THE NHS ENIGMA – DENIAL OF ITS SICKNESS AND REFUSAL TO TAKE ITS MEDICINE OF PATIENT AND PUBLIC INVOLVEMENT (PPI)

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CONTENTS
1 Summary conclusion – paternalism is keeping the NHS sick and in crisis
2. Recommendation – engage properly with patients
3 Government statutory requirements for PPI
4 ‘Involvement’ did not involve patients, public or staff
5 PPI is incompatible with paternalism
6 NHS constitution, which became statute law on 21.1.10
7 PPI rhetoric by Brighton and Hove Clinical Commissioning Group
8 Cross party support for Rewiring Public Services
9 Our CCG’s response to the Francis report, which calls for PPI at the heart of decision making
10 NHS England launches revolutionary plan to get patients more involved in their care
11 Friends and family test extended
12 Holism – a better way of knowing - how the British Holistic Medical Associaton (BHMA) sees the Berwick report
13 Conclusion – just do PPI
14 References

1 Summary conclusion – Paternalism is keeping the NHS sick and in crisis
Health Secretary Jeremy Hunt rightly says that the NHS is sick, and in my deputation (paper 9.60 of www.reginaldkapp.org) I say it has dementia (1) The cure is Patient and Public Involvement (PPI) for which managers have had the statutory duty since the 1980s. However, they discharged it with ‘consult and ignore’, so 4 years ago Parliament enacted the NHS Constitution which gives patients and the public the statutory right to be involved in the planning of healthcare services.

Despite these statutory duties and rights, PPI is still not happening, so more and more reports (see paragraphs 6-12 below) are recommending PPI as part of the cure for the NHS. This indicates that the resistance to PPI is stronger than statutory duties and rights. I call this the NHS enigma.

The NHS enigma is its resistance to PPI. This year almost every report on the NHS emphasises the importance of PPI, but it is still not happening. The NHS is an immovable object, which
requires an irresistible force to shift it, so more and more organisations are joining the call for PPI, as set out in paragraphs 6-13 below. This paper is one of many I have written to cure the NHS. As with any patient, the first thing to do is to understand the cause of their sickness, (paternalism) and remove it. (acknowledge that paternalism is just a habit, and break it)

The resistance to PPI is because of paternalism, which is characterised by a doctor on a pedestal telling patients on their knees to keep taking the pills. Paternalism is incompatible with PPI, as it requires a role reversal, with the patient on the pedestal telling the doctor what services to provide. His moral justification for this is summed up in the saying: ‘he who pays the piper calls the tune.’ The patient on the pedestal represents the taxpayer who pays for the NHS, including the doctor’s salary.

This role reversal is hard for both doctors and patients to take, because both have been habitually conditioned to think this way, and both get a secondary gain from it. The patient gains by dumping the responsibility for looking after his own health on the doctor, and having someone to blame when he is ill. The doctor gains by having his ego flattered. However, paternalism is a bad habit which is killing both patients and doctors, (1) and is part of the cause of the crisis in the NHS so must be broken if the NHS is to be cured.

The first hard pill for doctors and commissioners to swallow is this sentence: ‘All of the medical journals, from the BMJ and the Lancet, to the Journal of the American Medical Association and the New England Journal, have revealed the scale of the problem – that correctly prescribed drugs are the fourth leading cause of death, and that drug companies massage and make up data. (2)

2. Recommendation – engage properly with patients

Everybody from Jeremy Hunt downwards is calling for a culture change to engage with patients under PPI, but this message seems to be falling on deaf ears (hence this paper) It is clear that the NHS cannot heal itself of its bad habit of paternalism, and like any other patient, needs to acknowledge that it is ill, and that it needs outside assistance to be cured.

This is now available under the Health and Social Care Act 2012, which filled the democratic deficit in health, and created Health and Wellbeing Boards. These are now responsible for public health and the Clinical Commissioning Groups (CCGs) which control about two thirds of the NHS budget (£400 mpa in the city). Councillors now have the statutory power to heal the NHS by breaking the bad habit of paternalism. They should change the staff culture of the NHS and Social Care services from ignoring to welcoming suggestions from patients, fellow staff and the public by setting the standard following routine, which is the ‘golden rule’ of every religion - ‘do as you would be done by.’

2.1 Acknowledge every suggestion with a ‘thank you’.

2.2 Ensure that all suggestions are considered seriously by the appropriate manager(s).

2.3 Reply to the person making the suggestion stating whether and when the suggestion is to be implemented, or if not, why not.
2.4 Manifest the above procedure regarding the suggestions that I have made for a self referral primary care mental health service as described in paper 9.64 of www.reginaldkapp.org, (3)

3 Government statutory requirements for PPI
I have been a full time patient representative since 2000. I have served on countless committees and been to hundreds of meetings and conferences concerning the NHS and public health. The following remarks are based on my experience, together with previous work as a engineer economist in electricity supply, and a political activist.

For nearly 30 years there has been a statutory requirement to consult patients and the public in the design and provision of the NHS services, since the Community Health Councils (CHCs) were created in the 1980s. However, they were ineffective, because they were automatically ’consulted and ignored’ by the managers.

About 10 years ago, around 2003, the statutory duty to consult was strengthened to involve’, when the CHCs were changed to Patient and Public Involvement Forums (PPIFs) They did not work either, so were changed again under the Local Government Act 2007, which in April 2008 changed the PPIFs to Local Involvement Networks (LINks), still with the statutory duty to involve’.

These did not work either, because there were conflicts of interest built into them. The reasons are set out in my paper: ‘The way ahead for LINks and Healthwatch’ dated 7.7.10, (see paper 9.52 of www.reginaldkapp.org. The coalition government changed them again under the Health and Social Care Act 2012, which took effect in April 2013, when LINks became Healthwatch. The word involve was strengthened to engage’, and the duty was extended to engage with social care service users.

The word ‘engagement’ is meant to be stronger than the word ‘involve’. However, both words mean listening to what patients and the public are really saying, discussing the issues raised in meaningful debate, and designing services accordingly. This paper seeks to ensure that this change in word will change the culture from ignoring suggestions to welcoming and acting on them.

4 ‘Involvement’ did not involve patients, public or staff
In all my experience over the last 13 years, I was often asked to contribute to the discussion of topics, but I never felt consulted, involved or engaged in any decision making. Admittedly the questions were often complex, and needed time to be properly considered. Accordingly, I usually responded by writing papers in the days or week following, and then submitting them. These now total over 50 papers over the last 8 years, which I wrote for the NHS and Council, most of which are published on my website section 9 of www.reginaldkapp.org.

However, I never had any acknowledgement of receipt, nor thanks, nor any meaningful consideration of my proposals, nor reply, so never felt listened to or heard.

I used to think that this might be personal, but my observation is that everybody feels the same. A Channel 4 news report on 12.9.13 by Victoria Macdonald showed that there has always been a culture of hiding bad news, rather than acting on it to improve the service. She said that only 1 in 375 complaints were ever investigated, and that Sir David Nicholson had
denied seeing Sir Brian Jarman's publicised statistics that UK has the worst mortality figures in hospital of 6 western nations (and 45% worse than USA) yet his website had had 69,000 hits.

Whistle blowers are persecuted. I conclude that nobody feels listened to because nobody is listening. This is a psychological phenomena, which deserves attention, as the crisis in the NHS is getting worse and worse. The Royal College of GPs (Dr Gerada) and the health secretary (Jeremy Hunt) warns us that the whole system is ‘at breaking point.’

The NHS is our health service, so it is up to us to cure it. To do so, we have to find the cause, and remove it. I am writing this paper to share my thoughts on this matter. My observation is that there is not only a culture of hiding bad news, but also ignoring suggestions for improvement from patients, staff, and public alike.

5 PPI is incompatible with paternalism
I have written (1) that many of the problems of the NHS crisis result from paternalism, see other papers published on section 9 of www.reginaldkapp.org. Paternalism is characterised by a doctor on a pedestal telling patients on their knees to keep taking the pills. It is a false paradigm (unspoken belief system) with which both doctors and patients are conditioned (hypnotised). It is maintained because both doctor and patient get a secondary gain from it.

The doctor feels superior, and is glad to have his ego flattered. The patient feels like a dependent child, and is glad to dump the responsibility for looking after his own health on the doctor. The pills make him sicker with side effects, and he is glad to have someone to blame when he does not get better.

Proper PPI requires the patient to tell the doctor what service he expects, which is a role reversal of paternalism. The moral justification for this role reversal is summed up in the saying: ‘he who pays the piper calls the tune.’ The patient on the pedestal represents the taxpayer who pays for the whole NHS, including the doctor’s salary.

However, proper PPI cannot happen unless and until this role reversal happens, and paternalism is laid to rest as a dysfunctional belief system which is long past its sell by date. This role reversal is hard for both doctors and patients as it requires both to break this bad habit.

This false paradigm of paternalism is killing both patients and doctors (1) so must be changed, and the habit broken if the crisis in the NHS is to be cured, as I say in other papers (see 9.64 of the above website).

It is now up to patients to cure doctors of this bad habit by using PPI to teach them the truth. This is that both are interdependent on the other, and that neither is superior (as doctors themselves recognise in the CCG website, quoted in paragraph 7 below). Nobody feels inferior to their solicitor, accountant, garage mechanic, plumber, or other service provider. Why should anyone feel inferior to ones doctor?

The rest of this paper reprints extracts from public documents urging NHS staff, including commissioners, to listen to patients and the public, and redesign services to improve outcomes. My emphasis is shown in bold italics.

6 NHS constitution, which became statute law on 21.1.10
1 Principles that guide the NHS
The NHS aspires to put patient at the heart of everything it does... The NHS will **actively encourage feedback from the public, patients and staff, welcome it, and use it to improve its services.**

5 The NHS is committed to working jointly with other local authority services, other public service organisations, **and a wide range of private and voluntary sector organisations to provide and deliver improvements in health and wellbeing. (such as SECTCo)**

7 The NHS is accountable to the public, communities and the patients that is serves.

**3a) Patients and the public – your rights and NHS pledges to you**

You have the right to access NHS services. You will not be refused access on unreasonable grounds.

You have the right to expect your NHS to assess the health requirements of your community, and to commission and put in place the services to meet those needs as considered necessary, and in the case of public health services commissioned by local authorities, to take steps to improve the health of the local community.

You have the right to access certain services commissioned by NHS bodies within **maximum waiting times**, or for the NHS to take all reasonable steps to offer you a range of **alternative providers if this is not possible**. The waiting times are described in the Handbook to the NHS Constitution. (Maximum 18 weeks)

**Nationally approved drugs and treatments**

You have the right to drugs and treatments that have been recommended by NICE for use in the NHS, if your doctor says they are clinically appropriate for you.

You have the right to expect local decisions on funding of other drugs and treatments to be made rationally following a proper consideration of the evidence. If the local NHS decides not to fund a drug or treatment you and your doctor feel would be right for you, they will explain that decision to you.

You have the right to make choices about the services commissioned by NHS bodies and to information about those choices.

You have the right to be **involved, directly or through representatives, in the planning of healthcare services commissioned by NHS bodies, the development and consideration of the proposals for changes in the way those services are provided, and in the decisions to be made affecting the operation of those services**.

The NHS also commits to provide you with the information and support you need to influence and scrutinise the planning and delivery of NHS services (pledge)

**7 PPI rhetoric by Brighton and Hove Clinical Commissioning Group**

My local Clinical Commissioning Group (CCG) (Brighton and Hove City) pledges to involve patients and the public in the following ways (**my emphasis**), which is excellent. My only problem with it is that it is **rhetoric** (lip service only) and hitherto they have not practiced what they preach.

The chairman OF the CCG, Dr Xavier Nalletamby, has written (July 2012 PPG newsletter) : **‘We aim to put those who use our health services at the heart of planning and improving health care’. (4)**
'Every meeting we should be asking ourselves, "what would our patients think?" I think we are getting closer to be able to answer this. Getting our PPG’s right is essential for the future of our NHS.' (5)

The CCG website www.brightonandhoveccg.nhs.uk says the following under ‘Get involved’:

'Since the CCG is run by local GPs and nurses, we are that much closer to understanding what people in Brighton and Hove require from their health service but we also realise that we don't know everything and that we need to work with our patients side-by-side not face-to-face. We want to work in a partnership of equals where all of us share the same vision and enjoy a shared responsibility for making healthcare in Brighton and Hove the best it can be.

To run an outstanding health service, we require excellent planning, decision-making and problem-solving coupled with a full understanding of what services people need, what improvements would be welcome and what provision already works well so we can take what works best and replicate it across the city.

We want everybody's experience with the NHS to be successful, so we are offering you the opportunity to help us shape and design healthcare in Brighton and Hove. We need and actively want people to get involved, whether formally through the Patient Participation Groups, Healthwatch or at our public meetings which are held every two months, or informally by just letting us know when we get it right so we can copy this elsewhere or by telling us when we get it wrong so we can actively prioritise improving the services and care we commission.

You do not need to be a regular user of the health service to become involved. Indeed, we have a particular interest in hearing from people who are only occasional users because their views often go unheard.

Would you like to get involved?

If you would like to get involved with the NHS in Brighton and Hove, please use the information in this section. Alternatively, contact our Patient Engagement and Experience Lead, Jane Lodge, by email at jane.lodge1@nhs.net or by phone on 01273 574649.'

8 Cross party support for Rewiring Public Services

I was pleased to read the following statement in Cllr Geoffrey Theobald’s newsletter on 21.10.13 (my emphasis added) which supports the following initiative:

'Local Government Association’s cross-party ‘Rewiring Public Services’ campaign which has 3 key aims – (i) rejuvenating democracy and giving back to people real reasons to participate in civic life and their communities; (ii) transforming public services so they prevent problems instead of just picking up the pieces; and (iii) boosting economic growth in a way that offers prosperity to every place.’

9 Our CCG’s response to the Francis report, which calls for PPI at the heart of decision making

The following paragraphs are extracted from the Brighton and Hove City CCG’s response to the Francis report, by Soling Jerram, Lead Nurse, Director of Clinical Quality and Primary Care, accepted by the CCG 23rd July 2013. My emphasis of the CCG’s commitment to Patient and Public
Involvement (PPI) is shown in bold. The full report can be seen on the CCG website, www.brightonandhoveccg.nhs.uk. Again the rhetoric is excellent, and the problem is that the staff do not follow it. I have been campaigning for the last 4 years for the mass-commissioning of NICE-recommended mindfulness courses to reduce the waiting time from the present 20 years, but nobody will engage with me. Please note paragraph 129 below, which says: ‘We have the authority to commission alternative providers if necessary, for example to reduce waiting lists.’

1. INTRODUCTION
The publication in March 2013 of the 2nd report of the Mid-Staffordshire NHS Foundation Trust inquiries (Francis 2013) left without doubt a feeling of shame in anyone connected with the NHS. It clearly articulated that many individuals had been failed by this the institution whose intention is to support people from cradle to grave, to do no harm and to be open to all, free at the point of need.

Brighton and Hove Clinical Commissioning Group (CCG) became a statutory body on the 1st April 2013. It is responsible for commissioning (or buying) much of the healthcare required by residents and visitors to the area, alongside NHS England, who are responsible for commissioning specialist services. It is charged with both ensuring that clinical leadership and public and patient involvement is at the heart of decision making and with monitoring the quality and safety of the services provided.

CCGs are membership organisations. Brighton and Hove CCG is formed of the 47 member general practices in the city. This means that there is now a responsibility for all general practitioners and their staff to ensure that their clinical knowledge and their patients’ views and experiences inform decisions made about how services are run and developed. The Governing Body of the CCG acts on behalf of the membership, in terms of the overall strategy and organisation of the CCG, and in terms of accountability to and on behalf of the membership. The findings from both of the inquiries completed by Robert Francis QC (Francis 2010, & 2013) have specific importance to us as a developing organisation. The Governing Body of Brighton & Hove have reviewed Francis’ 29 recommendations. The following is the outcome of Brighton & Hove Governing Body’s

3.2 PUTTING THE PATIENT FIRST
The development of CCGs as commissioners of NHS provision for the local population is built on the premise that clinical input, influenced by clinicians’ day to day experience of supporting patients and their carers, will ensure that services develop in line with the needs of the local people they are there to serve.

As an organisation we have built a strong team of Clinical Leads. They work in local GP practices as well as contributing to the development of service provision and commissioning. This enables their lived experience of working with patients and carers to shape the CCG’s decision making.

3.3 FUNDAMENTAL STANDARDS OF BEHAVIOUR
As an employer we are committed to ensuring that we work in an environment of mutual respect, openness, and fairness. We believe that no less should be expected from us as a commissioning and monitoring organisation than the public expect from the staff in frontline services. We have discussed in governing body seminars the right for everyone to state their opinion and be heard. We encourage an environment of respectful challenge. This approach is expected from all our employees, the stakeholders and partners we work with, and in our engagement with the patients and public. We will not accept bullying from or toward our staff.
3.6 COMMISSIONING FOR STANDARDS
We are committed to being an open and transparent health service commissioner, working with individuals who use the services and enabling them to support the designing of those services. In order to keep populations happy and healthy and able to achieve, within their individual capacity, a life which is fulfilling and productive requires more than just a health response to illness. This makes the system of services required very complex.

We have large providers of acute, community and mental health services; however there are many other smaller providers who support the health and social care needs of the local population. This means we need to develop networks to ensure information is gathered from different groups and environments. We need to work closely with partners to robustly triangulate and challenge information, ensuring we explore all of the options and consider the effects of those decisions on the whole system.

We are developing a system which supports the role of General Practitioners to fulfill their responsibility to engage their practice population in meaningful feedback and in involvement in designing the health system for the population.

129. In selecting indicators and means of measuring compliance, the principal focus of commissioners should be on what is reasonably necessary to safeguard patients and to ensure that at least fundamental safety and quality standards are maintained. This requires close engagement with patients, past, present and potential, to ensure that their expectations and concerns are addressed.

We work with partner CCGs across the Surrey & Sussex locality to ensure the sustainability of health provision, and to maximise choice and cost effectiveness. We have the authority to commission alternative providers if necessary, for example to reduce waiting lists.

132. Commissioners must have the capacity to monitor the performance of every commissioning contract on a continuing basis during the contract period.
• Such monitoring may include requiring quality information generated by the provider
• Commissioners must also have a capacity to undertake their own independent audits, inspections and investigations. These should where appropriate include investigation of individual cases.
• The possession of accurate relevant and usable information from which the quality and safety of the services can be ascertained is the vital key to effective commissioning.
• Monitoring needs to embrace both compliance with the fundamental standards and enhanced standards.

A programme of visits by members of the CCG Executive and our quality and patient safety team are being developed. The CCG designated children’s safeguarding nurse and doctor provides supervision for all the named professionals in the local provider organisations.

133. Commissioners should be entitled to intervene in the management of an individual complaint on behalf of the patient where it appears to them it is not being dealt with satisfactorily, while respecting the principle that it is the provider who has primary responsibility to process and respond to complaints about its services. We consider our role is to maintain an oversight of providers’ management of complaints, ensuring that where complaints span organisations those organisations work together to investigate and learn from the issues and share that learning with other partners.
We should not intervene on a regular basis on individual complaints as there is a system in place for members of the public to escalate complaints if not adequately addressed at source. However we do require providers to present regular reviews of the themes of their complaints, their actions to address the issues and the standards of their response to complaints. (Is this true? Does that system work?)

134. Consideration should be given to whether commissioners should be given responsibility for commissioning patients’ advocates and support services for complaints against providers.

We have considered patient advocacy and support for complaints against providers. This is delivered via an Independent Complaints & Advisory Service (ICAS). The development of the new Healthwatch organisations will also support people in this regard. All providers are also legally bound to provide advocacy support for those who do not have mental capacity and to follow the requirements of the Mental Capacity Act and supplementary Deprivation of Liberty Safeguards (MCA 2005 and DoLS 2007 supplement).

135. Commissioners should be accountable to their public for the scope and quality of services they commission. Acting on behalf of the public requires their full involvement and engagement:

• There should be a membership system whereby eligible members of the public can be involved in and contribute to the work of the commissioners.
• There should be lay members of the commissioner’s board.
• Commissioners should create and consult with patient forums and local representative groups.

Individual members of the public (whether or not members) must have access to a consultative process so their views can be taken into account.

• There should be regular surveys of patients and the public more generally.
• Decision-making processes should be transparent: decision-making bodies should hold public meetings.

All new service developments include public/user engagement and consultation. In September 2013 there will be patient representatives on each Locality team, and their role will to ensure two way communications from the Practices’ Patient Participation Groups (PPGs).

3.8 OPENNESS, TRANSPARENCY AND CANDOUR
We value patient care and service provision that takes place in an environment of openness, transparency and candour.

Openness – enabling concerns and complaints to be raised freely without fear and questions asked to be answered.

Transparency – allowing information about the truth about performance and outcomes to be shared with staff, patients, the public and regulators.

Candour – any patient harmed by the provision of a healthcare service is informed of the fact and an appropriate remedy offered, regardless of whether a complaint has been made or a question asked about it.

Recommendation B&H CCG response and next steps
178. Every healthcare organisation and everyone working for them must be honest, open and truthful in all their dealings with patients and the public, and organisational and personal interests must never be allowed to outweigh the duty to be honest, open and truthful.
179. “Gagging clauses” or nondisparagement clauses should be prohibited in the policies and contracts of all healthcare organisations, regulators and commissioners; insofar as they seek, or appear, to limit bona fide disclosure in relation to public interest issues of patient safety and care. (This seems to apply to Sussex Partnership Foundation Trust, (SPFT) which has a block contract with secret non-disclosure agreements)

4. IN CONCLUSION
The reports published by Robert Frances QC, following extensive and robust investigation of the issues surrounding the failure at Mid-Staffordshire NHS Trust, have and will continue to have an impact on the management of the NHS. They do however also recognize that the NHS remains an institution with many dedicated staff, who work hard to provide support and care to the population of the UK. In its 65 years it has supported many many individuals and their families at their most vulnerable times and will continue to do so.

The commissioning of NHS services, and the infrastructure which monitors standards, has in the last two years undergone the greatest transition since the inception of the NHS. At the heart of decision making about local service provision are clinicians, more so than ever before. Alongside this is a requirement to work with the patients and public who live in the area in which services are provided.

All of the Governing Body and staff of Brighton & Hove CCG take their role very seriously and look forward to working with the residents of the area in order to ensure that individuals and their families have choices in the services they can access, and that each and every service we commission on their behalf is delivered in a safe, cost effective manner.’

10 NHS England launches revolutionary plan to get patients more involved in their care

Press release 25.9.13
NHS England is to launch a package of revolutionary measures designed to ensure the voices of patients, their carers and the public are at the centre of healthcare services. Transforming Participation in Health and Care is online guidance to commissioners that aims to put people in control of their own health and care.

The guidance is unveiled today (September 25) at the Commissioning Assembly being held at Edgbaston Cricket Ground, Birmingham.

The event is being attended by some 400 Assembly members, comprising medical directors, clinician groups and national leaders of specialised commissioning, who have been instrumental in developing the Guidance.

It aims to improve:

□ Individual participation - for example, ensuring every person with a long-term condition or disability has a digital personalised care plan supporting them to develop the knowledge, skills and confidence to manage their own health.

□ Public participation in decision making - for example, establishing a national Citizens Assembly that will give patients and the public a voice at the heart of decision making and hold the board of NHS England to account. It will give people a say on how services are developed locally and nationally, to ensure their communities have the services they need.

□ Patient insight and feedback - for example, gathering information from patients that give the NHS genuine insight into the outcomes that matter most to them across a range of specialised conditions, helping to shape services of the future
Transforming Participation in Health and Care also includes a new digital health literacy programme to help ensure everyone in the community has access to digital platforms and the training they need to be involved.

NHS England intends to appoint the Tinder Foundation to train people who need help with basic online skills. Tinder, who are leading experts in digital skills and digital inclusion, will reach 100,000 people over the next six months, with 50,000 actively trained in online skills.

Tim Kelsey, NHS England’s National Director for Patients and Information, said: “This will truly transform the way people participate in the health and care we provide. Through this we will be able to seize opportunities to deliver personalised and responsive care to all. Not only will it improve outcomes and quality of life for patients, but it will provide value for money. “It will lead to every person with a long-term condition or disability having a bespoke, personalised care plan supporting them so they have the skills, knowledge and confidence to manage their own health.

“This is another radical and positive step by the NHS towards putting our customers – our patients and their carers – at the very centre of all that we do. And it is another demonstration of how NHS England is fulfilling its commitment to be open and transparent and, more importantly, listening to what our patients and the public tell us and giving people a real say in what we do and what we deliver.

“It gives the public a chance to have their say and be heard on how and what health services are commissioned. It will mean Clinical Commissioning Groups (CCGs) are making informed decisions based on insightful and up to date views after listening to and responding to those who use and care about the services the NHS provides.

“It will also mean patients and carers, supported by GPs and health care professionals, can participate in planning, managing and making decisions about their care and treatment – providing them with their own digital care plan they can access online or through a telephone app.”

Lisa Harrod Rothwell, practising GP and clinical co-chair of the Commissioning Assembly Participation and Partnerships Working Group, said: "The people who have the worst health are usually the people who find it hardest to make their voice heard.

"The NHS must reach out to all parts of our communities and make sure we provide services that meet everyone's needs. It need not be hard to reach people and hear, understand and respond to their views - if you want to find out what young parents need then meet them at 9am and 3pm at the school gates whilst they are waiting to collect their children. The NHS must reach out to all parts of our communities and make sure we respond to the needs people are identifying."

NHS England plans to launch a new certification process so entrepreneurs develop and offer the best on-line tools and services to support the personalised care plans.

NHS England also wants to establish a People Bank of volunteers who are interested in health care and are willing to give up some time to look at giving their opinions on how to improve services locally and nationally.

And it will launch the Annual Excellence in Participation Awards where Trusts who demonstrate their commitment to involving local people in developing health services will be recognised for their dedication and achievements.

As part of the development of the Citizens’ Assembly, NHS England also intends to set up a Young Persons’ Forum at a national level to listen to young people and discuss how to best develop services that meet their needs and expectations.

It will also create a Participation Academy to educate and provide support to patient and lay leaders so they are not just knowledgeable about their own care but able to be confident in bringing their voice and expertise to influence NHS services. The Guidance promotes the use of the latest technology to put patients and their carers at the very heart of treatment decision making, transforming the way patients engage with the health service.

It is easy to access online, simple to navigate and promotes best practice and shared learning that will support commissioners in introducing programmes of support, for example personal health budgets that are tailored for patients and are more cost effective.
It will help health care commissioners improve individual and public participation and to better understand the needs of the communities they serve, ensuring they listen, act on and respond to patient and carer feedback at all stages; engage with patients, carers and the public when redesigning or reconfiguring healthcare services and demonstrate how this has informed their decisions; and require them to publish annual evidence of what ‘patient and public voice’ activity has been conducted.

**By putting patients in control and sharing decision making with their doctors, it will help people live more independently in the community.**

Gathering patient information remains crucial and as well as including the Friends and Family Test data other patient insight and feedback, it will give the NHS a clearer and more accessible picture of what people are saying about our services.

**The Participation Guidance pack will go live on the NHS England website from September 25, 2013. It includes information, best practice, case studies, evidence and tools that will support the needs of patients and public alike.**

ENDS

Note to editors


☐ Sir David Nicholson, Chief Executive of NHS England, describes how **we will only achieve a real patient-centred NHS by listening to patients and working partnership with them to do something about what they say** in the following YouTube clip. http://youtu.be/d9o_VuKGbWw

☐ Tim Kelsey, National Director of Patients and Information at NHS England, talks about why it is essential to **put citizen and patient voice at the heart of every decision we take in the NHS**, to transform patient outcomes and deliver a sustainable health service, now and for future generations. http://youtu.be/981pUOko0gY

☐ The Tinder Foundation are leading experts in digital skills and digital inclusion, and coordinate a national network of UK Online Centres. Tinder’s £1 million programme will reach 100,000 people and will give online training to 50,000 people over the next six months, with 1,000 of those becoming digital champions, passing on their skills even further into the community. It will ensure people without digital skills or access to computers can take advantage of new online ways of managing their health. A network of digital health flagships in deprived areas will receive grants through the programme. Some of these are in local centres (libraries, GP practices, community centres). Others are technology flagships. Their work is already helping communities make the most of technology, from using online translation services to make sure speakers of other languages can communicate with health professionals, to giving older people the basic skills they need to use the internet in finding out more about the management of their long-term conditions.
NHS England (formerly known as the NHS Commissioning Board) is the new body which leads the NHS in England. Its main aim is to improve the health outcomes for people in England, and it will set the overall direction and priorities for the NHS as a whole.

For further information, please email the NHS England media team at nhscb.media@nhs.net or call 07768 901293.

11 Friends and family test extended

Francis Maude today (1 October 2013) announced the extension of the Friends and Family Test (FFT) across the NHS and other public services, including further education, Jobcentre Plus and the National Citizen Service (NCS).

The simple test – answering the question “Would you recommend this service to your friends and family?” – will be extended to all NHS services in England, including mental health services, community nursing, and outpatient appointments by the end of March 2015. The test will also be used to assess Jobcentre Plus services (learning from which will be incorporated into the next phase of the Work Programme), further education courses and all service providers of government’s flagship youth scheme National Citizen Service.

This comes as the test is today rolled out to every maternity service in England, meaning that all new mothers will be asked if they would recommend their service to their friends and family. With over 700,000 births a year in England, this will be a fundamental change to the way the NHS listens to patients and will help parents-to-be make choices over the care they receive throughout pregnancy.

Announcing the extensions, Minister for the Cabinet Office Francis Maude said:

We know that transparency delivers better public services. It drives up standards, informs choice and holds providers to account. This extension of the Friends and Family Test will put more power in the hands of the public, allowing them to give clear and honest feedback on the services that hard-working families use every day.

Transparency is an idea whose time has come. Later this month, the UK will be hosting the Open Government Partnership summit which will bring together world leaders who want to push reforms harder and faster, and encourage civil society to hold their feet to the fire and generate inspirational new ideas.

Health Secretary Jeremy Hunt said:

In its first 4 months alone, over half a million patients have had their say through the Friends and Family Test. If their local service doesn’t listen to them, patients can vote with their feet and go elsewhere.

We’ve seen how services like Walsall Hospital have made huge improvements by listening to patients. Making the Friends and Family Test apply to all parts of the NHS will make those improvements go further and faster.

The NHS is embracing the need for more patient feedback – these are the seeds of lasting culture change. Patients will be given unparalleled opportunities to hold health services to account and choose their care as the Friends and Family Test is rolled out across the NHS.
The test, which has been available in A&E and inpatient hospital wards since April 2013, allows hospital trusts to gain real time feedback on their services, down to ward level, and increases the transparency of NHS data to improve choice for patients and so drive up quality. The scale of the roll out and volume of feedback is the largest ever in the NHS: existing national surveys, such as the National Inpatient Survey 2012, collected the views of 64,500 patients, whereas in the first 4 months alone in just 2 areas (A&E and inpatients), the Friends and Family Test has collected the views of more than half a million patients.

Notes to editors

1. The Friends and Family Test (FFT) is a survey which asks patients whether they would recommend the NHS service they have received to friends and family who need similar treatment or care. It also provides the opportunity for general feedback. The aggregate results are then published online, allowing service users to make comparisons between different providers, and hence driving up patient choice.

2. Following the Prime Minister’s announcement in January 2012, the FFT was initially introduced for providers of NHS funded acute services for inpatients (including independent sector organisations that provide acute NHS services) and patients discharged from A&E (type 1 & 2) from April 2013.

3. Across the NHS, patient involvement in and feedback on services has increased steadily over the past 12 months. The first year of patient-led inspections, where teams of patients inspect their hospital, has seen over 5,000 patients inspect more than 4,000 wards, with more than 400 of these inspections covering mental health services. From April to July, over half a million (596,587) patients have given their views through the FFT.

4. Guidance for the existing Health Friends and Family Test and other information is available from NHS England. In further education, the test will feature prominently in the Learner Satisfaction Survey from 2014/15. It will be available to all further education learners. For Jobcentre Plus, the test will be included in a customer satisfaction survey run by an independent social research agency. For NCS, the test will be included in the on-going evaluation of the programme and will be independently administered by NCS Trust. The government is committed to ensuring the FFT is conducted by an independent provider where possible.

5. The government will also look into how the test can be incorporated to maximum effect across other public services.

Case studies of changes implemented in the NHS as a result of FFT

Five Boroughs Partnership Trust, Cheshire

Patient feedback can lead to real and lasting change. For example, after listening to patients on a low-secure ward where patients often stay for a long time, Five Boroughs’ NHS Foundation Trust patients told staff that they would feel more comfortable and at home if they could choose their bedding. Staff listened and took patients to choose their bedding within a budget, so that they could feel more at ease. In their adolescent ward, young patients said that they would like to spend more time outside off the ward. There is now an “off the ward” activity every day.

Walsall Manor Hospital

We know that patient feedback can be used to make huge improvements in care. In the 2010 National Patient Survey, Walsall Manor Hospital scored in the bottom 20% on more than half the questions asked. They then introduced the FFT and now ask every patient, very simply, how likely they are to recommend Walsall Manor to their friends or family and to name one thing they could do to improve their stay.
From TV remote controls, to warmer rooms to staff shortages, patient feedback led to fast corrective action, including focusing more resources in wards that were under pressure. A year ago, their own patient satisfaction scores averaged 65. Today, they're up to 75%.

In that same period, C.Diff infections are down 80%, pressure ulcers are down 30% and falls down 20%. Not all of this is because of patient feedback, but it is thanks to a new culture of patient-centred ambition – as Richard Kirby, the Chief Executive says, “it’s changed the nature of the discussion”.

12 Holism – a better way of knowing - how the British Holistic Medical Association (BHMA) sees the Berwick report by Dr William House (6)

The headline title of his (Berwisk’s) review, “A promise to learn – a commitment to act”, puts the onus for learning and acting on the staff delivering clinical care. He expects the management to create the conditions for this to happen. This is very holistic thinking, although he may not call it that.

The idea of creating a culture of learning depends on the capacity for critical reflection. This requires time which must be built into the working day and protected. It is also vital that the reflections are shared with colleagues, preferably including senior managers. This demands a degree of trust which is not present in most clinical teams I have worked in. Sharing needs to happen in a safe space where honesty becomes possible and vulnerability can be shown. This may be particularly difficult for senior staff.

In the summary of his advice to senior government officials and senior health service executives (given in the form of an open letter), Berwick calls for “thorough and unequivocal transparency, in the service of accountability, trust and the growth of knowledge”. This is a big ask in an organization as used to secrecy and hierarchy as the NHS.

In the ‘learning organization’ knowledge is largely created and disseminated by the those providing the service. Of course, technical developments in treatment of disease from academic institutions are important but the ownership and dissemination of that knowledge should sit with those staff delivering and receiving the care – alongside (and no more important than) the knowing created within the learning organization itself.

The staff and patients are all ‘nodes’ in the complex system that generates, renews and disseminates knowledge and culture. Ultimately, this can move towards a healing community and these do exist in the NHS, though there is a long way to go before it reaches all across the service. But even a journey of a thousand miles begins with a single step.


13 Conclusion – just do PPI

The above press releases and reports show that the authorities now take their statutory duty to listen to the voice of the public seriously. However, it remains to be seen whether the above rhetoric is turned into practice, and whether the commissioners in the NHS and Councils actually do listen to patients and the public, and implement the revolutionary changes requested.

I ask you to do your best to implement the recommendations in section 2, as follows:

2.1 Acknowledge every suggestion with a ‘thank you’.
2.2 Ensure that all suggestions are considered seriously by the appropriate manager(s).

2.3 Reply to the person making the suggestion stating whether and when the suggestion is to be implemented, or if not, why not.

2.4 Manifest the above procedure regarding the suggestions that I have made for a self referral primary care mental health service as described in paper 9.64 of www.reginaldkapp.org,

14 References
1. Deputation to Brighton and Hove Council on 18.7.13, see paper 9.60 of www.reginaldkapp.org
2. Lynne McTaggart’s blog 23.10.13 ‘Big Pharma and the Mafia news@common.wddtyvip.com
3. Paper ‘Solving the crisis in general practice and A&E by co-creating a mindful primary care mental health service in the community.’ See paper 9.64 of www.reginaldkapp.org
5. Ditto issue 4 Aug 2013
6. From the BHMA chairman's newsletter, Sept 2013 (Dr William House) info@bhma.org