How will this initiative help move this forward in the region?
Increase the ways in which people who are not online can participate	Look to see how links between public transport providers and health facilities can be improved	I would like to have display posters and leaflets for use on stalls at public events
Break barriers for third sector to work with NHS especially when our service users prefer our service to CAMHS	Value Involvement don't re-invent the wheel. Some money pay for our time as VCS organisations who link with patients to encourage their involvement	How with my links across statutory / voluntary do I feed into Involvement to ensure how organisations register? Through CCGs? Public Health? Healthwatch?
More involvement of foundation trusts with public membership	More interaction of local services	Wider range of interaction services / tools
I'm not convinced about the 'rating' of others' work - this is meant to strengthen relationships but this could damage them!	The local offer is a requirement by an Act of Parliament to provide information to patients, carers and people living with disabilities	The concept of Involvement sounds good, but people (public, not just NHS / health sector) need to know about it. How will you do that?
To be told how systems work in detail, if we do not know. How can we make comments on how to improve or alter something?	Tried to upload a case study PDF - it didn't work. Need more around service users who can co-design not just complain	Engagement is 100% but the senior managers / the board and procurement and people making contracts don't care!
Only one of me for the whole organisation - need more resources. I can advise and offer guidance based on all of this best practice but need support / resources / materials / guidance to help the patients and staff on the ground to put it into practice	We have lives outside being a mere patient. We have skills and a vast array of life experiences. Exploit these qualities and use them not just for data and stories – lots of us can also carry out tasks outside the norm	Locally (Birmingham) there is the CLAHRC patient network - again a database of public engagement activities and people being created. UHB FT have a social media platform for patients and their clinicians called myHealth
More lay members	Shorter sign-up process	Listen more
Great to hook up with East Midlands delegates	Guidelines on patients' rights in making complaints	Work closely with all forms of providers
Make more publicly available	Remove the barriers	Remember that some don't have access to the internet