

PUBLIC HEALTH, WELLNESS AND CULTURE SCRUTINY PANEL

POLICY REVIEW 2013/14

PATIENT AND PUBLIC ENGAGEMENT IN HEALTH & WELLBEING

***DRAFT* FINAL REPORT**

Contents	Page
1. Foreword from the Lead Scrutiny Member	2
2. Introduction	3
3. Aim of Review	3
4. Terms of Reference	3
5. Membership of the Panel	4
6. Method of Investigation	4
7. Findings of Review	4
8. Conclusion	17
9. Recommendations	18
10. Acknowledgements	18
11. Background Papers	18
Appendix 1 Duty to Involve	19
Appendix 2 The Engagement Cycle	20
Appendix 3 The Patient & Public Engagement Framework	21

Foreword

We chose to explore the patient and public voice across health services in Sunderland partly because we had the impression that, while there was a lot of activity and opportunity, it could be very complex for people to negotiate their way through the maze.

We took evidence on how best to build on the strengths, eradicate duplication, how to ensure that patients and the public can access the system to have their voice heard and how to measure effectiveness and success.

The term 'patient and public engagement' is used within this report. In the view of the Panel, and for the purpose of this report, this encapsulates information sharing, consultation, feedback and engagement and all of the points at which people can express their views.

We are aware that there are times when organisations will have to make decisions that are unpopular about services. Sometimes there may be no alternatives but to close a service but, at the end of the day, people must feel that they have had the opportunity to express their voice on an issue, even if they disagree with the outcomes.

This review proposes an approach to patient and public engagement and consultation which includes the role of Health and Wellbeing Board incorporating the wider system of groups and partnerships that contribute to the delivery of patient and public engagement.

I would like to thank all the witnesses for their thoughtful contributions and the time they took to be involved in discussions.

I would also like to thank Panel members for their support, contributions, and most of all for their active participation in our evidence gathering sessions. I hope that this review will contribute to increased understanding of issues and better coordination of the activity already in place.

**Councillor George Howe, Lead Scrutiny Member
Public Health, Wellness and Culture Scrutiny Panel**

2. Introduction

- 2.1 In 2012-13, the Public Health, Wellness and Culture Scrutiny Panel produced, on behalf of the Health and Wellbeing Board a Protocol for working together between all of the member organisations of the Board.
- 2.2 The Protocol contained the following commitment:

Engaging with service users

All parties to this protocol recognise that they have both joint and separate approaches to engaging with service users and members of the public. Wherever possible all parties will ensure that such health, well-being and social care engagement activity is jointly planned and co-ordinated within the partnership and individual frameworks of the parties, to ensure maximum coverage and capacity, to avoid duplication and 'consultation fatigue' and to ensure appropriate quality and outcomes.

- 2.3 During 2013-14, the Scrutiny Panel, on behalf of the Board, investigated the options for coordinating engagement activities and this report is a summary of the evidence taken.
- 2.4 The outcome of the review is a proposed framework for patient and public engagement and establishing a statement of intent to inform activity. In the future, it is intended that this framework would support a co-ordinated approach to patient and public engagement by the whole local health economy so as to make best use of available resources.

3. Aim of Review

- 3.1 To review the adequacy of services to meet the key requirement of meaningful engagement with patients, carers and their communities

4. Terms of Reference

- 4.1 The Panel agreed the following terms of reference for the review:-
- a) To look at the core elements of engagement¹ with the intention of developing a collaborative framework²;
 - b) To explore the roles, responsibilities and expectations of those with a duty to engage patients and the public with the intention of defining shared expectations;

¹ Engaging with patients and the public can happen at: Individual Level – 'my say' in decisions about my own care and treatment and Collective Level - 'our say' in decisions about the commissioning of services.

² A framework to support a collective approach to patient and public engagement from the whole health economy as a means to best utilise existing resources. This does not override individual duties, responsibilities and operating environments which vary for different parts of the NHS.

- c) To explore how patient and public involvement enables an appropriate level of influence and where necessary leads to improved services;
- d) To hear about the development of strategies for equality and how all people including children and young people and those from seldom heard groups can be heard.

5. Membership of the Scrutiny Panel

The membership of the Scrutiny Panel consisted of:

Councillors George Howe (Lead Scrutiny Member), Louise Farthing, Fiona Miller, Julia Jackson, Rebecca Atkinson, David Errington, Paul Maddison.

6. Methods of Investigation

- 6.1 The following evidence was taken at meetings of the Panel: North East Ambulance NHS Foundation Trust; NHS England; Sunderland Clinical Commissioning Group; South Tyneside Foundation Trust.
- 6.2 In addition, the Health and Wellbeing Board were invited to contribute, Sunderland Healthwatch provided support in relation to the involvement of children and young people and invited their membership to contribute, and the Care Quality Commission attended the Panel to provide advice on their regulatory role.

7. Findings of the Scrutiny Panel

7.1 Engagement as a Strand of Quality

- 7.1.1 The Francis Report³ highlighted what can go wrong when patients, their families and the public struggle to have their voices heard. The Panel heard clear evidence that patient and public engagement (PPE) should be a strand of quality in its own right. However, we heard that PPE rarely has dedicated resources and for it to be embedded into an organisation, a culture of patient and public engagement is required. Further transformational work may be required to reach that stage.
- 7.1.2 It was clear that during the period of our review, organisations locally were embarking on ambitious programmes to transform the way that they engage with patients and the public.
- 7.1.3 For example, we took evidence from the Sunderland Clinical Commissioning Group (CCG) on the development of its PPE strategy. The strategy was being developed with comprehensive consultation using a stakeholder group and with particular interest groups that had historically been under-represented in the engagement practices of the Primary Care Trust. This work developed some clear overarching principles for public engagement and identified

³ The Mid Staffordshire NHS Foundation Trust Public Inquiry – Robert Francis QC February 2013

appropriate variances in approach for a range of interest groups. The CCG engagement cycle will be done through the JSNA with annual priorities reviewed.

- 7.1.4 The Health and Wellbeing Board has a duty to engage the public in their work as defined in the Health and Social Care Act (2012). As a minimum requirement, the Board has a duty to involve local people in the preparation of the Joint Strategic Needs Assessment and the development of the Joint Health and Wellbeing Strategy.
- 7.1.5 The Board is therefore is the logical and best place to bring together and share insight about what matters to local people and communities.
- 7.1.6 It is clear that the Board's start-up phase has been a demanding time and PPE could feel like an additional burden, however the Panel took the view that it is while new policies and relationships are being formed, new cultures are developing and priorities are being decided that engagement needs to be embedded.
- 7.1.7 We were aware that the development and publication of the Sunderland Joint Health and Wellbeing Strategy for Sunderland was underpinned by extensive consultation and engagement with the public, partners and stakeholders, led by members of the Board to ensure the objectives, actions and outcomes were the right things for the population of Sunderland.
- 7.1.8 Furthermore, in taking forward the delivery of the strategy it was agreed by the Board to put in place a consistent approach to patient and public engagement accompanied by an action plan for communications.
- 7.1.9 Health and Wellbeing Board members participated in a development session in October 2013 to outline the principles of effective engagement in strategic priority setting. The Board was asked to consider some key questions around 'engagement aspirations'; limitations and possibilities in light of resourcing; and the scope for health commissioners and providers to co-ordinate engagement practices.
- 7.1.10 The general view from research and from our own evidence is that a Health and Wellbeing Board does not necessarily need to have its own public profile for it to undertake meaningful PPE. However, the Panel felt that there was scope for the Board to make known its activities to the public and the fact that meetings are held in public, possibly through a separate web page.
- 7.1.11 The Panel's evidence showed that a unified approach to PPE should be supported and informed by sharing intelligence, joined up strategy and planning and making use of existing intelligence and engagement activity. This makes good use of scarce resources and helps avoid the unnecessary proliferation of engagement infrastructure and 'engagement fatigue'. For example, this could involve the development of a calendar of engagement activities across the partners identifying what can be done together.

7.1.12 As new issues develop such as policy documents and governance arrangements there should be routine screening to reflect the Board's responsibility for patient and public engagement and to understand and assess how to involve people's interest, and then evaluate the success of the engagement exercise afterwards.

7.1.13 In delivering these ambitions for PPE, the Panel was aware that all partners face numerous difficulties including constraints in financial and human resources and organisational capacity.

7.1.14 Individual resource challenges will mean it is challenging for partners to initiate engagement activities on behalf of the Board that do not fall into work that they would otherwise already be doing. There is however, a commitment from partner organisations, through their participation within the Board, to offer guidance and leadership to the Board to develop appropriate engagement responses to respective elements of its work. In this way, findings from individual engagement activity will be utilised, along with the professional expertise of individual Board members.

7.2 Accountability for PPE

7.2.1 The overriding characteristic of the Mid Staffordshire events was that patients' accounts of their experiences were either not heard, or not understood or ignored. Performance management systems were recorded and explained in ways that made it difficult to be clear what was happening to patients – and concerns about operational performance were overshadowed by apparent strategic successes.

7.2.2 Accountability therefore is not just about publishing data – this is important but should be linked to mechanisms that bring a reality check to make sure that patient's experiences are properly reflected.

7.2.3 Robert Francis identified that it was difficult for anyone 'on the outside' to check what was happening in the hospital. Therefore, everyone with a role to hold the NHS to account needs to work together to make sure they combine their powers and the information they gather so that stronger lines of accountability are developed for strategic direction and operational performance.

7.2.4 Each partner organisation is formally accountable to different parts of the system and through the Board there is a shared responsibility for delivering shared objectives and being accountable to communities, and service users to deliver on the shared objectives including on patient involvement which should be integral.

7.2.5 Accountability of clinical commissioning groups will come through assessment by the NHS Commissioning Board for financial performance, quality of services, health outcomes and governance, and they will also have a collective responsibility as members of the Board for delivering the Joint

Health and Wellbeing Strategy. There is also a Duty to Involve⁴, and to publish an annual report.

7.2.6 Providers have their own in-house procedures. Foundation Trusts are regulated by Monitor which publishes quarterly reports and CQC could also carry out an inspection. Added to this the implementation of the Friends and Family Test is designed to help standardise the views on patients and relatives.

7.2.7 We heard that through NHS England, each Area Team will have a high level Quality Surveillance Group (QSG) which will share intelligence about health services thereby pooling PPE in one place. QSG's will look at early warning signs and their purpose will mainly be assurance with separate mechanisms for monitoring service improvement plans.

7.2.8 Scrutiny by local councillors is an important part of the framework of health service accountability, and their role is different from the Care Quality Commission (CQC) and local Healthwatch. Francis had clear messages about council scrutiny with specific recommendations:

43 - Those charged with oversight and regulatory roles in healthcare should monitor media reports about the organisations for which they have responsibility.

147 - Guidance should be given to promote the co-ordination and co-operation between local Healthwatch, Health and Wellbeing Boards, and local government scrutiny committees.

149 - Scrutiny committees should be provided with appropriate support to enable them to carry out their scrutiny role, including easily accessible guidance and benchmarks.

150 - Scrutiny committees should have powers to inspect providers rather than relying on local patient involvement structures to carry out this role, or should actively work with those structures to trigger and follow up inspections where appropriate rather than receiving reports without comment or suggestion for action.

7.2.9 The Francis Report identified that council scrutiny should have been more proactive about responding to local concerns and that it should have been less trusting of managements' explanations of performance.

7.2.10 The Panel felt that consideration should be given to establish more robust ways to monitor data or information about the experiences of people who use health and care services, alongside 'triggers to act' when things seem to be

⁴ The Health and Social Care Act 2012 gives commissioners a statutory duty "to promote involvement of each patient". It states: "Each clinical commissioning group must, in the exercise of its functions, promote the involvement of patients, and their carers' and representatives (if any), in decisions which relate to— (a) the prevention or diagnosis of illness in the patients, or (b) their care or treatment." The phrase "in the exercise of its functions" means "in everything it does".

going wrong. Council scrutiny does not need to duplicate what others are doing but should maintain a wide network of intelligence so that it can use its powers effectively to hold the NHS account - having a clear understanding about the quality, safety and value of healthcare services and challenging providers and commissioners when it seems that good outcomes elsewhere are not being matched locally.

- 7.2.11 For example, there is a role for overview and scrutiny to review whether the type and extent of engagement is sufficient and appropriate. It also has a proactive role in bringing together representatives of key health bodies to work collaboratively and share learning of engagement processes. There are also opportunities to co-opt representatives of patient groups and the public, with no voting rights, to specific scrutiny panels when investigating key health issues.
- 7.2.12 A key point from the Francis Report is that council scrutiny should not passively accept responses from providers or commissioners but should seek to test these in light of what people who use services say about their experiences (relying only on results of Friends and Family tests and other formal surveys may not be effective enough).

7.3 **Coordination and Jointly Planning for a Whole System Approach**

- 7.3.1 Each representative on the Board has a separate and collective responsibility for public engagement and public engagement is also the responsibility of organisations who are not members of the Board but part of the wider system
- 7.3.2 We heard evidence of engagement aspirations and constraints in light of resourcing. Our evidence showed that, mostly, there are no dedicated resources for PPE, despite the fact that PPE is regarded as an aspect of quality in its own right. The challenge will be for PPE to become mainstreamed and integral to service developments.
- 7.3.3 Given the absence of a dedicated engagement resource, the optimal solution is to make use of available resources and expertise from partner organisations and the wider health network including the voluntary sector and local patient groups. Other stakeholders for a 'whole-system' approach to PPE might also include housing providers, NHS provider organisations and Police. Additionally, the development of a new Intelligence Hub is intended to support local decision making with an integrated Geographical Information System.

CASE STUDY 1: SHARED DECISION MAKING

Shared Decision Making is a process in which patients with current, clinical information relevant to their particular condition can be helped to work through any questions they may have, explore the options available, and take a treatment route which best suits their needs and preferences - *No decision about me, without me.*

To achieve this, NHS England will encourage the development of new relationships between patients, carers and clinicians, where they work together, in equal partnership, to make decisions and agree a care plan. This puts Shared Decision Making not only at the care level, but also at the strategic and commissioning level, with patients involved in the co-design, co-commissioning and co-production of healthcare. Without this change, the required transformational culture change of Shared Decision Making will not be achieved.

- 7.3.4 Healthwatch has a statutory responsibility to engage patients and the public on issues determined by the community as priorities for action to inform commissioning decisions. Healthwatch will work across the wider system for patient and public engagement, to gather evidence from the views and experiences of patients, service users and the public about their local health and care services and to provide feedback based on that evidence.
- 7.3.5 Clearly, public engagement cannot purely be the role and responsibility of the Healthwatch representative. Whilst Healthwatch may co-ordinate its efforts with existing decision-making and influencing structures (such as the Board) where it deems this to be appropriate to its own work plan, the expectation should not be that its work can be directed or instructed by a third party.
- 7.3.6 Requirements above and beyond planned activities may not be possible without additional resourcing. In terms of resources required, not all strategies will share the same expectations. If we mapped the activities requiring patient and public engagement across all partners and looked at what is required across the Board's activities to meet those expectations the challenge would be evident.
- 7.3.7 The Panel was informed that through the Health and Social Care Integration fund (now the Better Care fund) there is greater scope for a Joint Communication and Engagement Strategy for Sunderland. It is intended that this will maximise impact and have a joint agenda commissioning proposals and integrated ways of working.
- 7.3.8 The Panel concluded that a working definition of what the Board means by engagement covering the range of participatory activities from information to influencing decisions would support the Board in its role as the conduit of partner engagement information.

7.4 Information Gathering

- 7.4.1 The Panel heard that the data collected from patients can help organisations to make better decisions about how to improve services. The NHS Patient Engagement Framework is evidence-based which means that a large amount of evidence is collected in various ways to provide an overview of patient views. Evidence shows that if information is collected in isolation it often does not lead to service improvement.

7.4.2 We heard that organisations need a mixture of measures to provide immediate and recent data that is sufficiently detailed and meaningful to influence staff, managers and executives. As well as requiring different types of measure, the way that feedback is collected can also influence the type of information and what it is useful for.

7.4.3 Sunderland CCG informed us that the four main ways that they involve patients are: Governing Bodies held in public; measuring patient experience; community engagement and Locality Patient Groups. Locality Patient Groups are being established in the five areas with approximately 10-15 people registered with each group. In addition, each GP practice is encouraged to have a patient engagement group and some patient engagement will be through virtual meetings.

CASE STUDY 2: THE FRIENDS & FAMILY TEST

The Friends and Family Test (FFT) for acute in-patients and patients discharged from A&E became mandatory on 1 April. Now all providers of NHS funded acute inpatient and A&E services are asking patients:

“How likely are you to recommend our <ward/A&E department> to friends and family if they needed similar care or treatment?” with answers on a scale of extremely likely to extremely unlikely.”

The aim is to provide a simple headline metric which, when combined with follow-up questions, can drive a culture change of continuous recognition of good practice and potential improvements in the quality of the care received by NHS patients and service users.

This quick, consistent, standardised patient experience indicator will provide organisations, employees and the public with a simple, easily understandable headline metric, based on near real-time experience.

It will mean that employees from ‘boards to wards’ will be informed and empowered to tackle areas of weak performance and celebrate and build on what’s working well, using the results from this test and other sources of intelligence.

7.4.4 Other examples of engagement being undertaken by the CCG include work done at a secondary school giving information on primary care which raised lots of questions. Communication methods are being modified, for example, the CCG strategy is being developed to include a Digital Marketing Strategy. Use of Twitter and Facebook were being developed to add variety to the engagement tools. In addition, people can receive information on special areas of interest to them. Individuals can be invited to focus groups and events and surveys will be issued which are representative of the demographics of Sunderland.

- 7.4.5 We heard that patient stories are a powerful method of reflecting the views of service users. There is considerable value in staff hearing patients' stories directly.
- 7.4.6 The Patient Association has on several occasions told patients stories with dramatic effect, triggering task and finish reviews in to care standards and responses to those stories. Patient Opinion⁵ is an example of an online review and response tool for patients to let providers know about their experiences and for providers to respond.

CASE STUDY 3: PATIENT STORIES

South Tyneside Foundation Trust is leading a piece of work with a focus on 'Transparency in Care'. This is a national initiative and measures are being developed in terms of what this should look like. The initiative requires the publishing of patient improvement stories every month. In the last 12 months 906 individual patient qualitative stories have been logged and also 3,738 patients were interviewed at the time of their care. The use of patient diaries is another tool to provide an account of experience and feelings. These can be useful in areas such as palliative care, whereby a patient would want to be left to sleep this would be honoured as part of the diary system. Using this approach, cases of pressure ulcers have been reduced by about 50%.

- 7.4.7 Patient information is also available from a variety of sources beyond that collected by member organisations. This includes the council's scrutiny panels, the council as a whole, CCG locality groups, voluntary agencies, and local Healthwatch. The council carries out a range of consultations and collects health-related activity data. Voluntary agencies have deep insight into the needs of particular groups and may have done work on groups that are hard to identify and access. The council's locality arrangements i.e. Area Committees and People and Place Boards and the network of Health Champions have access to a variety of information within localities.
- 7.4.8 The Panel also considered compliments and complaints in order to review options for using intelligence to improve services and inform commissioning. Compliments and complaints are important in ensuring good quality healthcare, helping an organisation to find out about what they're getting right and what can be improved.
- 7.4.9 There were over 162,000 complaints about NHS care in 2012/13. This amounts to 3,000 per week. Additionally, compliments tell an organisation when things work well, so they can make sure examples of good practice are followed across other services
- 7.4.10 One of the key themes of the Francis Inquiry is to improve the complaints system. The report found that the Board of Mid Staffordshire never saw information about complaints as they viewed them as operational not

⁵ <https://www.patientopinion.org.uk/>

strategic. Francis wrote: *“A health service that does not listen to complaints is unlikely to reflect its patients’ needs. One that does will be more likely to detect the early warning signs that something requires correction, to address such issues and to protect others from harmful treatment. A complaints system that does not respond flexibly, promptly and effectively to the justifiable concerns of complainants not only allows unacceptable practice to persist, it aggravates the grievance and suffering of the patient and those associated with the complaint, and undermines the public’s trust in the service.”*⁶

7.4.11 It was the Francis Report that prompted the Government to commission a review of NHS hospital complaints handling.⁷ Although the review focused on acute hospitals, many of the reflections and comments could be as relevant to primary care, community services and social care as they are for acute hospitals. The review identified that complaints should be treated like ‘gold dust’ as a source of information for decision-makers.

7.4.12 Yet, our evidence indicated that many people find complaints systems complicated and hard to navigate. The charity Mencap, for example, referred to the findings of its two reports ‘Death by Indifference’ (2007 and 2012) on unnecessary deaths of people with learning disabilities. It said: *“Both reports stated that the complaints process was slow, bureaucratic and defensive. People told us that it was hard to find out who to complain to, what help they could get and what their legal rights were ... We were also told that people found complaints forms very inaccessible.”*

7.4.13 Healthwatch England, the independent consumer champion for health and social care in England, summed up the experience by saying: *“The complaints system can be off-putting, complex and slow... There is limited confidence that making a complaint will lead to learning and change.”*

7.4.14 The changes in NHS structures introduced by the Health and Social Care Act 2012 have had consequences for people making complaints. The NHS Confederation noted: *“We have serious concerns that following the NHS reforms the complaints system has become more difficult to navigate and risks leaving patients confused about who to complain to.”*

7.4.15 The NHS Confederation in evidence to the Clwyd Review suggested that Clinical Commissioning Groups should play a vital role using their leverage to ensure that providers have good complaints systems in place, *“we are calling for CCGs and NHS England to provide clear information to patients and the public about their complaints process.”*⁸

⁶ Public Inquiry into the Mid Staffordshire NHS Foundation Trust, Volume 1, Chapter 3 pp 245-287 Mid Staffordshire Inquiry Report

⁷ A Review of the NHS Hospitals Complaints System Putting Patients Back in the Picture Right Honourable Ann Clwyd MP and Professor Tricia Hart October 2013

⁸ NHS Confederation evidence to the Clwyd Review

7.4.16 The NHS Complaints Advocacy Service started in April 2013 and is delivered by the Carers' Federation Ltd. The NHS Complaints Advocacy services are commissioned through consortia of the north eastern authorities. The service supports people who want to make an NHS complaint. The Clywd Review recommended that the independent NHS Complaints Advocacy Service should be re-branded, better resourced, with protected funding, and better publicised. It should also be developed to embrace greater independence and support to those who complain.

7.4.17 The Parliamentary Public Administration Committee (PASC) launched an Inquiry in March 2013 focusing on how complaints in the NHS are handled.⁹ It is looking at whether the current complaints system delivers fairness, redress, and justice for people who complain, and to examine how departments and agencies use complaints as a source of information and challenge, to improve the delivery of public services

7.4.18 Evidence to the PASC Inquiry from the NHS Confederation stated, "*Having consistent national standards would be a very good place to start, partly because some of the regulation and oversight of the providers is now separated between NHS England from a national perspective, CCGs, and regulators, such as CQC. To have a set of national standards that everyone is working to would be a really good idea. To ensure we are then joining up the intelligence and the information-one of the problems with Mid Staffs was that we were not putting all the information in the same place-is going to be an important national function. Having the right sort of information technology to support that will be a national role.*"

7.4.19 The Panel felt that there needs to be more effective coordination of the data already collected about front line services and with the avoidance where possible of seeking fresh collections of data for their own purposes. There is value in "piggy backing" on other public events/meetings that are being held.

CASE STUDY 4: CARE CONNECT NHS

Care Connect is a new initiative designed to give patients a say in the delivery of NHS services in England.

The new service, currently being piloted in Newcastle and Gateshead, will enable patients to interact with the NHS in 'real time'.

The Care Connect system was inspired by the 311 hotline service in the US. Designed to make dealing with public bodies less frustrating, 311 services provide people with direct access to local services and information.

The service is just one element of a broader suite of digital initiatives that will be rolled out over the next few years.

Care Connect quickly puts people in touch with people in the NHS. The service has three main features, enabling patients to share an experience (whether good or bad), ask a question (answered within 24 hours) or report a problem with an NHS service.

Navigating through the NHS's different departments can be mind-boggling. This service makes it easy for people by having one single place to go to. The pilot, when rolled out, could provide an incredibly powerful tool in terms of giving patients a say in shaping the NHS. All submissions are collected and analysed and, over time, this information will become a powerful tool for change in the NHS.

7.4.20 The Panel concluded that, as part of a unified approach, findings from individual engagement activity must be utilised with all public consultations relating to health and wellbeing joined up and coordinated.

7.5 Involving Everyone

7.5.1 The Panel collected evidence on how and why organisations should involve a wide range of people. This includes groups who are likely to be vulnerable or marginalised either as a result of their medical condition or as members of a community whose voice is often not heard in service planning and improvement perhaps because of special requirements such as those for whom English is not their first language.

7.5.2 Members of the Panel were concerned that patient feedback should be representative of all patients' views and there is a risk of groups being dominated by vested interests. We were informed that, working with the North East Commissioning Service, CCG is conducting work to measure how representative the membership is using market research techniques.

7.5.3 As an example of the difficulties faced, the Panel was informed that different BME communities face different health problems from one community to another and from the general population. We heard of inequalities in access to, uptake of and satisfaction with health care services experienced by minority ethnic groups, which in turn have impact on poor health outcomes. Research at the Centre on Migration, Policy and Society (COMPAS) found key messages to inform the policy and research including the power of providing information and the need to consider how data gaps could be addressed.¹⁰

CASE STUDY 5: International Community Organisation of Sunderland

ICOS Sunderland works with all minority ethnic people but most members are recent economic migrants. This client group tends to lack the local knowledge and access to established support networks that the general population and the more settled communities may have.

¹⁰ COMPAS The health status of migrants and access to health care in the UK

In 2010 and 2011, ICOS worked with Sunderland LINK to establish the health needs of the Polish community, the largest new EU community both nationally and in Sunderland. Reports by Sunderland LINK confirmed that people do not have enough access to information, resulting in incorrect use of health facilities, for example, and over-reliance on A&E care to an even larger degree than the general population, non-registration with GP practices, and lack of awareness about help available with addiction/substance misuse issues. Difficulty in accessing information and services around mental and psychological health because of language barriers may also have a negative health impact.

- 7.5.4 It was apparent that within each strategy, organisations will need to analyse their equality performance against the objective of improving patient access and experience.
- 7.5.5 A review of Healthcare Commission national reviews and studies since 2006 highlights a need to improve the engagement of patients and their carers' in a number of specific NHS service areas, including:
- a) People with learning difficulties
 - b) Young people
 - c) Older people, particularly those with dementia
 - d) People from black and minority ethnic communities, particularly older people
 - e) Users of substance misuse services
 - f) Users of chronic obstructive pulmonary disease services
- 7.5.6 Studies identify some promising engagement practices in some services, such as the use of volunteers and advocates, and links with community groups.

CASE STUDY 6: HEALTHWATCH - ENGAGING CHILDREN AND YOUNG PEOPLE

Groundwork North East has engaged with 71 young people aged 13-24 over the last 3 months. This has involved face to face work with surveys and a focus group drawing out their views on health and social care and how they would like to be involved in Healthwatch.

The young people consulted had not been engaged in the development of health and social care services. They had never been asked to give feedback on a service they had used. Their involvement had been limited to sexual health guidance through schools or accessing health services for personal reasons.

The main way young people would like to be involved is through social media, Facebook or Twitter. They are particularly interested in the development of peer support. They are willing to share their experiences with people they have developed relationships with. This

is vital to young people as issues around confidentiality are paramount to them engagement.

Work will continue with the Children's Trust Advisory Network (CTAN), Youth Parliament and the Change Council.

7.5.7 The Panel concluded that a single Communication Plan and a coordinated and holistic approach to engagement within the wider context of corporate engagement would allow for a unified approach. This approach could include specific engagement strategies for key groups such as children and young people.

7.6 Engagement that makes a difference

7.6.1 'No decision about us, without us' is the vision of empowered citizens participating as partners in decision making about their health and health services.

7.6.2 A legal duty to involve is a key element of the NHS Constitution and evidence of the Government's commitment to place patients and public at the heart of the NHS. There are related duties on Health & Wellbeing Boards and NHS providers. Beyond legal compliance, good involvement can add commissioning value and help unlock benefits including better value for money and better patient experience.

7.6.3 We are aware that not everyone can be or will want to be involved in every decision, however, working in a smart, targeted way with relevant groups of patients and carers in co- designing services and approaches can help identify what may be decommissioned as well as commissioned; get the new services right first time; identify the culture and approaches that meet patients' preferences and are therefore more effective; make the overall case for the service change on the basis that the relevant patients who are most affected want it.

7.6.4 The 'ladder of participation'¹¹ model states that as you step up the ladder then the role of residents and interested groups becomes more meaningful. The more involved people are the more content they are likely to be with the final outcome.

7.4.21 The engagement cycle provides a valuable tool for planning and implementing involvement activity in the various stages of commissioning (see Appendix 2). Its importance in relation to the duty to involve (See Appendix 1) is to make explicit the requirement that involvement is required at all stages of commissioning - assessing needs, designing services, reviewing provision, deciding priorities, managing providers' performance and service evaluation.

¹¹ Often termed as "Arnstein's ladder", these are broadly categorized as: Citizen Power; Tokenism; Non-participation.

- 7.6.5 The Panel heard that there can be a mismatch between the responsibilities for patient and public engagement and the low expectation that patients and the public may have about being able to influence commissioning decisions. It was clear that future strategies should deliver involvement in a way that does not make the production of a strategy an end in itself, but a cornerstone of good quality health care. Beyond the legal compliance to involve people, good involvement can add value and help unlock benefits including better value for money and getting new services right first time.
- 7.6.6 It was clear from the evidence collected that sufficient time should be built into consultations to allow for meaningful dialogue, with venues and access carefully planned to maximise appropriate participation. There is also scope for better use of social media to achieve wider reach amongst local people, including making good use of Facebook and Twitter accounts.
- 7.6.7 The Panel concluded that evidence should be collected that shows how the outcomes of engagement have informed business activity and it should be possible to demonstrate how service changes are directly linked to patient and public views being expressed.

7.7 Patient and Public Engagement Framework

- 7.7.1 While there may be no “one size fits all” approach to an effective engagement approach, there are some key factors and themes that are important to consider, such as the need for a patient engagement to be embraced throughout the health system, the role of staff experience, the power of stories and the need to make the engagement central to the core organisational vision, strategy, quality reporting and service improvement work.
- 7.7.2 Seven key principles to guide Health and Wellbeing Boards for effective PPE are recommended by the NHS Confederation as:¹²
- 1) Engagement should take place from the start of the life of the health and wellbeing board and be woven into the DNA of the board throughout its work.
 - 2) There will be different types and levels of appropriate engagement depending on the situation.
 - 3) Patient and public engagement is the business of every board member.
 - 4) The board has a responsibility to ensure effective engagement is embedded within its day-to-day business and is taking place through the commissioning and delivery of services.
 - 5) Patient and public engagement has made a difference.
 - 6) Engagement activities should be based on evidence of what works.
 - 7) The effectiveness of patient and public engagement needs to be rigorously evaluated involving local communities concerned.

¹² Patient and Public Engagement: A Practical Guide for Health and Wellbeing Boards” (2012), NHS Confederation

7.7.3 A number of these principles can be supported through the existing activity of stakeholder organisations. The Panel has adapted these principles into an operational framework for which evidence can be provided which will test the delivery of effective and coordinated engagement activity (See Appendix 3).

8. Conclusion

8.1 Patient experience of health services came into sharp focus with the publication of the Francis Report which highlighted the consequences of patient feedback not being acted upon.

8.2 The Panel's evidence showed there is an extensive range of PPE activity although this can lead to public confusion. There is a need to convince people that their voices will make a difference across the system. Also, people who may be considered 'hard to reach' may be less successful at navigating complex public service or complaints processes.

8.3 A unified approach to patient and public engagement supports the council's cooperative agenda and allows for creating capacity through sharing resources.

8.4 There is no doubt that it doesn't make sense to try to go it alone. Collaboration is essential in order to gather and make the best use of information.

9. Recommendations

9.1 The Panel's recommendation is for the Scrutiny Committee to endorse the Patient and Public Engagement Framework as set out in Appendix 3 for forwarding to the Health and Wellbeing Board.

10. Acknowledgements

10.1 The Panel is grateful to all those who have presented evidence during the course of our review. We would like to place on record our appreciation, in particular of the willingness and co-operation we have received from the below named:-

- a) Sandra Sutton, Compliance Manager, CQC
- b) Mark Cotton, Assistant Director of Communications & Engagement, NEAS
- c) Lucy Topping, Assistant Director Patient Experience, NHS England
- d) Bev Atkinson, Director Nursing & Patient Safety, Louise Burn, Strategic Lead Urgent Care, Denise Horsley, South Tyneside Foundation Trust
- e) Ann Fox, Director of Nursing, Quality and Safety, Julie Whitehouse, Sue Goulding, Sunderland Clinical Commissioning Group
- f) Alesha Aljefri, Liz Greer, Sunderland Healthwatch

11. Background Papers

11.1 The following background papers were consulted or referred to in the preparation of this report:

- a) Sunderland Joint Health & Wellbeing Strategy
- b) Patient and Public Engagement: A Practical Guide for Health and Wellbeing Boards - NHS confederation 2012

DRAFT

Duty to involve and consult

The 2006 NHS Act, section 242 (updated December 2007), places a statutory duty on all NHS trusts to proportionally involve (through informing, engaging or consulting) patients and the public on:

- planning services they are responsible for;
- developing and considering proposals for changes in the way those services are provided; and
- decisions to be made that affect the operation of those services.

Where there is a proposal for substantial development or variation of health services, Section 244 of the Act sets out the duty on NHS organisations to consult the local Scrutiny Board (Health).

In the revised Operating Framework 2010-2011 the Secretary of State for Health identified four additional key tests for service change, which are designed to build confidence within the service, with patients and communities. These require existing and future service change proposals to demonstrate:

- support from GP commissioners;
- strengthened public and patient engagement;
- clarity on the clinical evidence base; and
- consistency with current and prospective patient choice.

The Engagement Cycle

The NHS Institute for Innovation and Improvement has published an online resource for commissioners planning to engage patients, carers and the public in the decisions being made about health service provision.

Engaging with patients and the public can happen at two levels:

- Individual level – 'my say' in decisions about my own care and treatment
- Collective level – 'my' or 'our say' in decisions about commissioning and delivery of services

The Engagement Cycle is a strategic tool that helps commissioning teams to understand who needs to do what, in order to engage communities, patients and the public at each stage of commissioning.

It identifies five different stages when patients and the public can and should be engaged in commissioning decisions:

- Community engagement to identify needs and aspirations.
- Public engagement to develop priorities, strategies and plans.
- Patient and carer engagement to improve services.
- Patient, carer and public engagement to procure services.
- Patient and carer engagement to monitor services.

At each of these five stages (identify, develop, improve, procure, monitor) The Engagement Cycle provides simple advice on what to do in order to undertake high quality patient and public engagement (PPE) that will enhance and support the decisions that commissioners need to make.

Each stage of the cycle provides useful intelligence for the next (like a baton being passed on from one stage to another). The Engagement Cycle can help commissioners towards authorisation and beyond by helping to:

- Develop a shared understanding of what good engagement looks like
- Providing a strategic direction and basis for planning
- Clarifying relationships, accountabilities, roles and responsibilities.
- Clinical Commissioning Group Board Members (Chairs, Vice-Chairs, Clinical Leads for Patient and Public Engagement, Lay Members and other Board Members)
- Clinical Commissioning Group managers (e.g. Chief Operating Officers) and staff
- PPE Practitioners working with CCGs and other commissioners
- Commissioning support organisations.
- Local authorities
- Health and wellbeing boards
- Health and social care providers
- Voluntary sector, patient and community organisations

- HealthWatch

DRAFT

DRAFT