Involving Patients in Commissioning: No decision about me, without me?

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Foreword

By Katherine Murphy, Chief Executive of the Patients Association

For the last few months, the Department of Health have adopted a mantra of "no decision about me, without me" with regard to the NHS. This mantra needs to go beyond shared decisions making during individual consultations with healthcare professionals and extend to broader reaching decisions on the commissioning of services.

Patients deserve services that are relevant to them and appropriate for local needs. The only way this can happen is if patients and the public are involved in discussions and decisions about services from the outset.

With the NHS changing so dramatically, we believe this is a unique opportunity to truly embed the patient voice into the new structures that are emerging. The NHS reforms as they stand do not give enough details or clarity on how they will involve patients and the public. We have heard from GPs that they are unsure what the best way is to engage with the public, and that guidance has not been forthcoming from the Department of Health.

When we surveyed the first 52 GP consortia pathfinders, we were disappointed by the results. Of those that did reply, only six had a patient engagement strategy in place. We are concerned that consortia are just not ready to take on commissioning and put patients at the heart of services. So, we worked with over 20 GP consortia and developed a series of recommendations for patient and public engagement in the commissioning of services. These essential recommendations have been developed by GPs, patient engagement managers and patients who worked with us and believe that real, sincere and effective patient and public involvement should be at the heart of the emerging consortia.

We hope that these recommendations will form the basis for patient and public engagement in all clinical commissioning groups, forming a bedrock on which they can continue to build and expand their involvement with the public, to the benefit of both patients, healthcare professionals and the wider NHS.

Katherine Murphy
Chief Executive of the Patients Association
Executive Summary

The Health and Social Care Bill, which follows on from the White Paper ‘Equity and excellence: Liberating the NHS’ proposes a new era for the NHS, where the commissioning of services would move away from Primary Care Trusts (PCTs) and fall within the remit of GP commissioning groups (now referred to as Clinical Commissioning Groups). The principle underlying this move is to shift decision-making as close as possible to individual patients.

The intention of the Bill is to create an NHS which is much more responsive to patients, and attains better outcomes, but there is a lack of detail and clarity as to how moving towards GP and clinician-led commissioning will help to achieve this. Although GPs have greater interaction with patients than PCTs do, it does not necessarily follow that GPs are better placed to represent the patients’ viewpoint or understand the complex needs of patients in relation to healthcare. Furthermore, GPs will be involved and/or responsible for commissioning a wide range of services – from mental health to diabetes - and it will be an extremely difficult task for GPs to understand and reflect the needs of patients with such varying conditions and requirements, in the breadth of services they commission.

To determine the extent of CCGs engagement with patients, the Patients Association surveyed the first wave of 52 GP consortia pathfinders about this topic. Only 23% of consortia replied adequately. The majority agreed that patient engagement was useful and contributed to improving the work of medical practice. However, there was significant variation in the forms of patient and public engagement used and in awareness of tools that could help develop new methods.

Building on the results of the survey, the Patients Association convened a Working Group of the more proactive CCGs to discuss examples of best practice in terms of patient engagement. In particular, it was noted that patient engagement in commissioning services can lead to real improvements in patient outcomes. As part of these discussions we discussed the mechanisms needed to underpin patient engagement in service design and delivery and how CCGs would be held monitored and held accountable when ensuring patient involvement.

The Working Group developed a series of 10 recommendations which the Patients Association would like to see piloted at various CCGs across the country.

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1 Equity and excellence: Liberating the NHS, Department of Health, July 2010
**Recommendations**

**Service Design and Delivery**

1. CCGs should undertake active engagement with the public when determining the local public’s healthcare needs and planning or designing new pathways or services. This engagement should be innovative, proactive and not passive; going out to find the public’s views on specific issues, rather than waiting for the public to submit their views. CCGs should share learning and best practice with other CCGs. CCGs must continuously seek patient feedback and experiences to use as an indicator of the quality of the services they are commissioning.

2. CCGs should use effective local engagement structures and other channels to actively connect with a diversity of groups including community networks, local authorities, Healthwatch and third sector groups. This should include those who may not directly associate their concerns with health, e.g. housing associations and social groups, to ensure they engage with all members of the public, including those from traditionally ignored groups.

3. Members of the public involved in commissioning should be offered training and a role profile so that they understand the issues being discussed, the processes and procedures, and so can engage fully. The role of public representatives should be valued and as such they should be reimbursed for their time and given administrative support.

**Accountability and Monitoring**

4. CCGs should involve the public in the development of the CCGs’ public engagement strategy. The CCGs public engagement strategy must form the basis and agenda of their wider commissioning strategy and be published in a variety of media and venues so that it is accessible to all members of the public.

5. The CCGs public engagement strategy should define Key Performance Indicators (KPI) for public engagement which must demonstrate how they support the KPIs defined for commissioning. The CCG will report every quarter regarding progress against these KPIs and publish a publically available action plan to show the public what actions they are taking to meet the KPIs, with particular reference to KPIs they are failing to meet.

6. CCGs must demonstrate how they will communicate with the local population on a regular basis to inform them of any changes to services and how they will actively gain and publish patient feedback on the services they are providing. Any action taken or not taken as a result of this feedback should be reported and justified to the public in a transparent and easily understandable format.

7. There must be public representation at every level of the commissioning process within the CCG. There must be a two-way flow of information between public representatives at every levels of the CCG, from the Board to the individual practice and every level in between.

8. There must be a clear accountability structure for public engagement within the CCG and this must be defined in the CCG’s Governance. The responsibility for public involvement ultimately rests with the CCG Board. There should be:
a. On the Board - a nominated public involvement Governance lead who is a paid member of staff.
b. On the Board - a public involvement champion who is responsible for promoting public involvement.
c. Within the CCG structure - a person whose role it is to manage public involvement on a day to day basis and ensures that services meet the reasonable needs of service users.

9. CCGs must be transparent; keeping accurate records of previous actions, publishing their findings and reporting back to patients how they have decided to action feedback or recommendations and clearly outline the reasons behind this.

10. CCGs are accountable to the NHS Commissioning Board, HealthWatch and Health and Wellbeing Boards. They must establish and maintain relationships with these organisations as well as other key health stakeholders in the local health economy. They must report on locally agreed measures, and report on how patient engagement has influenced commissioning services. CCGs should also ask the NHS Commissioning Board for examples of best practice from other CCGs when developing their public engagement strategies.
Patient Engagement in commissioning health services

Introduction

The Health and Social Care Bill, which follows on from the White Paper ‘Equity and excellence: Liberating the NHS’ proposes a new era for the NHS, where the commissioning of services would move away from Primary Care Trusts (PCTs) and fall within the remit of GP commissioning groups (now referred to as Clinical Commissioning Groups)\(^2\). The principle underlying this move is to shift decision-making as close as possible to individual patients.

Clinical Commissioning Groups (CCGs) will commission the majority of NHS services on behalf of patients including elective hospital care and rehabilitative care, urgent and emergency care (including out-of-hours services), most community health services, and mental health and learning disability services.

Commissioning primary medical services will not fall within the remit of CCGs but will fall to the responsibility of the NHS Commissioning Board which will be a newly established independent body. However, the Clinical Commissioning Groups will have a responsibility for driving up the quality of general practice.

Our response

The intention of the Bill is to create an NHS which is much more responsive to patients, and attains better outcomes, but there is a lack of detail and clarity as to how moving towards GP and clinician-led commissioning will help to achieve this. Although GPs have greater interaction with patients than PCTs do, it does not necessarily follow that GPs are better placed to represent the patients’ viewpoint or understand the complex needs of patients in relation to healthcare. Furthermore, GPs will be involved and/or responsible for commissioning a wide range of services – from mental health to diabetes - and it will be an extremely difficult task for GPs to understand and reflect the needs of patients with such varying conditions and requirements, in the breadth of services they commission.

The public has a right to be involved in the planning and development of healthcare services and in decisions that may affect the operation of current services under the NHS Constitution. CCGs have a duty, as set out in the NHS Act 2006 to engage with the public when determining the healthcare needs of the local population and planning or designing new pathways or services.

Commissioning is defined as the process of ensuring that care services are provided effectively and that they meet the needs of the population. It has many facets including assessing the needs of the population, setting priorities and developing strategies to meet those priorities, securing services from providers, and monitoring and evaluating outcomes.\(^3\)

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\(^2\) Equity and excellence: Liberating the NHS, Department of Health, July 2010

\(^3\) Giving GPs Budgets for Commissioning: What Needs to be Done? Nuffield Trust June 2010
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The Patients Association has several areas of concern around the issue of GP led commissioning which are outlined below:

1. Patient-doctor relationship

Patients have contacted us through our Helpline, via our Ambassadors network and through a survey we conducted about the White Paper. Many patients raised concerns that with GPs becoming the purse holders will they now refer patients to services that are most economical as opposed to services that offer the most clinically effective treatment? Even if this is not the case, there is a real danger that the GP and patient relationship will be damaged as a result of this perception.

2. Expertise

GPs are generalists and the Patients Association question whether they have the expertise to commission for highly specialist services. Clear pathways and guidance will need to be defined. How can GPs commission services when they may only see 2-3 patients with a specific condition over their career, which is the case for rare conditions such as Meningitis? Another example is pain services – every year, over 5 million people in the United Kingdom develop chronic pain, and of that number only two thirds will recover. The Patients Association’s recent report on pain highlighted that there was not a clear pathway in the NHS for pain services. Without clearly defined pathways, it will make it very difficult for GPs to commission services.

3. Local variability

Decisions on what services and treatments to buy will be made by an individual consortium which raises the possibility of increasing variability with one consortium providing treatment X whereas the one down the road may not. This could lead to patients moving practices to ensure they are within a consortium that provides the treatment/service that they want. However, patients may be unable to exercise this level of choice and move practices due to mobility issues or being based in a location, such as a rural area, where this is no other choice of GP consortia. In this instance the impact on health inequalities and equity of access could be profound.

4. Service structure

There is a lack of clarity as to what will happen to out of hours services once PCTs are abolished - will this go back to GPs? Patients contacting the Patients Association were confused and unclear about who was responsible for out of hours care when this previously moved to PCTs in April 2004. With the

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4 Personal communication, Sue Davie, Chief Executive, Meningitis Trust, Ap
5 Pain: Breaking Through the Barrier; Chief Medical Officer’s Report 2008
6 The Patients Association, Public Attitudes to Pain, November 2010
abolition of PCTs it is likely that further confusion will be created around this service and there is lack of clarity around whether this will move back to GPs.

Within the changes proposed in the Bill, a GP practice may enter into a commissioning arrangement with a local hospital for the provision of specific services, but under the ‘Choose and Book’ system, a patient may wish to be treated elsewhere. There is a lack of clarity in the Bill as to how the potential conflict of interest of the GP as ‘commissioner’ and the patient as ‘chooser’ will be reconciled.

5. Patient engagement

The area of greatest concern for the Patients Association is around the issue of patient engagement in CCGs. We welcome that the CCGs have a duty to reduce inequalities and promote patient involvement and enable patients to make choices. However, this needs further detail as promoting patient involvement could mean simply displaying a comments box at the reception of a GP surgery. There needs to be prescriptive guidelines in place as to how this will be achieved.

The White Paper suggests that patient participation can be achieved by using Patient Participation Groups (PPGs) at individual GP practices. However, a recent survey by the National Association of Patient Participation suggests that only 37% of English practices have a PPG and that this is likely to be an over-estimate as practices with a PPG are more likely to respond to the survey. The absence of any clear guidance from Government on what CCGs should engage patients about and importantly how they should go about it will undoubtedly fail to improve the current situation where current mechanisms for engagement are not being taken up by 63% of GP practices. Additionally, whilst we would urge all practices to establish PPGs, this in itself does not guarantee adequate patient participation. There is a need to ensure that PPGs can, in practice, adopt a wide agenda, and are known and accessible to all patients, or that they are complemented by other mechanisms which have these features.

Patients with long term conditions and those with complex conditions (for example, the elderly and those with learning disabilities) are often the heaviest users of the NHS. It is essential that the voices of these patient groups – who are often the hardest to reach – are heard by consortia.

The Patients Association are not alone in their concerns around the move into GP-led Commissioning. The British Medical Association (BMA), Royal College of General Practitioners (RCGP) and General Medical Council (GMC) have all expressed concerns. Dr Hamish Meldrum, Chairman of the BMA said, “The BMA has consistently argued that clinicians should have more autonomy to shape services for

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patients, but pitting them against each other in a market-based system creates waste, bureaucracy and inefficiency".⁸

Meanwhile Claire Gerada, Chair of the Royal College of General Practitioners has said “At worst, the negative impact for GPs could be patients lobbying outside their front door, saying, ‘You’ve got a nice BMW car but you will not allow me to have this cytotoxic drug that will give me three more months of life’. I’m concerned that my profession, GPs, will be exposed to lobbying by patients, patient groups and the pharma (sic) industry to fund or commission their bit of the service. There could be letters from MPs and patient groups, and begging letters from patients”.⁹

⁹ http://www.guardian.co.uk/society/2011/mar/30/nhs-trusts-equipment-funding
Patients Association Survey of Pathfinder Consortia

To further explore the issue of patient engagement in GP consortia, the Patients Association decided to carry out a survey of the GP Pathfinder consortia. The survey was to investigate whether the GP Pathfinders were carrying out patient engagement, the type of engagement being carried out, the views of the consortia on patient engagement and whether they had a specific strategy in place.

At the time of the survey (January 2011), we contacted the first wave of 52 Pathfinder consortia which were announced. Of the 52 CCGs contacted, only 12 responded adequately (23%), with a further 4 respondents declining to complete the survey with 2 stating they were too busy to respond and 2 felt they were not in a position yet to answer the questions.

The GP consortia ranged in size from one practice to 53 practices covering between 19,000 to 298,234 patients.

The majority of consortia were already involved in some capacity in commissioning services. The level of this involvement varied, however some consortia were very active and were involved in commissioning a range of services from Glaucoma Referral Refinement to enhanced nursing for the house bound.

Only 5 consortia had a patient engagement strategy although a further 5 said that they might develop one in the future.

When asked about the effect patient engagement had on the work of their consortium, there was a mixed response. While 6 consortia agreed that patient engagement had improved the work of their consortium, 5 did not express an opinion either way and 1 disagreed.

When asked whether they wanted to see more patient engagement at their consortium, the majority (9) agreed while 3 neither agreed nor disagreed.

Similarly, the vast majority (11) agreed that patient engagement should be mandatory with only 1 consortium saying that it neither agreed nor disagreed.

The consortia were also asked whether they thought patients had enough information to help in commissioning decisions. Of the respondents, 5 said that patients did not have enough information, 4 said that patients did have enough information while 3 neither agreed nor disagreed.

On whether patient engagement had slowed down the work of the consortium, the majority (8) said that it did not slow down the work of the consortium while 3 did not have an opinion either way and 1 strongly agreed that it did slow down the work of the consortium.

The consortia gave examples of the effective initiatives and practices in patient engagement that they are currently undertaking. These included:

- Patient Participation Groups (PPGs)
- Focus groups
• Feedback forums
• Public events
• Patient Council
• Independent Engagement
• Input into service design planning
• Analysis of complaints
• Information events and meetings with existing community groups

Again there was much variation between the respondents in the range of initiatives they were undertaking. One said that it was too early in the process to define what was effective and one said that they disagreed with having a "one size fits all" approach to patient engagement.

There was also significant variation in awareness of the tools available to design patient engagement strategies.

Tools which the consortia mentioned included:

• Tools supplied by the NHS Alliance
• Tools supplied by the DH
• Tools supplied by the National Association of Patient Participation
• Tools supplied by the NHS Institute
• MOSAIC Tool
• EHRC
• Design by dialogue
• Local Government Improvement and Development Agency

It was clear that Patient Engagement was by no means embedded in the emerging GP Consortia architecture and rather alarmingly seemed to be a term used to mean a host of different activities, some of questionable value.

The Patients Association concluded that considerable value could be gained from setting out some recommendations of how patient engagement should be designed and embedded in the commissioning and evaluation of NHS services.
Developing a series of Recommendations

The survey findings had demonstrated the significant gap in current arrangements for true Patient Engagement and had exposed the lack of emphasis placed on this important aspect of commissioning by the emerging CCGs. As a result, the Patients Association decided to convene a Working Party, drawing representation from the survey respondents who were ahead of the pack when it came to developing a strategy for Patient Engagement locally.

The aim for the working group was to put together a series of recommendations for patient involvement which highlights all the critical areas for consideration and which can be used by CCGs, across the country to design their patient engagement strategies.

The working group shared examples of best practice which enabled members to examine in some detail the reality of patient engagement in the NHS at the moment. Thereafter using models of best practice to show how improvements in practice locally can help achieve the vision of "no decision about me, without me".

This document summarises the main discussions of the working group, the recommendations and outlines the proposed GP commissioning patient engagement Blueprint.
Main discussions of the Working Group:
The working group discussed several key principles that underpin meaningful Patient Engagement in Commissioning. These are summarised below.

**A duty to engage with patients.**

There must be an inherent duty to engage with patients and patient involvement should be a part of everything that a GP does. Where good examples of patient engagement exist, it is clear that they not only help patients but also help doctors to engage. Many find that with greater engagement they have more active and involved patients with better health outcomes. When Sir David Nicholson, Chief Executive of the NHS wrote to NHS staff on the subject of managing the transition to GP consortia, he said that the NHS should remain true to the values of the NHS. At the centre of that is putting the patient first and ensuring that the patient voice is heard in decisions about their healthcare.

Engagement with patients needs to be involved at every level of the NHS in the country and the agenda of engagement needs to begin running from the start of GP commissioning. This needs to include receptionists, GPs and nurses and anyone working with patients but there needs to be someone who is responsible for the patient engagement strategy; an overarching plan to ensure more long term engagement with patients.

**Clear local responsibility for patient engagement?**

Who, ultimately, would be responsible for engaging with patients; would it be the individual practice or the consortium? While practices would have some responsibility, it would ultimately be the consortium’s responsibility to ensure that patient engagement was being fulfilled.

In any situation it was felt that there needed to be a named person whose role it would be to coordinate patient engagement within the organisation. The variation between the different GP consortia would make it difficult to specify who or where that person should sit within the structure of the consortium but patient engagement needed to be part of the business plans of the GP consortia to make it incumbent on them to carry out patient engagement. In addition, whoever was to take on the role of patient engagement would need to have the right skills and abilities to fulfil the role.

The Government is building a new system which needs to engage with patients as part of what it does all the time. If we are to have a patient revolution, it needs to be embedded in GP consortia so that it is part of the system from the outset. For example, new consortia in Kent, Surrey and Sussex are working with the PCT in their area before it is dissolved on patient engagement to ensure that they are in a position to provide these services from the outset.

**Sharing Information**

It is impossible to imagine making real and effective choices without adequate information. Therefore, decision-making has to be based on robust information and patients need to be given enough information to make effective decisions about commissioning services. An example given during the
meeting was that of a hospital with old buildings and modern buildings with a plan to close one of them to preserve services. It was recognised that the automatic reaction of many people would be that neither should be closed but if they were given the full picture, that if there was no closure some services would need to be limited, they might make a different decision.

Patients need to take ownership of the services they use and to that end patients need to be fully informed. They have to feel that they are impacting on services and changes being made to them. Patients do have rights but they also have responsibilities for their own health and the health of those around them. Many doctors state that more effective consultations occur with patients that are better informed and who have taken greater control of their healthcare. By giving patients greater responsibility over services, they may take their own care and public health more seriously promoting better health in general.

The role of HealthWatch

While it was recognised that the patient voice was needed to improve services, the question remained of how to encourage the patient voice; in particular to ensure that it was not dominated by single issues. HealthWatch is being set up by the Department of Health as part of its reforms to provide a democratic accountability function. HealthWatch local could in principle serve as an effective medium for communicating local patient views to consortia and practices and communicating changes being made in the consortia back to patients. However, if HealthWatch local were to have this type of function, it would be necessary to ensure that they were established on a large enough scale with enough resources to carry out this function across all the practices in their area and are properly trained and prepared. It would not be sufficient for HealthWatch to communicate only centrally with a large consortium, which very few patients might hear of or identify with. There needs to be dialogue directly with practices, and the local HealthWatch bodies need to be well networked with a wide variety of local community and voluntary organisations at neighbourhood level.

Engaging with harder to reach groups

There is a need to widen engagement to include those who would not usually engage with or use healthcare that often, for example younger people and people from more deprived socioeconomic backgrounds. In order to include the views of these groups, patient engagement would need to be imaginative and relevant to those groups in order to be effective. In particular, consortia would need to make a bigger effort to engage with harder to reach groups. Voluntary groups should be engaged with as through these groups it would be easier to engage with typically hard to reach groups such as BME groups. They would also have a place in providing education and training for both patients and providers on specific issues that might need to be considered, for example diabetes care. A joined up approach would also be needed to reach into communities that would not usually be involved in engagement with healthcare. To that end, there should be an effort to engage with groups that do not see themselves as necessarily health related like housing associations, community associations, sports clubs, social clubs, tenants’ and residents’ associations and local umbrella groups from the voluntary and community sector.
through an open agenda to improve neighbourhoods. An example of this was given in the presentation by Peter Wasson with the Beacon Project in Falmouth where the Penwerris Tenants and Residents Association was set up to improve conditions in the Penwerris Estate. This concentrated largely on housing but because of their efforts health improved as well. While not framing the engagement in health terms, this would include health issues and would bring out changes that could be made to improve local people’s health.

**Utilise a Partnership Approach**

The relationship between GPs and patients is central to patient confidence but often GPs do not understand that they have to consult and engage with patients. There is a need to move away from the traditional paternalistic view of the doctor-patient relationship and towards a more partnership based approach. Patients need to be informed about the issues that affect healthcare in their area and be able to input into decision-making but it needed to be understood that patients have responsibilities as well as rights. By giving them greater control of their healthcare it will be easier for healthcare professionals to treat them. But in order to take greater control of their healthcare, patients need to be educated about the consequences of the choices they make before they make it. GPs need to begin to understand that these policies often work for GPs as well as patients, but in order to spread this best practice it is important that there is evidence that it works.

**Use outcomes of engagement to inform actual decision-making**

There was some discussion of how patients might be able to feed effectively into decision-making and it was felt that it should be down to the local consortia to establish how this would operate whether by an advisory council, a specific engagement policy with local HealthWatch or lay members on the board of the consortia, for example. In any event, there needs to be a two way dialogue between communities and the health services providers to allow information on what is affecting local people to feed into decisions about their healthcare. The option of an advisory council merited further discussion particularly with regard to its place within a consortium: would it sit in a practice, at board level or at another stratum of consortium organisation? At practice level it would be able to feed in about particularly local matters that affect the practice only but with a consortium wide advisory council made up of representative from practice advisory councils could have an impact on consortium policy. This model may not be suitable for all consortia and it should be up to each individual consortium to decide what model would work best for them.

On the flip side, there also needs to be feedback from providers to patients so that patients can see the good that is coming out of their engagement and encourage an ongoing relationship. There need to be clear goals for the outcomes expected of any service design so a measure of their effectiveness can be made and improvements devised.
Patients need to be part of service redesign or else it will not be able to effectively provide care for them and it is vital that patients are involved in identifying health needs. Methods suggested for doing this include:

- Patient representation on Clinical Commissioning Groups
- Designated Patient and Public Engagement person and process
- Questionnaires
- Surveys
- Patient Participation Groups
- Newsletters
- Website feedback
- Other focus groups

**Continuously Evaluate impact of Patient Engagement**

In order to ensure continuing patient satisfaction there needs to be an effective measure of patient experience before and after any changes that are made. While the patient voice is needed when service design takes place, in measuring the success of those services patients must be engaged with to get an accurate measure of how well they are working for patients. There also needs to be evidence that when patients do feedback on services, changes have been made. Continuous interaction with patients on redesign would improve services but this would require a change in the culture. This could be facilitated by a Patient and Public Involvement report, possibly submitted to the Health and Well Being Board. This would further emphasise patient ownership of services and their improvement.

**Information Gathering & Sharing**

While it is essential that patients be asked for their opinions it would be necessary to ensure that there is better coordination of information gathering. In particular we need to ensure that patients are not overburdened, for example with surveys, and that feedback is received from a wide range of patients and not just those who are likely to reply. As part of this, a better system of intelligence management would be needed to allow easy access to different sources of information, for example local newspaper reports.

**Incentivise GPs**

Changing the culture within GP consortia would be difficult but could be made possible by further incentivising GP consortia to engage with patients and the public more. This would need to incentivise proactive actions on patient engagement and not simply passive ones. The design and redesign of services should not be done without public involvement and could be a mandatory part of commissioning services. However, it is important to note that involving patients does not mean that everybody will get what they want. At a practice level, incentives could be provided by incentive budgets.
Up until now, PCTs have had to submit Patient and Public Involvement Statements. These are statements describing the outcome of the patient and public involvement exercises such as consultation and surveys. PCTs are expected to say how they went about involving patients, whether they followed the outcome of the patient engagement, a consultation for example, and if they had not followed it, why they had taken a different course of action. It is unclear with so many changes happening whether these will be continued. We urge that they should not only be continued but enhanced and used as a tool in incentivising patient engagement and also incentivising action on patient engagement work. Consortia would need to justify why they had not taken action in line with their patient engagement.

Part of the discussions of the working group involved sharing examples of best practice in terms of patient engagement. Further examples are give in the appendix but two examples that stood out as extremely effective by the working group are highlighted here.

**Case Study - NHS Derbyshire – Dental Access Helpline**

In 2008 staff working in the PALS teams across Derbyshire noticed that they were receiving a high volume of calls about dentistry and in particular from patients who wanted to know how to get access to dental services. They decided to set up a Dental Access Helpline which was staffed by a temporary member of staff.

They then brought together a publicity campaign to raise awareness of the Helpline and the committee which worked on the publicity campaigns which included a PPI manager and a lay representative. The group designed posters and “credit cards” with the Helpline number which have been widely distributed. They have also had the Head of Dental Commissioning speaking on the radio to spread the word.

The Dental Access Helpline receives more calls than any other part of Derbyshire PALS and they now have a full time dedicated member of staff working for the Dental Access Helpline.

The Helpline works with the dental commissioners to ensure the information for patients is accurate and up to date. They also share the information on provision of services with other PALS services so they can use it to help give advice to dental patients.

The Dental Access Helpline has also been using information from patients to help inform how services are commissioned by sharing information and learning with dental commissioners. For example, many more patients are seeking NHS dental treatment because private treatment is proving too expensive. By having this two way flow of information, services can be commissioned in a way that suits the people that need it.
Case Study - NHS Cumbria – Children and Young People: Choosing a new provider

NHS Cumbria wanted to involve young people and children in the selection of a new lead provider for children and young people’s health services. Children and young people have very specific needs and by directly involving those for whom the service is aimed, it was hoped a more tailored service was possible.

They brought together 10 children and young people aged between 11-18 from a variety of social backgrounds to discuss the issues surrounding the decision of picking a new lead provider. They were asked to give their experiences of the going the NHS and what mattered to them aside from clinical contact, for example, how they wanted to be treated by staff.

There was considerable discussion at the focus groups on a variety of subjects and the young people who were participating then gave a presentation on their ideal care pathway to the rest of the group.

The participants were also invited to a Trust selection day, where the NHS trust gave a presentation on their ideas for health services in Cumbria. The feedback gathered by the group was used to challenge the provider, focussing on:

- staff attitudes to young people
- transition from child to teen health
- equipment
- travelling to other areas for care

As a result of this work and the information gathered, 7 new care pathways were developed for children and young people healthcare.

The young people involved in this group work have been kept up to date on the progress of the project and as a direct result of their involvement a new lead provider was selected.
The Patient Association’s Recommendations for Patient Engagement in GP-led Commissioning

As part of the Working Group discussions ten recommendations were formulated that would ensure effective patient engagement in GP commissioning. These recommendations are summarised below.

**The Patient Association’s Recommendations for Patient Engagement in GP-led Commissioning**

**Service Design and Delivery**

1. CCGs should undertake active engagement with the public when determining the local public’s healthcare needs and planning or designing new pathways or services. This engagement should be innovative, proactive and not passive; going out to find the public’s views on specific issues, rather than waiting for the public to submit their views. CCGs should share learning and best practice with other CCGs. CCGs must continuously seek patient feedback and experiences to use as an indicator of the quality of the services they are commissioning.

2. CCGs should use effective local engagement structures and other channels to actively connect with a diversity of groups including community networks, local authorities, Healthwatch and third sector groups. This should include those who may not directly associate their concerns with health, e.g. housing associations and social groups, to ensure they engage with all members of the public, including those from traditionally ignored groups.

3. Members of the public involved in commissioning should be offered training and a role profile so that they understand the issues being discussed, the processes and procedures, and so can engage fully. The role of public representatives should be valued and as such they should be reimbursed for their time and given administrative support.

**Accountability and Monitoring**

4. CCGs should involve the public in the development of the CCGs’ public engagement strategy. The CCGs public engagement strategy must form the basis and agenda of their wider commissioning strategy and be published in a variety of media and venues so that it is accessible to all members of the public.

5. The CCGs public engagement strategy should define Key Performance Indicators (KPI) for public engagement which must demonstrate how they support the KPIs defined for commissioning. The CCG will report every quarter regarding progress against these KPIs and publish a publically available action plan to show the public what actions they are taking to meet the KPIs, with particular reference to KPIs they are failing to meet.
6. CCGs must demonstrate how they will communicate with the local population on a regular basis to inform them of any changes to services and how they will actively gain and publish patient feedback on the services they are providing. Any action taken or not taken as a result of this feedback should be reported and justified to the public in a transparent and easily understandable format.

7. There must be public representation at every level of the commissioning process within the CCG. There must be a two-way flow of information between public representatives at every levels of the CCG, from the Board to the individual practice and every level in between.

8. There must be a clear accountability structure for public engagement within the CCG and this must be defined in the CCG’s Governance. The responsibility for public involvement ultimately rests with the CCG Board. There should be:
   a. On the Board - a nominated public involvement Governance lead who is a paid member of staff.
   b. On the Board - a public involvement champion who is responsible for promoting public involvement.
   c. Within the CCG structure - a person whose role it is to manage public involvement on a day to day basis and ensures that services meet the reasonable needs of service users.

9. CCGs must be transparent; keeping accurate records of previous actions, publishing their findings and reporting back to patients how they have decided to action feedback or recommendations and clearly outline the reasons behind this.

10. CCGs are accountable to the NHS Commissioning Board, HealthWatch and Health and Wellbeing Boards. They must establish and maintain relationships with these organisations as well as other key health stakeholders in the local health economy. They must report on locally agreed measures, and report on how patient engagement has influenced commissioning services. CCGs should also ask the NHS Commissioning Board for examples of best practice from other CCGs when developing their public engagement strategies.

The rational for each of the recommendations is summarised below.

Rationale for Recommendations 1-4 on Service Design and Delivery:

- There do need to be standards but they need to be localised to make them relevant to the needs of local people – for example the needs of people in Newham will different to those in West Staffordshire;
- There are already legal obligations in place under section 242 of the NHS Act 2006 to consult with the public when designing or redesigning services. Patient and the public should be aware of their legal recourse to this statute if they do not feel the public have been properly engaged with;
- Any duties to engage with patients and the public needs to be in line with section 242 of the NHS Act 2006. Any legal duties and best practice needs to be clearly defined;
Simply publishing all the documents from a meetings does not fulfil the requirement for transparency and the documents need to be summarised in a way that people understand; 

CCGs need to value public involvement not just do it because of legal obligations; 

It is important to engage with existing structures but only if they are effective. In addition, “voluntary groups” do not cover the many groups that work to represent patients and so any reference to this should be changed to “third sector groups”;

Those who are being asked to get involved need to be targeted to ensure they are the right people for the right issues; 

Instead of talking about hard to reach groups, which some consider to be a label to allow a group to be ignored, talk about “traditionally ignored” groups; 

All references to “patient engagement” should be changed to “public engagement” as it is important to also capture the views of healthy people before they need to access health services; 

Training needs to be relevant to the needs of people being engaged with and appropriate for the “level” of engagement, i.e. those involved in actual commissioning decisions will need specific understanding; 

Training should not be forced on people as this may put some people off becoming involved. Instead, training should be offered where people feel they need extra support; 

GPs will also need to have additional training to help them effectively engage with patients and to allow an equal relationship between clinicians and the public; 

There needs to be an option for reimbursement whether through money or vouchers to recognise the value of the work performed by the lay representatives; 

"You said, we did" – there needs to be more input from patients on what they need and want and more feedback from commissioners on what they have done to help. Commissioners should justify their decision to act or not act upon the input of the public and be accountable to the public regarding this decision; 

From the outset it needs to be clear that patients and members of the public who are engaging with CCGs are looking into issues with commissioning not providing services.

Rationale for Recommendations 5-10 covering evaluation and monitoring: 

CCGs should be required to publish their engagement strategy but they should go further and should demonstrate how public engagement has set the agenda for their commissioning aims and how this has been tied in with the CCG’s commissioning strategy; 

Patient and the public need to be involved in the development of the patient and public engagement strategy; 

CCGs should establish Key Performance Indicators (KPIs) and report back to the public, demonstrating how they have fulfilled their patient engagement strategy;
• It is the responsibility of the CCG to prove that public engagement has occurred and this must be demonstrated in clear and transparent terms to the public;
• The patient and public engagement strategy should be published in a variety of methods and venues;
• Any reference to providers should be removed. It is the Commissioner’s role to hold providers to account for what they have been commissioned to do. The Commissioners should ascertain what patient want and need and then commission a provider to provide it;
• Naming specific committees and boards which should have lay representation would limit the number of organisations that this might be useful for as there are many different setups across the country. Rather there should be a duty to demonstrate pathways of public involvement throughout the entire commissioning process;
• The role of lay representation on a Board is not to coordinate public engagement but to champion it;
• The responsibility for ensuring public engagement rests with the Board as a whole and they should be held to account for this as part of their commissioning plan;
• Although responsibility for coordinating patient and public engagement rests with the Board, there should be senior members of staff who are responsible for the day-to-day management of public engagement;
• CCGs should establish and maintain relationships with key stakeholders in the local health economy to allow them to become involved in decision making.
Relevance to the latest revision of the Health & Social Care Bill

Since March 2011, there have been significant changes to the Health and Social Care Bill and in particular the specifically regarding GP consortia, now to be called Clinical Commissioning Groups.

NHS Listening Exercise

On the 4th April, the Prime Minister, David Cameron, and the Secretary of State for Health, Andrew Lansley, announced that there would be a 2 month pause in the passage of the Bill through the House of Commons. The purpose of this pause was to hold a “listening exercise” to address the concerns that medical professionals and the public had raised with regard to the reforms.

Speaking to MPs in the House of Commons, the Secretary of State for Health, Andrew Lansley said, “We recognise that this speed of progress has brought with it some substantive concerns. Some of those concerns are misplaced or based on misrepresentations but we recognise that some are genuine. I can therefore tell the House [of Commons] that we propose to take the opportunity of a natural break in the passage of the Bill to pause, listen and engage with all those who want the NHS to succeed, and subsequently to bring forward amendments to improve the plans further in the normal way.”

It was announced that the Listening Exercise would focus on the following issues:-

- The role of choice and competition for improving quality;
- How to ensure public accountability and patient involvement in the new system;
- How new arrangements for education and training can support the modernisation process; and
- How advice from across a range of healthcare professions can improve patient care.

Professor Steve Field, former Chairman of the Royal College of General Practitioners was appointed Chair of the NHS Future Forum which was the conduit through which views would be gathered during the Listening Exercise.

The Patients Association held its own independent listening events across the country which were attended by over 200 people and sent out a survey on the NHS reforms which was answered by well over 1,000 patients, members of their families and carers.

Patients told us that they had major concerns about the reform plans for the NHS. The move to GP commissioning continued to be a constant concern for the vast majority of patients. In particular, patients were concerned that by holding the purse strings GPs may be torn between commissioning the most cost effective services and those that are the most clinically effective for patients. Patients who we spoke to told us that they feared that the move to GP consortia would damage the trust between doctors and patients. It is widely acknowledged that patient trust is important in ensuring effective

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10 HC Deb 4 April 2011 cc767-770
11 Patients Association: PAUSE: Patients Association Urges Serious Examination: 2011
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If patients do not feel that they are able to trust their healthcare professional, patient outcomes may suffer, in particular due to non-adherence to medicines. There needs to be real accountability and transparency within the GP consortia to ensure that the trust of patients is preserved.

We believe that the needs of patients must be at the centre of all stages of the decision making process when commissioning services. It would mitigate the concerns that many patients share that commissioning decisions will be based on price rather than what is best and most appropriate for patients. By involving patients and the public in these decisions, they can help influence these decisions and make the result more acceptable to the public at large. For example, in Lancashire the local PCTs decided that they needed to reorganise their mental health services, and in particular to reduce the number of mental health facilities from 15 small facilities to 3 large ones. After consultation with patients, carers and the public, it was decided that this option was acceptable but only if more community services were available including home help and respite facilities.

**NHS Future Forum**

The NHS Future Forum announced its recommendations on the 13th June 2011 which included many significant changes to how services would be commissioned.

On the issue of accountability and transparency, Professor Field said, "Because the NHS 'belongs to the people' there must be transparency about how public money is spent and how and why decisions are made and the outcomes being achieved at every level of the system."

The report of the NHS Future Forum found that many of the people they had spoken to said that they felt it was the patient who had to adapt to the changes of services around them rather than the services adapting to their needs. Patients wanted services to be closer to them or indeed to be provided for them at home if required.

While services could benefit from a wider range of expertise on commissioning boards, the Future Forum advised against specifying which professionals should be involved and how many should sit on the commissioning board.

The Future Forum felt that the Health and Wellbeing Board would have an important part to play in making sure patient involvement in decision making becomes a reality. GP consortia would have to agree their commissioning plans with the Health and Wellbeing Board and if the Health and Wellbeing Board have concerns about the plan, they can refer it to the NHS Commissioning Board. One of its key

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14 S. Field et al; NHS Future Forum: Summary report on proposed changes to the NHS; 2011
recommendations was to strengthen the definition of patient and public involvement with reference to the duty to involve patients and the duty to promote involvement which the Bill supplies. They further recommended that there needed to be independent lay representation on the governing body of a commissioning consortia but again did not specify any role they should have or the number of representatives there should be.

**Government changes to the Health and Social Care Bill**

The Prime Minister, David Cameron, responded to the changes proposed by the Future Forum on the 14th June accepting a large number of them. Notably, the governing bodies of commissioning consortia were to include at least one nurse, at least one specialist Consultant and at least two lay representatives. This was despite the advice of the NHS Future Forum not specify which professionals should sit on the governing body of commissioning consortia. As a result, the name of GP consortia is to be changed to Clinical Commissioning Groups (CCGs).

Health and Wellbeing Boards will have a duty to involve patients, the public and carers and will also be heavily involved throughout the process of commissioning services and have the power to refer CCGs to the NHS Commissioning Board. CCGs would have a duty to consult with patients, the public and carers on their commissioning plans and ensure real opportunities for patients to be able to give their input. In addition, patients and the public will have to be involved in decisions that make any changes to patient services and not only those that will have a “significant impact”. However, there is little detail on how this will happen.

There must be at least two lay representatives on the Board of the CCG and they have been assigned specific roles. One must be responsible in some way for a key element of governance such as finance, auditing or accounting and the other must be responsible for championing patient engagement. One of these lay members would have to take the role of Chair or Deputy Chair of the governing Board.

Speaking to the House of Commons, the Secretary of State for Health, Andrew Lansley, gave a statement on the NHS Future Forum on the 14th June. On the issue public involvement he said, “For commissioning to be effective, the process of designing services must draw on a wide range of people, including clinicians, patients and patient groups, carers and charities. We will amend the Bill so that the governing body of every clinical commissioning group will have at least two lay members, one focusing on public and patient involvement and the other overseeing key elements of governance, such as audit, remuneration and managing conflicts of interest...[and] we will further clarify the duties on the NHS commissioning board and clinical commissioning groups to involve patients, carers and the public.”
Commissioning groups will have to consult the public on their annual commissioning plans and involve them in any changes that would affect patient services.\footnote{HC Deb 14 June 2011 cc644-647}

By and large the response by the Government has been broadly welcomed by professional groups including the British Medical Association (BMA) and Royal College of General Practitioners (RCGP).

*The Patient Associations views of the Government’s proposed changes*

Although the changes to the Bill proposed by the Government have helped to take the issue of patient and public involvement forward, the Patients Association are concerned that they have not gone far enough. There are still many outstanding concerns and areas in the Bill that lack detail. How will GP consortia engage with harder to reach groups such as Black and Minority Ethnic (BME) groups and elderly patients? How will lay representatives be given the support they need to fulfil their role? CCGs will have a duty to consult with patients on their commissioning plans but this is not the same as having patients involved in the design and development of the initial plans. There is also a lack of clarity around what is meant by patients being consulted if a change will result in a ‘significant impact’ on services. We welcome the strengthening of the role of the Health and Wellbeing Boards but more information is required in terms of how they will determine whether they have fulfilled their duty in involving patients in commissioning services.

The Patients Association welcome the Government’s commitment to involving patients and the public in decisions making about services in their local community but we still believe this is not a high enough priority for the Government. Public involvement needs to be a priority for it to have an effect. It could be all too easy for CCGS to put a patient and public engagement strategy in place without having to take any action on it. If there really is to be “no decision about me, without me” then patient and public engagement needs to be at the heart of commissioning decision making. We still believe that there are too many unanswered questions and a lack of enough detail to fully understand the place of public involvement in commissioning decisions. We have heard from many GPs and commissioners who are taking on this role for the first time, which they want and need guidance and help to get patient and public engagement right. Coupled with the concerns of patients regarding their involvement in the commissioning of local services, it is in that context that we developed the Blueprint.
Conclusions

There is a clear need for firm and definitive guidelines for CCGs on how to effectively engage with patients during all stages of the commissioning process. While some CCGs have already taken the first steps and have plans in place, the majority of CCGs that we contacted still have a long way to go before they are involving patients and the public in decisions about local services.

The fact that so few CCG pathfinders responded to our survey suggests that patient engagement is a low priority for CCGs and is not a focus when setting up a newly formed CCG. This goes against the Government’s reasoning behind the policy for GP commissioning, which was to ensure patients are at the heart of the local NHS.

The responses we did receive demonstrate a wide variation in how CCGs are engaging with patients and the public with some feeling that a Patient Participation Group was sufficient while other CCGs were actively seeking out public opinion on a variety of topics. Furthermore, several of the CCGs we contacted said they would be keen to have guidance on what to do in terms of patient and public engagement.

The recommendations on patient engagement detailed in this report have been developed through discussion with a Working Group of representatives from CCGs from across the country. This included GP leads, patient engagement leads and patient representatives from CCG boards as well as representatives from the Patients Association. We believe that these recommendations for patient and public engagement set the benchmark by which all CCGs should be measured. Having been developed by healthcare professionals in partnership with patients, they are practical, effective and attainable and are applicable to any CCG across the country. We plan to trial these recommendations at several CCGs across the country to provide evidence as to their benefits to CCGs, patients and public alike.
Appendix

Full text of Section 242 of the NHS Act 2006:

(1) This section applies to—

(a) Strategic Health Authorities,
(b) Primary Care Trusts,
(c) NHS trusts, and
(d) NHS foundation trusts.

(2) Each body to which this section applies must make arrangements with a view to securing, as respects health services for which it is responsible, that persons to whom those services are being or may be provided are, directly or through representatives, involved in and consulted on—

(a) the planning of the provision of those services,
(b) the development and consideration of proposals for changes in the way those services are provided, and
(c) decisions to be made by that body affecting the operation of those services.

(3) For the purposes of this section a body is responsible for health services—

(a) if the body provides or will provide those services to individuals, or
(b) if another person provides, or will provide, those services to individuals—

(i) at that body’s direction,
(ii) on its behalf, or
(iii) in accordance with an agreement or arrangements made by that body with that other person, and references in this section to the provision of services include references to the provision of services jointly with another person.

(4) Subsection (5) applies to health services for which a Strategic Health Authority is not responsible by virtue of subsection (3), but which are or will be provided to individuals in the area of the Strategic Health Authority, and for which—

(a) a Primary Care Trust any part of whose area falls within the Strategic Health Authority’s area, or

(b) an NHS trust which provides services at or from a hospital or other establishment or facility which falls within the Strategic Health Authority’s area, is responsible by virtue of subsection (3).

(5) A Strategic Health Authority may give directions to Primary Care Trusts falling within paragraph (a) of subsection (4), and NHS trusts falling within paragraph (b) of that subsection, as to the arrangements which they are to make under subsection (2) in relation to health services to which this subsection applies.

Patient engagement examples

**East London Integrated Care – Wider Patient Engagement**

This is an ongoing project in its beginning stages and the hope is to ensure that patients are engaged and continue to be engaged with decision making.

The first step they are taking is to work with the existing patients groups at practices within the consortium to re-engage with them. In recent years it was realised that these groups had dwindled and in some cases ceased to exist. The lay representative from the board of the ELIC has been attending practice manager meetings and meetings of patient groups to speak to them. Working with them, the plan is to resurrect these groups to ensure that all practices have a Patient Participation Group as a basic level of patient engagement.

The next step is hoped to reach out to those who the group may not be reaching by utilising new media, particularly social media using Twitter and Facebook for example. Many patients, particularly younger patients, may not have the time or inclination to attend meeting but would be happy to respond to comment on the internet. By making patient engagement easier, this may allow new patients who have not been engaged before with their healthcare providers to make themselves heard.

This is still in its embryonic stages but forms a good example of active and enthusiastic approach to patient engagement, seeking to hear patients’ opinions rather than waiting for patients to come to them.
**Tower Hamlets PCT**

In Tower Hamlets, around 18% of people live with one or more long term condition. For example, obesity rates in Tower Hamlets were significantly higher than in London or across the country.

There is a very ethnically diverse population with large number of recent immigrants. It is also one of the more socially deprived areas of London. There was a similar concern that their was lack of health literacy particularly amongst many people from BME groups in the Borough.

The PCT aimed to improve the take up of courses about long term conditions.

They undertook research independently and along with local community leaders and individual patients to inform their response

Have increased uptake of such course by ensuring that language tailored, culturally sensitive and well placed courses were available

They engaged with local community and faith leaders to tailor information and the courses to people from specific including providing courses in languages other than English.

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**Beacon Project – Falmouth**

There was chronic anti social behaviour on the Penwerris estate which was affecting residents physical and mental health.

In 1995, two health visitors, decided to implement a joined up approach to tackling health, to incorporate direct factors such as smoking/diet/alcohol of the residents as well as indirect factors that were influencing health such as housing and lifestyle.

They therefore set up the Penwerris Tenants and Residents Association (PTRA) to take this joined-up approach to services and care forward

They applied for a £2.2 million grant and on the back of this the PTRA went about improving housing – helping residents improve their gardens and providing activities such as dancing and singing to get children off the streets. They also set up a full time advice centre and community activities.

Between 1995 and 2000, the changes and improvements made by the PTRA reduced Postnatal
depressions rates by 77%, lower incidence of asthma and lost schooldays an reduced the childhood accident rate by 50% along with other improvements in social and educational life.

The model has also been reproduced in a similar so called "sink estate", Redruth North to great effect where there has been, amongst other beneficial outcomes, a reduction in underage drinking incidence of 20% and an 18% reduction in ambulance call-out rates

With commissioning being moved locally to the Local Authority it is hoped that this type of initiative – that encompasses health and wider social services may be able to be commissioned.

**South Staffordshire PCT**

There is no set way in which PPGs work - the aims and work of each group entirely depends on local needs - but they all should share the aim of making sure that their practice puts the patient, and improving health, at the heart of everything it does. One problem with this is that as there is no set format of how they work they can be subject to local variability. Much debate about their effective often down to how well they are resourced, skills of the volunteers amongst others things

South Staffordshire PCT decided to take PPGs one step further and introduced PPGs not only at the GP level but also a district group.

They formalised this relationship with a Local Enhanced Services (LES) agreement

The agreement formalises the remit and work of the PPG in the PCT meaning they cannot be sidelined or ignored when it is criticising decisions allowing it to have a more large ranging scrutiny function.

Information can flow 2 ways

- Patients can take forward issues identified at practice level that may impact the wider population. They can influence the PCT’s strategic and commissioning objectives so the specific needs of the community are met when designing services
- Commissioners have a direct connection with the patients and public that they look after to understand the issues that will affect them.

In addition, a PCT wide Patient Council was set up to feed into issues that lie outside the remit of the commissioners and affect the community

One outcome in particular was that patient information was tailored by individual PPGs to ensure that their contents were relevant and sensitive to local people.
Involving Patients in Commissioning: No decision about me, without me?