



# HEALTHWATCH AND PUBLIC INVOLVEMENT ASSOCIATION

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**Patient and Public Involvement in Health  
and Social Care**

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## ANNUAL REPORT AND FINANCIAL STATEMENT

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For the year ended 31 December 2016

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**HEALTHWATCH AND PUBLIC INVOLVEMENT ASSOCIATION**

**WWW.HAPIA2013.org**

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Special Thanks

- John Larkin – Company Secretary ... for his outstanding work
- Polly Healy and Lynn Clark for their excellent support with our research projects, reports, publicity and websites

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## HAPIA STEERING GROUP MEMBERS 2016 and their PORTFOLIOS

RUTH MARSDEN Yorkshire and Humberside <b>Trustee, Vice Chair</b>	Information Communications
MICHAEL ENGLISH London	President of HAPIA
ANITA HIGHAM South East	Integrated Care for Older Adults, Care of Young People with MH Problems
ELLI PANG South West	General Practice, Success Regime
ELSIE GAYLE West Midlands <b>Trustee</b>	Maternity, Obstetrics, Patient and Public Voice Patient Safety
JOHN LARKIN <b>Trustee</b>	Company Secretary
LEN ROBERTS South East	Briefings and Lobbying
MARY LEDGARD East of England	Rural Healthwatch
MALCOLM ALEXANDER London <b>Trustee, Chair</b>	Patient Safety, Mental Health Medical Revalidation

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[WWW.HAPIA2013.org](http://WWW.HAPIA2013.org)

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**REPORT AND FINANCIAL STATEMENT FOR THE YEAR ENDED  
31st DECEMBER 2016**

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The Trustees have pleasure in presenting their Report and Financial Statement for the year ended 31 December 2016.

**DIRECTORS AND TRUSTEES**

The Directors of the company are its Trustees for the purpose of Charity Law. As provided in the Articles of Association, the Directors have the power to appoint additional Directors.

The Trustees, who have served during the year and subsequently, are:

- Malcolm Alexander
- Elsie Gayle
- John Larkin
- Ruth Marsden (re-elected 19<sup>th</sup> December 2016)

Healthwatch and Public Involvement Association (HAPIA) comprises of members of the public, including patients and carers who are members of Local Healthwatch. The office of Healthwatch and Public Involvement Association is located in London.

**OBJECTS OF HEALTHWATCH AND PUBLIC INVOLVEMENT ASSOCIATION**

Healthwatch and Public Involvement Association (HAPIA) was formed under its original name of National Association of LINKs Members (NALM) as a not-for-profit company with exclusively charitable objects. The Company is committed to acting for the public benefit through its pursuit of wholly charitable initiatives, comprising:

- (i) The advancement of health or the saving of lives, including the prevention or relief of sickness, disease or human suffering.
- (ii) The relief of those in need by reason of youth, age, ill-health, disability, hardship or other disadvantage, including by the provision of accommodation or care.

## **MISSION STATEMENT**

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### **HAPIA seeks to:**

1. Provide a national voice for Healthwatch and Healthwatch members.
2. Promote public involvement that leads to real change and the ability to influence key decisions about how care services are planned and run.
3. Promote the capacity and effectiveness of Healthwatch members to monitor and influence services at local, regional and national levels and to give people a genuine voice in their health and social care services.
4. Support community involvement in consultations about changes to services, to influence key decisions about health and social services and hold service providers and commissioners and the DH to account.
5. Promote open and transparent communication between communities across the country and their health service.
6. Promote accountability in the NHS and social care to patients and the public.
7. Support the involvement of people whose voices are not currently being heard, and to promote inclusivity, diversity and equal opportunities.

## **HAPIA MANIFESTO**

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- HAPIA has produced a Manifesto based on its aim to provide Healthwatch and the wider public with a better understanding of HAPIA's work. The Manifesto is based on the following key points:
- Build HAPIA as the independent national voice for Healthwatch and users of health and social care services.
- Promote the long-term development and strengthening of Healthwatch, as powerful, independent and influential bodies for patient and public involvement in policy, strategy and delivery of care services.
- Support the growth and development of the NHS as the provider of health services free to all at the point of use.
- Campaign for the right of all vulnerable people to get the care and support that they need to lead fulfilled lives.

## HAPIA WEBSITES

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HAPIA operates several websites. The main HAPIA website is updated regularly and provides information about Healthwatch and other major developments in the NHS and social care provision. The 2016 websites were as follows:

- **[www.hapia2013.org](http://www.hapia2013.org)**  
The main HAPIA website.
- **<http://www.healthwatchdevelopment.net>**  
Details HAPIA's research into the development of LHW and its funding.
- **<http://www.rule43inquests.com>**  
Details of research into instances of Coroner's 'Preventing Future Deaths' (PFD) reports following an Inquest.
- **<http://www.revalidatingdoctors.net>**  
Contains information about revalidation of doctors and leaflets for patients.
- **<http://www.achcew.org>**  
An archive site celebrating the work of the Community Health Councils, and public involvement between 1974 and 2003.
- **CONFERENCE reports and presentations** can be seen at:  
[www.hapia2013.org/2015---agm.html](http://www.hapia2013.org/2015---agm.html)

# HAPIA ACHIEVEMENTS IN 2016

## A. Providing a national voice for Healthwatch and Healthwatch Members.

### HEALTHWATCH INDEPENDENCE DEBATE – LORD HARRIS

Continuing with colleagues in the House of Lords is HAPIA's long term liaison on matters of concern regarding the lack of any genuine independence of many LHWs. This culminated in the questions asked on our behalf in the House on: Service User Representation in Health and Social Care. We were fortunate to obtain on 15 December 2016 a lengthy slot for this important issue and an opener tabled by Lord Harris of Haringey (Labour):

That the House of Lords will debate the following motion:

*“To move that this House takes note of the case for effective service user representation in health and social care, and of the case for enhancing the independence and capacity of Healthwatch England and of Local Healthwatch”*

Many members of the House of Lords contributed: Baroness Chisholm of Owlpen, Lord Tunnicliffe, Baroness Walmsley, Baroness Watkins of Tavistock, The Earl of Listowel, Baroness Warwick of Undercliffe, Baroness Masham of Ilton, Baroness Brinton, Baroness Pitkeathley, Lord Lansley.

One of the most telling points in the debate was the comment by Lord Harris when referring to the downgrading of LHW from an independent statutory body, to a social enterprise accountable to local authorities:

“The noble Lord, Lord Lansley (Andrew Lansley), speaking 10 years ago, said that LINks may ‘*struggle* to be credible as long as they are funded through local government’. Just a few years later, he felt impelled by something or someone—we now know it was not the Liberal Democrats—to say that the new system *should* be funded through local government, with the consequences that I have described”. **The motion was carried by the House of Lords.**

Some of the other key points made by Lord Harris during the debate follow:

1) “I warned that the late changes to the Healthwatch Bill risked weakening the new bodies by starving them of resources and laying them open to conflicts of interest with local councils, which were to be their paymasters. The arrangements for Healthwatch England also inhibit its independence and effectiveness”.



2) "Healthwatch England remains a sub-committee of the CQC. For Healthwatch England to be located there compromises its independence and must limit its scope to highlight when the CQC is not being as effective as it should be".

3) "Recent changes appear to have made Healthwatch England more subservient to the CQC. David Behan, chief executive of CQC, wrote: "The National Director for HWE will be line-managed and accountable to myself as the CQC Chief Executive and the HWE Chair is already accountable to the CQC Chair. The strategy of Healthwatch England has to be submitted to the CQC board for endorsement". That hardly sounds like independence".

4) "Healthwatch England is reasonably generously resourced for what it does, with a budget of £4.5 million, but in 2015-16 it could not spend that and used only £3.7 million, a 17.3% under-spend".

5) "A very small proportion of HWE's budget goes on developing and supporting local Healthwatch. Nor does local Healthwatch feel that Healthwatch England is there for them and they have little scope to influence it or its work".

6) "In 2013- 14, the DH passed over £43.5 million to be included in the LA block grant to fund LHW, but the total funding given to local Healthwatch groups in that year amounted to only £33.5 million—£10 million had disappeared along the way".

7) "While there was £33.5 million to fund LHW in 2013-14, that fell to £31.8 million in 2015-16 and again to £29.9 million in this financial year—a third less in cash terms than the DH thought was necessary and had handed over three years earlier".

8) "Local authorities have a conflict of interest and I am told of a number of local Healthwatch areas where this has a deadening effect, particularly on the willingness of staff members to criticise those who pay their monthly paycheques".

9) "Some LHW did not Enter and View (E&V) because they were unclear about what would justify a visit. Others felt E&V was justified only when "serious or multiple concerns are raised".

10) "The Minister told the House that the CQC would in future be deciding the funding of Healthwatch England, which seems to put even more into question the way in which that independence would operate. If it really wants to get this right, and deliver what all your Lordships have said they want to happen, then it needs to resource local Healthwatch organisations properly through a freestanding Healthwatch England. I suspect we might then well find that we have a system which genuinely delivers a user voice and influence into the centre of health and social care in this country".

Other statements from the debate are in Appendix 5 or the Hansard website.

<https://hansard.parliament.uk/lords/2016-12-15/debates/87B30CB6-1013-4F53-8AD4-D169FD5501C2/HealthAndSocialCare>

## **NHS LEADERSHIP ACADEMY**

HAPIA NORTH has continued contributing to the NHS Leadership Academy's Nye Bevan course, specifically designed to develop senior leaders, through teaching and tutoring. HAPIA joins a world-class expert faculty of global business leaders, educationalists and practitioners in healthcare, to train and support the people who will be leading and developing the NHS of the future.

## **INFLUENCING THE DEPARTMENT OF HEALTH**

During 2016, and despite the recent elections and ministerial reshuffles, HAPIA has continued to press Philip Dunne, Minister of State for Health and holder of the portfolio for patient experience, to create a more explicit and dedicated portal for patient and public involvement and to give patient involvement and empowerment greater prominence within the Department of Health.

## **HEALTHWATCH IS A CAMPAIGNING ORGANISATION**

Many Healthwatches believe campaigning is not permitted as a means of changing local health and social care policy. This is untrue. But, campaigning activities must seek to achieve objectives that emerge from local communities and are not party political. There is no prohibition with campaigning that seeks to improve local services. HAPIA was active in ensuring that the right of Healthwatch to campaign was well publicised, despite poorly written Regulations.

The NHS Bodies and Local Authorities (Partnership Arrangements, Care Trusts, Public Health and Local Healthwatch) Regulations 2012, which describe the right to campaign, were challenged in the House of Lords on February 5<sup>th</sup> 2012 because of their lack of clarity. We sought to have the Regulations rewritten so that they are transparent and clear in their meaning.

The House of Lords was packed as HAPIA had campaigned actively with Peers to ensure that the campaigning issue was discussed in the public arena. The House of Lords 'Secondary Legislation Scrutiny Committee' had reported that: "The Regulations may imperfectly achieve their policy objective", i.e. they were badly written. This was particularly worrying as they were supposed to promote more effective public involvement. The Minister made it clear in the House of Lords that campaigning was legal and that it should be encouraged, provided it was for the purpose of improving services.

HAPIA discussed the issue with two Ministers: Lord Howe and Norman Lamb MP. Lord Howe confirmed the commitments made during the passage of the Health and Social Care Act 2012, that LHW would be free to conduct campaigns

in relation to its statutory (s221) activities. He added that: “The ability of LHW to speak out publicly is an absolutely critical part of its role ... LHW has to ensure it is indeed reflecting a body of local opinion”. Furthermore LHW must not engage ... in ‘political’ activity other than where such activity is integral, and subsidiary, to its principal role. We tried to persuade Norman Lamb to rewrite the Regulations when he was Health Minister, but he would not agree to this and said that in his view the Regulations were clear in intent.

**See also:**

**Healthwatch England guidance on campaigning.**

[www.healthwatch.co.uk/sites/healthwatch.co.uk/files/20130204\\_healthwatch\\_england\\_position\\_on\\_local\\_healthwatch\\_regulations.pdf](http://www.healthwatch.co.uk/sites/healthwatch.co.uk/files/20130204_healthwatch_england_position_on_local_healthwatch_regulations.pdf)

**House of Lords Debate:**

<https://publications.parliament.uk/pa/ld201213/ldhansrd/text/130205-0002.htm#13020573000440>

**Regulations relating to the right of Healthwatch to campaign**

The NHS Bodies and Local Authorities (Partnership Arrangements, Care Trusts, Public Health and Local Healthwatch) Regulations 2012

[http://www.legislation.gov.uk/ukxi/2012/3094/pdfs/ukxi\\_20123094\\_en.pdf](http://www.legislation.gov.uk/ukxi/2012/3094/pdfs/ukxi_20123094_en.pdf)

**B. Promoting public involvement that leads to real change and the ability to influence key decisions about how care services are planned and run.**

**GP COLLABORATIVES – HAPIA INVOLVEMENT**

The increasing pressures on primary care, conspicuously on GPs as the ‘gatekeepers’ of the health care system, has propelled the growth of GP collaboratives, with a variety of markedly different administrative and accountability chains, and often with very different modes of delivery in terms of provision, availability and location.

Too often these changes were made without any involvement from, or consultation with, the patients thus affected. Representations on this exclusion of patient involvement were met with the response that the changes were “not substantial”, hence no consultation was necessary.

Unhappy with this response, HAPIA NORTH demanded a place at the table of such planned changes but this was denied on the basis that “you are only the public and this is for the professionals”.

GP colleagues locally, wholly unhappy with the way many of their own concerns had been sidelined, as well as with the exclusion of their patients from decision making, put HAPIA Vice Chair, Ruth Marsden on a contract as an Assistant Manager, to give her professional status and access to negotiations.

The CCG then demanded to see the contract, but the GPs and Practice Managers challenged this, saying they had not been asked to show *their* contracts and Ruth Marsden should not be required to show hers. The CCG was obliged to back down. The rhetoric of patient and public involvement is obviously still light years away from being a genuine reality in some parts of NHS England's bureaucracy!

## **CUMBRIA - CONSULTATION ON THE FUTURE OF MATERNITY CARE**

HAPIA participated in the 'Cumbrian Healthcare for the Future' public consultation which ran from 26 September 2016 through to 19 December 2016, in relation to changes to maternity services in west, north and east Cumbria.

We met with leaders of campaign groups that are struggling to develop more effective health care in Cumbria and to stop the run down of their local services by the so-called 'Success Regime'. We also gathered information from the North Cumbria University Hospitals by FOI to assist the campaign. We worked with local groups to prepare a letter to Sir Neil McKay, Chair of the Cumbrian Success Regime, which made the following key points about the future development of safe effective maternity services:

- 1) Full participation for the community in decision making and co-production in service development is essential.
- 2) At the core of maternity services development in Cumbria is the recognition of the particular nature of rural areas and the services that residents need.
- 3) The Success Regime must recognise the importance of rurality. This means ensuring that morbidity and mortality does not increase for the population, because local regimes fail to recognise the binary risks of distance to critical services and lack of specialist staffing. Effective services provided by both consultant obstetricians and midwives are essential.
- 4) Midwifery is the only professionally trained clinical speciality to give maternity care in its entirety and provide a very safe model of care for most mothers:  
[www.thelancet.com/series/midwifery](http://www.thelancet.com/series/midwifery)

- 5) Expert, adequate and appropriate clinical care is needed from midwives who provide care to all women, and by consultants who specialise in care for specific medical conditions – not just ‘cover’.
- 6) West Cumberland Hospital (not Carlisle) is the right location for a Consultant Unit and specialist maternity service, and it is essential that the local Trust urgently reviews its approaches to recruiting consultants and “middle-grade” doctors. If the Trust fails to employ adequate numbers of consultant obstetricians to provide a safe service, alternative models must be considered, e.g. a unit run by highly skilled midwives, advanced neonatal nurse practitioners and a rapid pathway to consultant obstetric support where necessary.
- 7) Mothers must have choice, based on where they feel safest to give birth, including units staffed by well trained and autonomous midwives as the main care givers.
- 8) Full weight must be given to the views of all parties in the process of consultation: patients, families, the general public, clinicians, the CCG, Success Regime and local health and social care services.

In response to our questions to the Trust, they confirmed that women in labour are currently never transferred from West Cumberland Hospital to the Cumberland Infirmary (Carlisle), but eight women had been transferred in the period 2013-16 from Whitehaven to the Cumberland Infirmary (presumably not yet in labour) and none resulted in the death of mother or baby. They also confirmed that they did not have a system to assess moderate and serious harm and risk quantification using RAG ratings (which are used by most NHS Trusts).

The Trust confirmed that, if a consultant led unit was abandoned at West Cumberland Hospital women in labour transferred to Carlisle would be accompanied by a midwife and paramedic. But the same ambulance would be required to transport children needing emergency care in Cumbria, creating the risk of greater morbidity or mortality if both events happen simultaneously.

Their assessment of harm and death of mothers and babies if a midwife led unit was established by the Trust was stated to be no greater than for a consultant led unit. The Trust was unable to give an assessment of the time it would take for a helicopter to collect and transfer a patient from Whitehaven to Cumbria because: “The Helicopter service is run by the Northwest ambulance service”.

**C. Promoting the capacity and effectiveness of HAPIA members to monitor and influence services at local, regional and national levels, and to give people a genuine voice in their health and social care services.**

## **WRITTEN EVIDENCE TO THE MATERNITY SERVICE INQUIRY JUNE 2016**

### **A summary submitted by HAPIA**

A) National policy must ensure that quality maternity care fully embeds the voice and decision making capacity of the mother into each care pathway. This model significantly improves the physical, psychological and emotional outcomes for mothers and babies and their partners.

B) Failure to achieve effective patient and public involvement in maternity services nationally, has come about because of an imbalance in the power relationship of the patient and the professional.

C) Hierarchical organisation of maternity services puts the patient voice at a low level, resulting in variable involvement and participation across the country. Consequently those who have little or no input into their care become most vulnerable and are at the greatest risk of poor outcomes.

D) The current resources allocated to keeping the patient voice at the centre of maternity care are not compatible with the requirements of national policy.

HAPIA welcomed the opportunity to contribute to the work of the Health Select Committee Inquiry and the National Maternity Review Report 'Better Births – Improving outcomes of maternity services in England', but is concerned about the following challenges to patient and public involvement in maternity care.

1. The current mechanism for mothers to liaise with maternity caregivers is the 'Maternity Services Liaison Committees' (MSLCs) [www.chimat.org.uk/mslc](http://www.chimat.org.uk/mslc) (set up in 1980's). MSLC forums were designed to be user led, with membership including provider and commissioning organisations and agencies involved in supporting child-bearing women.
2. Significant changes to NHS structures led to some areas abandoning MSLCs preventing service users from being involved at local levels. Loss of a statutory requirement for MSLCs has led to inadequate involvement of mothers in their care plans, which should be agreed with service providers.

3. 'Better Births' noted the lack of involvement at fundamental levels in making decisions and choices which met users' needs and values. It noted that mothers were being 'told what to do', and that increasingly mothers were cared for in a fragmented way in which their views were not respected.
4. Many mothers and in particular those from more vulnerable backgrounds complain of not having their voices heard, and of difficulties in engaging meaningfully with maternity services, especially when things go wrong.
5. Over the years of monitoring maternity outcomes, HAPIA notes an inability to redress the worst outcomes for the most vulnerable communities around perinatal mortality, morbidity and perinatal mental health. It is noted that babies that are black or black British Asian or Asian British, have a greater risk of stillbirth - 50% higher than for white English babies.' (May 2016, MBRRACE-UK Perinatal Mortality Surveillance Report).
6. The Five Year Forward View: 'Patient and Public Participation' published in 2016, lays out expectations and responsibilities for insightful and effective involvement. It specifically requires plans to be based on the insight of patients where they or particular groups have experienced poor services.
7. The 'Forward View' calls for full involvement of patients and public in the design of specific services, pathways and features to meet their needs.

**Recommendations for action:**

1. Introduce the requirement for **each** and every new model of maternity care provision to implement a 'bottom-up' and effective approach to patient involvement, where the mother's own participation in her care is integral and fundamental to the design of her care pathway.
2. Introduce the requirement for the commissioning of adequate resources, including funding, to support mothers in high level partnership working with maternity professionals.

**Useful references regarding the maternity review:**

A) The Five Year Forward Patient and Public Participation- Requirements in developing Sustainability and Transformation Plans May 2016  
[www.hapia2013.org/uploads/6/6/0/6/6606397/stp\\_patient\\_and\\_public\\_participati\\_on\\_guidance\\_draft\\_\\_\\_1\\_may16\\_copy.pdf](http://www.hapia2013.org/uploads/6/6/0/6/6606397/stp_patient_and_public_participati_on_guidance_draft___1_may16_copy.pdf)

B) National Maternity Review – Better Births. Improving Outcomes of Maternity Services in England, 2016  
[www.england.nhs.uk/wp-content/uploads/2016/02/national-maternity-review-report.pdf](http://www.england.nhs.uk/wp-content/uploads/2016/02/national-maternity-review-report.pdf)

## **SPECIALISED COMMISSIONING – INVOLVEMENT UNDERMINED BY STPs**

Specialised commissioning caters for patients who have relatively rare conditions, such that the entire cohort of patients using these services in England may be under 400 or at most about 1000.

Examples are rare forms of cancer; renal disease; neurosurgery and rare metabolic disorders. There are over 130 specialised services that are currently commissioned. These services have not been immune from organisational re-shuffles. The specialised commissioning teams (or hubs) were grouped by the NHS England regions – North, Midlands and East, London, and South. The South region is split into South West, South East and Wessex. These regional teams have increasingly been realigned alongside STPs [Sustainability and Transformation Plans] and Ruth Marsden's work within Specialised Commissioning team in Yorks and Humber has consequently stopped.

### **CASE LAW ON PUBLIC INVOLVEMENT**

The most famous case law dealing with the duty to involve the public is *Gunning v Brent Borough Council* (1985) where it was agreed the decision-maker's discretion is not unbounded and cannot consult on a decision already made, because the outcome of the consultation is pre-determined and the process pointless (Sheldon 2012). The following 'Gunning principles' must be adhered to:

- (i) Consultation must take place when the proposal is at a formative stage;
- (ii) Sufficient reasons must be put forward for the proposal to allow for intelligent consideration and response;
- (iii) Adequate time must be given for consideration and response;
- (iv) Outcome of consultation must be conscientiously taken into account.

### **COLLABORATION WITH THE ROYAL COLLEGE OF SURGEONS**

Following work with the Royal College in 2013, HAPIA NORTH provided a patient-team for further consultations on Gallstones guidance.



## COPYING LETTERS TO PATIENTS

HAPIA investigated the use of the Department of Health Guidelines (2003) on copying letters to patients: 'Copying letters to patients - Good Practice Guidelines'. We investigated the use of these guidelines following several reports of patients not receiving copies of letters sent to their GPs. We were also concerned that NHS Patients Choice knew nothing about the guidelines.

The Guidelines say:

“As a general rule and where patients agree, letters written by one health professional to another about a patient should be copied to the patient or – where appropriate, parent or legal guardian. The general principle is that all letters that help to improve a patient’s understanding of their health and the care they are receiving should be copied to them as of right. Where the patient is not legally responsible for their own care (for instance a young child, or a child in care), letters should be copied to the person with legal responsibility, for instance a parent or guardian”.

### **COPYING LETTERS GUIDELINES: <http://tinyurl.com/y7kdubew>**

In November 2016 we sent FOIs to a number of Trusts asking for details of the implementation of these Guidelines and whether the Trusts include diagnostic radiology reports e.g. MRI and CT scans within the scope of copying letters to patients. We also asked whether Trusts have a system to monitor compliance with the guidelines. A typical response came from Ashford & St Peter’s Hospitals NHS Foundation Trust in Surrey:

*“The Trust uses an outsourced transcription service to produce the majority of its clinical correspondence, where a patient has attended an outpatient clinic. An electronic copy of each letter is sent to the patient’s GP and a hard copy is sent to the patient through the postal service. The sending of letters is usually an automated process, so there is no guarantee a letter would not be sent unless the clinician gave explicit instructions to the clinical office administrator. Therefore, it is possible that letters are sent to patients who do not wish to receive them for whatever reason and therefore 'Copying letters to patients - Good Practice Guidelines' is not being fully implemented at the Trust. **In addition, there is no system in place at the Trust to monitor compliance since these are guidelines and therefore not necessarily Trust policy.***

*The Trust’s radiology department would not want to send reports directly to patients either as often they have a diagnosis in them that needs to be discussed before being given to the patient. That diagnosis would then be included in any subsequent letter. With regard to imaging in particular, the*

*guidelines indicate that imaging reports are not expected to be sent directly to patients (see extract below):*

*'Raw data': 2.3 'Raw' data, such as single test results, should not normally be sent directly to patients. Such data could include, for instance, an x-ray and its accompanying report, or the results of blood tests taken as part of a wider investigation of symptoms. In due course, the outcome of such tests should be included in a letter that is copied to the patient. Where no such letter is needed (for instance where a general practitioner has commissioned a range of tests), some other means of communicating the results to patients will be necessary".*

We decided to investigate this matter further and requested a meeting with Ashford and St Peters Hospitals. We met: Suzanne Rankin, Chief Executive, Dr David Fluck, Medical Director and Dr Jane Hibbert, Consultant Radiologist. The outcome of the meeting was as follows:

- 1) Suzanne Rankin confirmed that letters are routinely sent out to patients from OPD at the same time as sending to GPs.
- 2) We expressed concern that some patients are not receiving the letters and that reports from imaging are not routinely sent to patients. We also expressed concern that the terminology used in letters to GPs can be difficult for patients to understand. We suggested including a reference to NHS Choices in letters to GPs and patients because of the high quality information on the site about clinical conditions.
- 3) We discussed the GMC's 'Good Medical Practice' document, describing doctors' duties towards patients, which include communicating information effectively.
- 4) We were told that if a patient does not wish to receive the letter sent to the GP about their medical condition, the system is not sensitive enough to record this decision and delete the letter from the distribution list.
- 5) Not sending letters to patients may also be important, where there is evidence of domestic abuse. For example an abusive partner may use information in a hospital letter to enhance coercive control or other abuse.
- 6) We discussed the process of sending letters to people who lack capacity and may have appointed a family member to act on their behalf (power of attorney). We agreed that person should be flagged on the system. Flagging should also include PAS (Patient Administration System) and Ibis care plans.
- 7) We agreed the Trust may be able to flag the IT system used to send letters to patients, to identify those to whom a letter should not be sent. The administration is reviewing the operation of the system used to send letters.
- 8) Translation of letters sent to GPs may be possible. The Trust has access to translation services – but it was not clear how a patient would use this system to translate a copy letter.

- 9) If patients do not receive copy letters they should call the PALS service on: 01932 723553. The PALS team will return the call within 24 hours or by the next working day: PALS@asph.nhs.uk. Alternatively, the patient can contact the consultant's secretary.

The hospitals we contacted were clear about their duty to forward letters to patients, but had poor governance of those situations where patients did not wish to receive letters, where sending letters could cause harm and where letters were not being sent. We acknowledged that sending MRI and other diagnostic radiology reports to patients could be confusing and that a discussion was needed regarding interpretation of reports and terminology. Ensuring that patients receiving letters have access to an interpreting service needs to be reinforced, as well as making a reference to NHS Choices, which provides a good source of accessible information about medical terminology.

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**E. Supporting the involvement of people whose voices are not currently being heard, and to promote inclusivity, diversity and equal opportunities.**

## **THE UK TUBERCULOSIS EPIDEMIC**

Newham in east London has the highest rate of TB in western Europe. Most infections in that area are caused by latent TB, meaning that the person has been infected for a long time, but the infection has not been diagnosed by the person's primary care team. Latent TB is usually symptom free until another event occurs in the person's life, e.g. immuno-suppression, cancer or some other event that interferes with the person's immunity.

We had met with Yvonne Doyle, the PHE (Public Health England) Medical Director for London and Andy Mitchell, the NHS England Medical Director for London, in October 2015 and presented them with our report on the TB epidemic. They advised us that PHE was in its second year of implementing its Collaborative TB Strategy, which aims to decrease incidence year on year and achieve the elimination of TB in England. We presented a number of recommendations to PHE which Yvonne Doyle replied to in September 2016.

**1. CCGs and NHS England should ensure that all GPs are adequately trained to diagnose TB in the community.**

**REPLY:** PHE are unable to give assurances that all GPs were adequately trained to diagnose TB. They added: the Royal College of General Practitioners has a TB e-learning package with CPD accreditation. This has been updated by PHE as part of the work on implementing the national TB strategy and was re-launched in July 2016. It is available, not only to GPs, but also to other health care professionals who want to update their knowledge of TB.

**2. The Secretary of State for Health should publish Directions making the NICE Tuberculosis Guidance legally binding on NHS England, PHE, Home Office and CCGs, in order that treatment is provided to all patients until their infection is fully treated.**

**PHE replied:** NICE published new, updated guidance in January 2016 with a further update published in May 2016. As it is 'guidance' it is not possible for the Secretary of State for Health to make it legally binding. The application of 200+ pages in the NICE guidance is not mandatory as this enables health care professionals to make decisions appropriate to individual patients in consultation with the patient.

**3. Health Protection Regulations should require that those with TB who are most at risk to have full access to antibiotics and social support throughout the entire period of their treatment – including those who are at risk of deportation/removal (see Appendix four for proposed draft regulations).**

**PHE replied:** Access to TB treatment and care including access to TB medication is free to all individuals irrespective of an individual's status in the UK. Care, including social support, is provided on a case by case basis reflecting local provision and arrangements.

PHE did not show appropriate regard to the fact that many people are scared to ask for treatment for fear of deportation, and that deportation is equivalent to exporting an infectious disease. Our proposed Regulations are intended to ensure that a duty exists to treat the infected person, to protect the person during treatment and to protect those with whom the infected person shares space.

**4. NHSE through their IRC (Immigration Removal Centre) contracts, should ensure that doctors working for healthcare providers in IRCs, follow NICE Guidance in relation to the duration of TB treatment, and the advice they give to the Home Office on deportation/removal of detainees with TB.**

PHE replied: NHS England's contract requires the primary care health service to follow NICE guidelines in the management of TB. The healthcare team works with PHE health protection teams and the local TB team in Hillingdon. Where a detainee is undergoing treatment, the primary care service would advise the Home Office to stop the removal on medical grounds. However, it is ultimately the decision of the Home Office whether to discontinue with the removal.

This reply suggests that there is no PHE or local public health control over the Home Office with respect to decisions it makes to deport people with TB.

**5. PHE should establish a rapid response public information service, to provide fast, accurate information for people with TB about access to treatment and 'deprivation of liberty' in relation to infectious diseases.**

HAPIA tried on numerous occasions, using mystery shopper techniques to get information about TB treatment and deprivation of liberty (detention for treatment), but could get little information from PHE, local PALS or local authorities. The excellent range of TB Alert leaflets, funded by the NHS, were not mentioned once by the 30 PALS services that we contacted:  
[www.thetruthabouttb.org/wp-content/uploads/2016/08/LatentTBTreatment\\_web-1.pdf](http://www.thetruthabouttb.org/wp-content/uploads/2016/08/LatentTBTreatment_web-1.pdf)

**PHE replied:** TB Alert and NHS Choices websites provide good information on access to TB treatment.

**6. PHE and local authorities should collaborate to produce an information pack for people detained on 2A Orders (detention for treatment), and commission a national advocacy service to provide advice and empowerment to detained people with TB.**

HAPIA wrote to 30 local authorities, the bodies responsible for implementation of statutory Deprivation of Liberty 2A Orders, but not one was able to provide any information for patients who are detained or provide information about access to advocates for those patients.

**PHE replied:** Information for people under part 2A orders is provided on a case by case basis.

PHE TB Annual Report was published on 27 September 2016 and is available on the PHE Website:  
[www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/581238/TB\\_Annual\\_Report\\_2016\\_GTW2309\\_errata\\_v1.2.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/581238/TB_Annual_Report_2016_GTW2309_errata_v1.2.pdf)

## **DUTY OF DOCTORS TO PROTECT THE CONFIDENTIALITY OF PATIENTS**

We raised with the General Medical Council the duty of doctors to ensure that they did not disclose to the Home Office information about the immigration status of their patients. We asked them if the GMC had issued guidance to doctors or to the public on the disclosure of information by doctors about a patient's immigration status.

We described the case of a patient being treated for TB in the NHS, who was an irregular migrant (did not have leave to remain), and who was told by her GP that she would be reported to the Home Office, because she had no right to stay in the country and receive treatment for TB.

We advised that the GP was mistaken and that the patient has a legal right to receive TB treatment and that her GP was bound by GMC guidance not to disclose information about the patient to the Home Office. The GP withdrew his threat, but we decided to seek clarification on GMC guidance in case the person received any further threats. We asked the GMC Chief Executive if he would provide public assurance that doctors breaching the confidentiality of patients who are 'irregular migrants' would be subject to disciplinary procedures?

The GMC provided a detailed response (Appendix three) but not an absolute assurance that the patient was safe. PHE have confirmed that they cannot override a Home Office decision to remove a person who is suffering from TB and has a right to treatment in the UK. The Home Office also failed to give an assurance on this point. We are continuing to seek assurances from the GMC regarding disciplinary action against doctors who disclose information to the Home Office, without the consent of the patient, and have asked them to produce advice to doctors and patients on this issue in view of the fact that deportation of a person with TB who is not treated may suffer harm or cause harm to others.

### **TB-BCG Vaccination**

HAPIA has also been concerned about the variable rate of TB vaccination. In some areas there is a very high rate of vaccination of babies and in others the rate is extremely low. This is related to a shortage of BCG vaccine, but may also be due to vaccination being a low priority in some areas. BCG vaccine supply is now improving, and the latest situation is summarised in the PHE Vaccine Update Special Edition July 2017 (URL below). Priority groups continue to be infants (0-12months) with parents/grandparents who were born in a high incidence country, infants (0-12months) living in high incidence areas (London is included in this), and previously unvaccinated children from 1-5 years of age who have parents/grandparents who were born in a high incidence country. The lowest priority group continues to be individuals at occupational risk.

URL:www.gov.uk/government/uploads/system/uploads/attachment\_data/file/625783/VU\_bcg\_july2017.pdf

### **Training of GPs in the Identification and Treatment of TB**

We also contacted a number of CCGs to seek information on the training of GPs. We were trying to establish whether there was a link between the competence of GPs in the diagnosis and treatment of TB and local incidence of the disease.

### **We put the following FOI questions to 30 CCGs:**

- a) How many GPs in your CCG area received training to develop strategies in their practice to improve the prevention, diagnosis and management of TB?
- b) How many GP practices in your CCG area employ staff who have received training to develop strategies within their practice to improve the prevention, diagnosis and management of TB?
- c) How many health care professionals other than GPs, within your CCG area, have received training to develop strategies within their practice to improve the prevention, diagnosis and management of TB?
- d) What TB services are there in your CCG area, how many staff in each team, the profession of each person in each team and the location of each team?
- e) How many outreach workers are there in your CCG area responsible for TB case finding/ and contact tracing in the community?

The results from the CCGs were mostly disappointing, for example:

- Oxfordshire CCG had no information about the training of GPs and other primary care staff, but were able to tell us that there were 3 nurses employed in the TB nursing service and two consultants in the infectious diseases service who treat TB.
- North of England CCGs (commissioning support unit) could provide no information and suggested we asked PHE or local authorities.
- Wolverhampton CCG could provide no information at all.

Some provided excellent and detailed data, e.g. Bradford and Leicester:

**The number of GPs in your CCG area who have received training to develop strategies within their practice to improve the prevention, diagnosis and management of TB?**

All our practices across **Bradford City** have received instruction on the management of both TB and Latent TB Infection screening (LTBI) and refer patients as appropriate. We also use the Flag 4 data which acts as a safety net to ensure all appropriate patients are referred into the LTBI screening service.

A protected learning time (PLT) session in **Leicester** was delivered in January 2016 by Dr Manish Parikh (Senior Clinical Lecturer in Infectious Diseases) and Dr Pranab Halder (Senior Lecturer (Respiratory Medicine)) to approximately 60 GPs and approximately 50 Practice Nurses on the identification and diagnosis of Latent TB Infection and Blood Borne Virus Infections (LTBI) in migrants. A separate session on the Latent TB Infection screening programme was delivered by Fiona Pimm, Lead Nurse Clinical Care to Practice Nurses, in March 2016 to approximately 50 practice nurses.

See also: [WWW.HAPIA2013.NET](http://WWW.HAPIA2013.NET) for detailed information on 30 responses to our FOIs.

The advice received by HAPIA was that our questions were reasonable. Generally, with a few notable exceptions, we could find no agency able to answer our questions. In conclusion most CCGs we contacted could not answer our questions in detail, despite the fact that they are the commissioners for healthcare in their area. Public health services were not able to answer our questions either; see for example the response from Manchester public health below and PHE does not hold the information requested. So despite the UK having the worst rates of TB in western Europe, not a single body required GPs to be adequately trained in the diagnosis of TB.

**RESPONSE FROM MANCHESTER PUBLIC HEALTH DEPARTMENT**

I have asked my Health Protection Team to look at the questions and we will do our best to collate a response for you. The questions on numbers of GPs and Practices receiving training (a and b) will be difficult to answer, as record keeping on courses attended is done by individual practices (90 +) in Manchester. This will also be true for question c as individual organisations (i.e. 3 hospitals with associated community health services in Manchester) will send staff on courses not only in Manchester but further afield as well. However we will be able to look at numbers attending specialist courses provided by our main TB treatment centre in Manchester and also answer questions d) and e). We will aim to get a response to you before Christmas 2016 (a response was finally received in 2017 and will be published on the HAPIA website).



## **NHS ENGLAND – FAILURE TO CONSULT ON DEVELOPMENT OF IRCs**

We worked with Medical Justice to make a complaint against NHS England when they assumed responsibility for medical care in IRCs (Immigration Removal Centres). We emphasized the importance of ensuring that the experiences of detainees and their advocates influenced the way services are provided and the quality of services.

Unfortunately, there was no public consultation on the design of the new service before it became operational, although NHSE did hold a consultation exercise **after** they had made a decision about how to organize the new system, but did not involve any detainees or their advocates. Our joint campaign eventually led to NHSE agreeing to consult on the developing services.

HAPIA was invited to attend a workshop on the development of the new system and then, because of an objection from the Home Office, removed from the attendance list. There were no representatives from Healthwatch England or local Healthwatch at the workshop and the final service specification failed to differentiate between needs of people in prisons and those in IRCs.

NHSE then set up a Clinical Reference Group (CRG), chaired by a clinician working for a provider to develop the new system, but it had no understanding of public consultation nor of the duty to consult. There were no service users or advocates on the CRG and therefore no involvement in development of the service specification.

In February 2016, we raised the issue of consultation on development of KPIs (Key Performance Indicators) in IRCs with Sue Staddon, Head of Health and Justice Commissioning for South Centre England. She refused to involve Medical Justice, HAPIA and service users, even though NHS England had already agreed to: “engage in additional patient involvement and wider consultation as part of an ongoing and evolving process within the organisation, with a view to informing subsequent refinements to the IRC service specification in the future”. We were promised that “Medical Justice and the Healthwatch and Public Involvement Association (HAPIA) could join those bodies that are already taking part in this activity”.

We advised Sue Staddon that consultation should have taken place when the KPIs were being developed to enable Medical Justice, HAPIA and service users to exercise influence, and that she should have been able to produce evidence that views are genuinely taken into account. We advised that NHSE should be able to show that it has considered the outcome of the consultation process carefully and be prepared to change course in response to the outcome of consultation.

NHSE have now agreed that up to four patients and carer members are eligible to become members of the CRG and have appointed Julie-Jaye Charles, Chief Executive of Equalities National Council for disabled people and carers from BME communities, to become a member. Medical Justice has recently been invited to have observer status on the CRG.

**URL: [www.england.nhs.uk/commissioning/health-just/health-justice-crg/](http://www.england.nhs.uk/commissioning/health-just/health-justice-crg/)**

## **GOVERNMENT'S CONSULTATION GUIDANCE 2016**

### **A. Consultations should have a purpose**

Do not consult for the sake of it. Ask departmental lawyers whether you have a legal duty to consult. Take consultation responses into account when taking policy forward. Consult about policies or implementation plans when the development of the policies or plans is at a formative stage. Do not ask questions about issues on which you already have a final view.

### **B. Consultations should be informative**

Give enough information to ensure that those consulted understand the issues and can give informed responses. Include validated assessments of the costs and benefits of the options being considered when possible; this might be required where proposals have an impact on business or the voluntary sector.

### **C. Consultations are only part of a process of engagement**

Consultation is not just about formal documents and responses. It is an on-going process.

### **D. Consultations should last for a proportionate amount of time**

Judge the length of the consultation on the basis of legal advice and taking into account the nature and impact of the proposal. Consulting for too long will unnecessarily delay policy development. Consulting too quickly will not give enough time for consideration and will reduce the quality of responses.

### **E. Consultations should be targeted**

Consider the full range of people, business and voluntary bodies affected by the policy, and whether representative groups exist. Consider targeting specific groups if appropriate. Ensure they are aware of the consultation and can access it. Consider how to tailor consultation to the needs and preferences of particular groups, such as older people, younger people or people with disabilities that may not respond to traditional consultation methods.

## **F. Consultations should be agreed before publication**

Seek collective agreement before publishing a written consultation, particularly when consulting on new policy proposals. Publish consultations on gov.uk.

## **G. Consultation should facilitate scrutiny**

Publish any response on the same page on gov.uk as the original consultation, and ensure it is clear when the government has responded to the consultation. Explain the responses that have been received from consultees and how these have informed the policy. State how many responses have been received.

- This document does not have legal force and is subject to statutory and other legal requirements. For more advice: **Sue Gray, Propriety and Ethics Team, Cabinet Office - Sue.Gray@cabinetoffice.gov.uk**

[www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/492132/20160111\\_Consultation\\_principles\\_final.pdf](http://www.gov.uk/government/uploads/system/uploads/attachment_data/file/492132/20160111_Consultation_principles_final.pdf)

## **F. Promoting accountability in the NHS and social care to patients and the public.**

### **ABUSE OF CARE STAFF AND PEOPLE RECEIVING DOMICILIARY CARE**

Our members reported on very disturbing experiences of domiciliary care. As several reports came from the area covered by Northamptonshire County Council, we wrote to Cllr Jim Harker, Leader of Northamptonshire County Council, in March 2016 and asked him about the governance of the Council's 8 contracted domiciliary care providers.

We advised Jim Harker that legal requirements in relation to the minimum wage and other conditions of service are being ignored by some Council social care providers and highlighted the following eight issues:

- New domiciliary care starters are required to undertake several days of unpaid induction training. Providers then count the employee's start date as the date of their first assignment and not of their training. Employees cannot start working without this training. The practice contravenes the National Minimum Wage legal duty.

- Call times are allocated back to back. Care workers are forced by the employer to cut back the time they spend with a client in order to arrive at the next client by the agreed time, e.g. clients assessed as needing 45 minutes care may receive 30 minutes, and a 60 minute call compressed down to 40 minutes. This speeds up and reduces the time to provide personal care and undermines the dignity of care.
- Falsified diary time entries and falsified mobile log in/log outs are used to cover up the fact that staff are forced to cut down the time they provide care for.
- If ambulance services have to be called by care staff they don't get paid for remaining with clients beyond their set call time until the emergency services arrive. This practice contravenes the National Minimum Wage legal requirement.
- Staff are paid only for clients' contracted care time and not the time spent travelling to clients. Therefore, care workers could work from 6am to 6pm and only be paid for half that time, dependent on the distances travelled in between clients.
- Front line staff are not paid travelling expenses, but told in some cases, quite wrongly, that they can reclaim all their mileage expenses from HMRC annually.
- Because travel expenses are often not paid, the costs of travel by car between clients substantially decreases the actual value of take home pay for front line staff, which is then well below the national minimum wage.
- Some contracted providers charge staff directly for enhanced DBS assessments, at a rate significantly higher than the published rate of £44.

We asked Cllr Harker to take urgent action to ensure that the Council's governance arrangements are not being breached, by funding care agencies that are acting unlawfully and in a way that is harmful to both vulnerable clients and staff.

Mark Grimes, Strategic Commissioning Manager for Quality and Contracting Community Services in Northamptonshire County Council (NCC), replied to HAPIA and said NCC will investigate our concerns with the home care providers and share the results of their investigation with the CQC and HAPIA. He said that providers in breach of acceptable standards and/or the law will be required

to remedy their conduct immediately and that NCC is committed to ensuring that services provided to vulnerable people are supported by providers that operate within the law and recognised acceptable standards, and will work with providers to maintain that position.

However, the NCC then asked us to reveal information that would identify our sources, which we could not do, because those people would be liable to be sacked and probably blacklisted in the care industry. NCC stated they could not therefore direct Quality Monitoring Officers / Safeguarding Officers to undertake additional investigative work with specific providers. They did ask each contracted care provider to respond to our allegations and to report their findings to NCC. The data produced was then used by the Quality Monitoring regime to challenge and to put right practices that fall below reasonable contractual expectations.

Andrea Sutcliffe, Chief Inspector of Adult Social Care for the CQC, wrote to HAPIA welcoming the information that we had sent to her and expressed the CQC's commitment to ensuring that, where domiciliary care providers fail to meet regulatory or legal standards, this information will be taken into account and action taken. The matter was then passed to Maggie Hannelly, Inspection Manager for Northampton, who agreed to meet HAPIA to discuss any further evidence that we had available (Maggie.Hannelly@cqc.org.uk).

**Out of court settlement with MiHomeCare: “Thousands of care workers could get payouts after landmark minimum wage case - Caroline Barlow took legal action against ex-employer MiHomeCare for time spent travelling to and from clients”**

**URL: [www.gov.uk/national-minimum-wage](http://www.gov.uk/national-minimum-wage)**

## **REVALIDATION OF DOCTORS -**

When Revalidation (licensing) of doctors was started in 2013, we signed a joint letter, with other charities, to the Secretary of State, Jeremy Hunt, agreeing to support the programme, but asking for the following assurances:

- That patients are regarded as a key resource in helping to improve medical practice. The scope and frequency of patient feedback in the initial revalidation model is too limited and must be expanded beyond 20 patient comments every 5 years.
- That the GMC will be committed to active and constructive engagement with patients' organisations in all aspects of the development of Revalidation.

- That the patient perspective must play a prominent and meaningful role in the development of revalidation policy and practice, and in reviews of the limitations of feedback in the initial model.
- That opportunities should be identified to strengthen the involvement of patients in the various stages and levels of the Revalidation process.

We knew that, once the process started, the GMC would fail to work effectively with patients and patients organisations, because that is the culture of the GMC. But we attempted to work with them, and also sat on the English Revalidation Implementation Board (ERIB) until it was closed down in 2017 - without even a note from NHS England to advise us of their decision. The replacement system for monitoring Revalidation by NHS England is known as “Business as Usual”, which aptly describes the approach of NHS England to public involvement.

The GMC did accept our advice to place the names of Responsible Officers on their website against each doctor’s name - allowing issues to be raised with doctors when a problem is identified, and enabling employers to trace a doctor’s previous Responsible Officer. But the ERIB and GMC refused to support genuine patient involvement and stuck to their original ineffective process of inviting 20 patients’ comments every 5 years.

After 5 years of Revalidation, most patients have no idea what Revalidation is and are never asked for comments in a way that identifies such requests as being connected with Revalidation of their doctor.

However, for those who do know about the Revalidation system, it can be a powerful tool for challenging doctors who are providing poor care and need to hear the patient’s voice to tell them how to provide more effective patient centred care.

## **HAPIA AGM AND ANNUAL MEETING**

This event was convened on 9 December 2016 in London but the AGM was not fully quorate. The annual meeting consisted of a review of the Annual Report followed by a discussion about the following issues:

- Publications, activities and reports for 2015-6
- Impact of the STP and Success Regime on the NHS
- House of Lords debate on failing Healthwatch
- The impact of Healthwatch England
- Role in Healthwatch in campaigning for better services
- Defibrillator campaign
- Tuberculosis epidemic - campaign

The formal Annual General Meeting was duly adjourned as inquorate in accordance with Articles 9 to 12 of the Company's Articles of Association; the AGM was ordered to be duly reconvened by Directors to allow a minimum of

seven clear days' notice pursuant to Article 10 of the Company's Articles of Association, and was directed to take place on 19 December 2016 at the Company's registered office when the business was duly concluded.

## WEBSTATS 2016

MONTH	HAPIA	ACHCEW	RULE 43	HW DEVEL	REVALIDATION
<b>FEBRUARY</b>	5206	1825	4238	9871	1462
<b>MARCH</b>	4623	1617	3030	6360	1755
<b>APRIL</b>	3761	3989	2494	8200	1833
<b>MAY</b>	5224	1849	2709	10302	2130
<b>JUNE</b>	5930	2149	2909	9159	2646
<b>JULY</b>	6051	3699	2861	9060	3450
<b>OCTOBER</b>	4856	3105	3423	13132	3933
<b>NOVEMBER</b>	3285	3285	3005	11425	3292
<b>DECEMBER</b>	3181	1930	2741	6698	3114

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## HAPIA PUBLICATIONS

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<b>HAPIA CONFERENCE REPORT 2014</b> Catherine Gleeson and Mary Ledgard	Summary of Speakers' Presentations. Conference Speakers' Biographies.
<b>PATIENT TRANSPORT SERVICES (PTS)</b> HAPIA's recommendation for changes to PTS contracts  October 2014	For everybody connected with PTS – service users, Local Healthwatch and community organisations working with service users and with commissioners and providers of PTS. The report is intended to help improve patient transport services across the UK.
<b>QUALITY ACCOUNTS AND THE SCRUTINY ROLE OF LOCAL HEALTHWATCH</b> HAPIA Briefing Note Catherine Gleeson 27 October 2014	Among the many priorities for Local Healthwatch Groups (LHW), commenting on Trust's draft Quality Accounts (QA) is of great importance. By providing knowledgeable commentary on QAs, LHW can influence improvements in local health services.
<b>HEALTHWATCH AND IMMIGRATION REMOVAL CENTRES</b>  Healthcare for Asylum Seekers in	Numerous reports from Her Majesty's Inspector of Prisons (HMIP) indicate serious problems in the standards of healthcare provided. As HM Chief Inspector of Prisons, Nick Hardwick

Detention Centres August 2014	points out "...away from public scrutiny, it is easy for even well intentioned staff to become accepting of standards that in any other setting would be unacceptable".
<b>COMPLAINTS AGAINST DOCTORS.</b> <b>SHARING INFORMATION WITH PATIENTS AND CARERS</b> Improving doctors performance	This Good Practice Guide has been prepared by HAPIA, to enhance an understanding of the principles and benefits of sharing information with patients and carers, when a doctor is being revalidated, or undergoing complaints investigation or remediation
<b>HAPIA'S GUIDE TO CASUALTY WATCH 2014</b>	Guidance Notes for Casualty Watch Examples of Data Collection 30 & 60 Minutes Handover Breaches
<b>REVALIDATION OF DOCTORS</b> The Role of Case Manager in Improving the Performance of Doctors Sharing Information with Patients, Carers and the Public	Good Practice Guide to support Case Managers in understanding the principles and benefits of sharing information with patients, carers and the public when a doctor is undergoing investigation or remediation.

#### LEAFLET

<b>REVALIDATION OF DOCTORS</b> Working with Your Doctor to Improve Medical Care – A Guide for Patients	August 2014
See also: <a href="http://www.revalidatingdoctors.net">http://www.revalidatingdoctors.net</a>	



## MEMBERS AND AFFILIATES

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During the year ended 31 December 2016, membership remained steady. Each member guarantees, in accordance with the Company's Memorandum of Association, to contribute up to £10.00 to the assets of the Company in the event of a winding up.

Membership is open to:

- Local Healthwatch
- Individuals who live anywhere in the UK, who are either members of a Local Healthwatch or other organisations that support the objectives of HAPIA.
- Individuals active in developing more effective health and social care service and who support the objectives of HAPIA

Members are entitled to attend meetings of the Charity and to vote thereat.

The annual membership fee for individuals is £10.00 and for Local Healthwatch the fee is £50.00. New members are welcome to join.

Affiliation is open to other organisations and individuals with an interest in supporting the objects of HAPIA. Affiliates are fully entitled to attend meetings of the Charity, but not to vote thereat.

The annual Affiliation fee for local and regional groups/organisations is £50.00 and £200.00 for national organisations.

New Affiliates are welcome to join.

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This Report was approved by the Trustees on

\_\_\_\_\_ 2017

and is signed on their behalf by:

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Malcolm Alexander  
Director/Chair

John Larkin  
Director/Company Secretary

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**INCOME AND EXPENDITURE ACCOUNT  
FOR THE YEAR ENDED 31 DECEMBER 2016**

	<b>2016 Unrestricted Funds</b>	<b>2016 Total</b>	<b>2015 Total</b>
	£	£	£
<b>Incoming Resources</b>			
Donations	-	-	-
Membership and Conference Fees	490	490	1121
Payment for use of HAPIA resources	-	-	-
<b>Total Incoming Resources</b>	490	490	1121

<b>Resources Expended</b>			
Hire of Conference Halls and Events Management	-	-	779
Steering Group Expenses (including hire of rooms)	52	52	199
Stationery, websites and other administrative expenses (including data analysis)	-	-	131
<b>Total resources expended</b>	52	52	1109

<b>Net Income (expenditure) for the year</b>	438	438	12
<b>Total funds brought forward</b>	406	406	394

<b>Total funds carried forward</b>	844	844	406
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**BALANCE SHEET**  
**31 December 2016**

<b>CURRENT ASSETS</b>	<b>2016 £</b>	<b>2015 £</b>
Cash in hand	-	-
Cash at bank	844	835
Debtors - (outstanding payments for annual conference)	-	350
<b>CREDITORS</b>		
Amount falling due within one year	-	779
Total assets less current liabilities	844	406
Total net assets	844	406
<b>RESERVES</b>		
Unrestricted funds	844	406
Total Charity Reserves	844	406

**NOTES**

1. These accounts have been prepared in accordance with the provisions applicable to companies subject to the small companies' regime and in accordance with the financial reporting standard for smaller entities historical cost convention and the charities statement of recommended practice 2005.
2. For the year ended 31 December 2016 the Company was entitled to exemption under Section 477 of the Companies Act 2006.
3. No notice from members requiring an audit of the accounts has been deposited under Section 476 of the Companies Act 2006.
4. Directors acknowledge their responsibility under the Companies Act 2006 for:
  - (i) Ensuring the Company keeps accounting records which comply with the Act, and
  - (ii) Preparing accounts which give a true and fair view of the state of affairs of the Company as at the end of its financial year, and of its income and expenditure for the financial year in accordance with the Companies Act 2006, and which otherwise comply with the requirements of the Companies Act relating to accounts, so far as applicable to the Company.
5. HEALTHWATCH AND PUBLIC INVOLVEMENT ASSOCIATION is a Registered Charity and a Registered Company Limited by Guarantee and not having a share capital; it is governed by its Memorandum and Articles of Association. This Report and Financial Statements were approved by the Trustees on

\_\_\_\_\_ 2017 and signed on their behalf by:

\_\_\_\_\_  
Malcolm Alexander  
Director/Chair

\_\_\_\_\_  
John Larkin  
Director/Company Secretary

## GLOSSARY

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AvMA ...	...	Action against Medical Accidents
CB ...	...	Cross Bench
CPD ...	...	Continuing Professional Development
CCG ...	...	Clinical Commissioning Group
CQC ...	...	Care Quality Commission
CRG ...	...	Clinical Reference Group
DH ...	...	Department of Health
E&V ...	...	Enter and View
GMC ...	...	General Medical Council
HAPIA ...	...	Healthwatch and Public Involvement Association
HMIP ...	...	Her Majesty's Inspectorate of Prisons
HWBB ...	...	Health and Wellbeing Board
HWE ...	...	Healthwatch England
IAS ...	...	Independent Advocacy Service
ICAS ...	...	Independent Complaints Advocacy Service
IMB ...	...	Immigration Monitoring Board
IRC ...	...	Immigration Removal Centre
LA ...	...	Local Authority
LHW ...	...	Local Healthwatch
NHSE ...	...	NHS England
NHSLA ...	...	NHS Litigation Authority
NICE ...	...	National Institute for Health and Care Excellence
OPD ...	...	Outpatients Department
OSC ...	...	Overview and Scrutiny Committee
PHE ...	...	Public Health England
PPI ...	...	Patient and Public Involvement
RAG ...	...	Red Amber Green
QA ...	...	Quality Audit
STP ...	...	Strategic Transformation Plan
TB ...	...	Tuberculosis
URL ...	...	Uniform Resource Locator

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**APPENDIX ONE – SUMMARY OF INFORMATION ABOUT HAPIA**

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**Company Secretary:**

John Larkin – Flat 6, Garden Court, 63 Holden Road, LONDON, N12 7DG

HAPIA Contact Details:

**HEALTHWATCH AND PUBLIC INVOLVEMENT ASSOCIATION - NORTH**

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The Hollies, George Street, COTTINGHAM, HU16 5QP

Tel: ... .. 01482 849 980 or 07807519933

Email: ... .. ruth@myford.karoo.co.uk

**HEALTHWATCH AND PUBLIC INVOLVEMENT ASSOCIATION - SOUTH**

30 Portland Rise, London, N4 2PP

Tel: ... .. 020 8809 6551 or 07817505193

Email: ... .. HAPIA2013@aol.com

Website: ... .. WWW.HAPIA2013.org

**Trustees of the Charity:**

John Larkin	Malcolm Alexander
Elsie Gayle	Ruth Marsden

**Michael English is the President of HAPIA.**

**Rotation of Directors**

One third of Directors (or the number nearest one third) retire(s) each year by rotation in accordance with the Company's Articles of Association and may be eligible for re-election.

**Date of Registration as a Charity: 27 September 2010**

Charity No: 1138181 ... .. Originally known as National Association of LINKs Members until company name changed in December 2013 to Healthwatch and Public Involvement Association.

**Date of Registration as a Company: 20 May 2008**

Company No: 6598770. Registered in England. Company Limited by Guarantee.

Originally named National Association of LINKs Members from May 2008 to November 2013 until a new Certificate of Incorporation on Change of Name issued by Companies House on 2 December 2013 in name of Healthwatch and Public Involvement Association.

**Governing Documents:**

Memorandum and Articles of Association as incorporated.

**Charitable Objects:**

1. The advancement of health or the saving of lives, including the prevention or relief of sickness, disease or human suffering.
  
2. The relief of those in need by reason of youth, age, ill-health, disability, hardship or other disadvantage, including by the provision of accommodation or care.

**Classification:**

WHAT	The advancement of health or saving of lives
WHO	Elderly / old people - People with disabilities - People of a particular ethnic or racial origin - The general public / mankind
HOW	Provide advocacy / advice / information - Sponsor or undertake research / Act as an umbrella or resource body

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## **APPENDIX TWO – MORE ABOUT HAPIA**

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### **AIMS AND OBJECTIVES**

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- (1) Support the development of Local Healthwatch (LHW) and Healthwatch England (HWE) as powerful and effective bodies that enable the public to monitor, influence and improve health, social care and public health services.
- (2) Promote democratic and accountable public involvement organisations across England, which genuinely empower patients, care receivers, carers, and all individuals and communities to influence planners, commissioners and providers of health, social care and public health services, in order to achieve safe and effective services.
- (3) Investigate, challenge and influence health, social care and public health bodies which fail to provide or commission safe, effective, compassionate and accessible services.
- (4) Collaborate with other community and voluntary sector bodies, patients and service users, to achieve HAPIA's objectives.
- (5) Hold the government to account for its legislative and policy commitments to public influence in health, social care and public health services.

### **KEY GOALS**

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- (1) To scrutinise effectiveness of HWE, LHW, IAS (Independent Advocacy Service) and complaints investigation as vehicles for public influence, redress, and improvement of health, social care and public health services.
- (2) To reflect continuously upon the effectiveness of Healthwatch in relation to recommendations of the Francis Report.
- (3) To advise on effective ways of influencing commissioners, providers, regulators and policy makers.

- (4) To advise on effective ways of learning from complaints, incidents, accidents and systemic successes and failures that occur in health and social care services.
- (5) To communicate key messages and information rapidly and continuously to HAPIA's membership, communities and the media.
- (6) To promote the accountability of providers, commissioners and regulators of health, social care and public health services.

## **PRIORITIES**

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- (1) Equality, inclusion and a focus on all regions and urban / rural diversity.
- (2) Continuous and timely information flows from and to members and the wider community.
- (3) Influence through interaction with Ministers, the Department of Health, NHS England, Regulators, Local Authorities, the Local Government Association (LGA) and other national and local bodies.
- (4) Ensuring members of HAPIA shape the strategy and policy that drive our work.

## **BUILDING RELATIONSHIPS WITH OTHER BODIES AND CHARITIES**

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Sustaining and developing relations with LHW, HWE, the DH, NHS England, LGA, National Voices, Action Against Medical Accidents (AvMA) and other national and local voluntary sector bodies on the basis of shared interests and objects, e.g.: National Association of Voluntary and Community Action (NAVCA), Community and Voluntary Services (CVS) and the NHS Alliance Patient & Public Involvement (PPI) Group.

## **FUTURE MEMBERSHIP**

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Membership will be invited from:

- Current membership
- Local Healthwatch organisations
- Individual Local Healthwatch members / volunteers / participants



- Individuals who support the aims and objectives of the Association and who are active in their community and / or nationally
- Organisations working locally and / or nationally to influence NHS, Local Authority, social care and public health services
- Lay people involved in Patient Participation Groups, Clinical Commissioning Groups, Specialised Commissioning Groups, Local Area Teams (NHS England) and Quality Surveillance Groups

## **FUNDING**

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- Subscriptions for individuals, LHWs and other organisations.
- Consider applications for funding to the DH, Department of Communities and Local Government (DCLG), HWE and grant giving bodies.
- Consider raising funds from payments for commissioned research and survey work.
- Consider raising income via an independent fundraiser working on a commission basis.

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## **APPENDIX THREE – ADVICE FROM THE GENERAL MEDICAL COUNCIL REGARDING PATIENTS WITHOUT LEAVE TO REMAIN**

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**The relevant principles in the GMC guidance that every GP should be following when considering making a disclosure to the Home Office regarding deportation of a patient.**

“In our guidance to doctors on *Confidentiality* (2009) we make clear that patients have a right to expect that information about them will be held in confidence by their doctors. However, whilst confidentiality is an important duty, it is not absolute and personal information (such as your immigration status) can be disclosed to a third party (such as immigration authorities) without your consent if it is required by law or can be justified in the public interest (paragraph 22). There are some circumstances in which NHS hospitals are obliged to share information with the Home Office about patients who are classed as ‘overseas visitors’ (which includes people who have no legal basis to remain in the UK) who have outstanding debts to the NHS. Our understanding is that this obligation does not apply to GP practices, but we are unable to advise you on the details of the policy”.

“If information is not required by law, then a doctor will need the patient’s consent or another legal basis for making the disclosure. Some disclosures can be justified in the public interest. The framework that your GP should be applying if he is considering making a disclosure in the public interest is set out in paragraphs 36-39, 51-52 and 53-55 of our *Confidentiality* guidance. When considering the public interest, your GP must consider whether the benefits (to you or anyone else) of the disclosure outweigh both the public and your interest in keeping the information confidential, as well as whether the possible harms (to you or to anyone else) of not releasing the information outweigh the possible harms of doing so, both to you and to the overall trust between patients and doctors”.

“At paragraphs 53-55 of the guidance we advise doctors that disclosure of personal information without consent may be justified in the public interest if failure to disclose:

- may expose others to a risk of death or serious harm, or
- would be likely to assist in the prevention, detection or prosecution of serious crime, especially crimes against the person.

There is no agreed definition of 'serious crime'. *Confidentiality: NHS Code of Practice* (Department of Health, 2003) gives some examples of serious crime (including murder, manslaughter, rape and child abuse; serious harm to the security of the state and public order and 'crimes that involve substantial financial gain or loss' are mentioned in the same category). It also gives examples of crimes that are not usually serious enough to warrant disclosure without consent (including theft, fraud, and damage to property where loss or damage is less substantial)".

"Whether or not a disclosure can be justified in the public interest is a matter for a doctor's professional judgement. We would expect the doctor to take into account the principles set out in our guidance when considering the issues, and to be able to explain the reasons for the decisions he has reached".

"Turning next to your question as to whether there is anything that you can do to prevent your GP informing the immigration authorities of your immigration status. I would suggest having a further discussion with your GP so that you can bring our guidance to his attention and explore further his reasons as to why he considers disclosing your immigration status to the authorities without your consent can be justified".

"If following your discussion, your GP still decides to make a disclosure and you continue to disagree with his reasons then you can of course make a complaint under the local complaints process. Your GP should be able to provide you with more details on this".

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**APPENDIX FOUR – HAPIA’s DRAFT HEALTH PROTECTION (CONTINUITY OF CARE) REGULATIONS**

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**DRAFT STATUTORY INSTRUMENT**

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2016 No. 000

**PUBLIC HEALTH ENGLAND**

**The Health Protection (Continuity of Care) Regulations 2016**

Made ----- 000  
Coming into force ----- 000

The Secretary of State makes these Regulations in exercise of powers conferred by Sections 45B (1)(c), 45B(2)(b), 45C(1), 45F(3) of the Public Health (Control of Disease) Act 1984, for the purpose of preventing, protecting against, controlling or providing a public health response to the incidence or spread of infection or contamination in England and Wales (whether from risks originating there or elsewhere).

A draft of this instrument has been approved by resolution of each House of Parliament pursuant to section 45Q(2), (3) and (4) of the Public Health (Control of Disease) Act 1984.

**Citation, commencement and application**

- (1) These Regulations may be cited as the Health Protection (Continuity of Care) Regulations 2016 and shall come into force on 000
- (2) These Regulations apply in relation to England only.

**Interpretation**

2. In these Regulations-

“the Act” means the Public Health (Control of Disease) Act 1984;

“practitioner” means a registered medical practitioner or a registered nurse practitioner;

“P” means a patient.

**Duty on practitioner to give notice of inadequate care for infectious diseases**

3.- (1) This regulation applies where a registered medical practitioner or nurse practitioner, having made reasonable inquiries, and having made reasonable attempts to arrange for care to be provided to P, considers that P is not receiving appropriate and adequate care and treatment for an infectious disease.

(2) In relation to the care that the practitioner is of the opinion that P should receive for the treatment of an infectious disease, such care should in the opinion of the practitioner have been provided in a way that shows due regard to the relevant clinical Guidelines produced by the National Institute for Health and Care Excellence in Health and Social Care, consequent upon the provisions of the Health and Social Care Act 2012 sections 236 and 237.

(3)The practitioner is of the opinion that the failure of those responsible for the care for P to show due regard to Clinical Guidelines produced by the National Institute for Health and Care Excellence, is having or is likely to have a deleterious effect on the health and safety of P and/or the health of those with whom P is or may be in contact with.

### **Duty on practitioner to advise when care for an infectious disease is inadequate**

4.- In relation to section 45B (1)(c) of the Act these regulations allow the practitioner to advise :

- a) the clinical commissioning group for the area where P has habitual residence in a local authority area;
- b) NHS England where P does not have habitual residence in a local authority area;
- c) Public Health England; and
- d) the Secretary of State for the Home Department, where the person is detained in one of Her Majesty's Prisons or an Immigration Removal Centre or a youth offender institution,

whenever it is the opinion of the practitioner that P's care and treatment is such that P's health and safety are being or may be compromised.

### **Appointment of an Appointed Person**

5.- In relation to section 45B(2)(b) of the Act, these regulations enable the practitioner to advise all or any of the bodies in regulation 4.- a) to d) hereof that in the view of the practitioner P's care and treatment are such that P's health and safety are being or may be compromised. In that event NHS England shall appoint an 'appointed person' for the purpose of:

- i) ascertaining whether in the opinion of the 'appointed person' P's treatment is such that P's health and safety is being compromised;
- ii) deciding where P's care should be provided if in the opinion of the 'appointed person' P's treatment is such that P's health and safety are being or could be compromised.

Signatory text                      Name (Minister) Department of Health  
Address  
Date

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## **APPENDIX FIVE – ADDITIONAL STATEMENTS FROM THE HOUSE OF LORDS DEBATE ON 15 DECEMBER 2016**

### **Lord Harris of Haringey (Lab)**

- 1) “Incidentally, on the issue of personal experience, I seem to recall seeing all sorts of statements on what various clinicians would like to do to the noble Lord Lansley if they ever found him in their care, but fortunately that never happened during his period of brief notoriety in that role”.
- 2) “A very small proportion of HWE budget goes on developing and supporting local Healthwatch. Nor does local Healthwatch feel that Healthwatch England is there for them and they have little scope to influence it or its work”.
- 3) “Healthwatch England also seems to fail in capturing and articulating the views and concerns of local groups, so much so that a private company, Glenstall IT, has stepped into the void by collating reports and publications of local Healthwatch groups, something you might have expected Healthwatch England to do, and selling the digest back to 2,000 health and social care professionals”.
- 4) “The DH acquiesced in allowing the money to go across to local authorities un-ringfenced”.
- 5) “There is a big variation in the funding of individual local Healthwatch groups. Bristol provides £400,000, while Manchester only £80,000”.
- 6) “One example is of a 30% reduction in funding imposed on Oxfordshire Healthwatch by Oxfordshire County Council, which seemed to follow, as night follows day, from criticisms that the local Healthwatch had made of the county council record on social care—precisely the job that Healthwatch was created to do. As the King’s Fund put it in its review carried out for the Department of Health: “Local Healthwatch organisations are very small in comparison to the potential scope of their statutory activities, and the population and services they cover”.
- 7) “Local Healthwatch could provide an enormous resource to supplement and inform inspections by the CQC, but its potential enthusiasm is simply being stifled”.
- 8) “The tragedy is that Healthwatch has enormous potential. It could be a tremendous force for good in enabling health and social care services to be much more effective and user-centred”.

### **Lord Lansley (Con)**

- 9) “We did not create Healthwatch on the basis that we were simply re-badging something that had come before. We were setting out to recreate the independence and impact that we had seen in the best Community Health Councils in the past, and I think that is the measure by which we should judge it”.

**Baroness Pitkeathley (Lab)**

- 10) “The power issue. The involvement of patients challenges orthodoxies, vested interests and established ways of doing things. If you share power with patients, which everyone says they want to do, it means that someone—the doctor, the nurse, the administrator—has to give up a bit of their power, and that is hard for them to do”.

**Baroness Masham of Ilton (CB)**

- 11) “We hear a great deal about the patient-centred health service. This should not just be words; patients and patient associations should be part of the system and the patients’ voice should be listened to. They should be part of the team, not just a number to be dealt with”.
- 12) “I feel that Healthwatch bodies do not represent rural areas; they are situated in large towns and cities and are spread too thinly to do the job of helping communities”.
- 13) “Independent Age, a voluntary organisation, has joined with Healthwatch Camden. Independent Age has developed a quality assessment for care homes based on the things that older people and their families want and need. Because Healthwatch Camden has a statutory right to enter care homes on request, it has partnered with Independent Age as part of a pilot programme”.

**Baroness Warwick of Undercliffe (Lab)**

- 14) “NHS England published its *Patient and Public Participation Policy*, which pledged to “work in partnership with patients and the public, to improve patient safety, patient experience and health outcomes; supporting people to live healthier lives”.

**Baroness Chisholm of Owlpen (Con)**

- 15) “Under the new arrangements it retains a line of accountability to the Secretary of State, via the CQC chair, because the Healthwatch England chair is a Secretary of State appointment”.
- 16) “In fact its number one priority as set out in its business plan for 2016-17 is: “To provide leadership, support and advice to local Healthwatch to enable them to deliver their statutory activities and be a powerful advocate for services that work for people”.
- 17) “I do not consider that the funding and accountability arrangements for local Healthwatch organisations undermine their effectiveness or independence. We are not aware of any specific accusations that a local Healthwatch has felt unable to raise issues for fear of repercussions”.
- 18) “Central control of local funding decisions would diminish the voice of local communities and ignore other voluntary or partnership arrangements that a local authority may already be funding for the benefit of its population. But let me be clear on one important point: local authorities are still accountable for the funding that they allocate to local Healthwatch”.

- 19) "Healthwatch England publishes figures showing how much councils are spending so that local communities can hold their councils to account. I will say upfront that the data show that some local Healthwatch organisations have large reductions in their funding".
- 20) "Going forward, much more of Healthwatch England's resources will be spent on supporting local Healthwatch as this strand is being given a stronger priority by Healthwatch England".
- 21) "My noble friend Lord Lansley mentioned the independence of Healthwatch England within CQC. I agree with him that Healthwatch England is independent and acts as a rigorous scrutineer to use its place within CQC as leverage to support the voice of users".
- 22) "Healthwatch England will be closely monitoring the ability of local Healthwatch organisations to deliver their statutory functions while also continuing to engage with local authorities in order to support the sustainability of local Healthwatch organisations".
- 23) "Simon Stevens and Jim Mackey wrote a letter on 12 December to STP leaders saying how important local engagement is and that rural areas must be included in this. It is an ongoing problem which we must keep addressing".

URL: <https://hansard.parliament.uk/Lords/2016-12-15/debates/87B30CB6-1013-4F53-8AD4-D169FD5501C2/HealthAndSocialCare>